"When your life is turned upside down without warning, you need someone to talk to who understands; It's that simple."
—Santo Garcia, President, Board of Directors; Liaison,
GBS|CIDP Foundation International

As we find with so many ailments—awareness, recognition, and an early and accurate diagnosis are key to mitigating the serious health consequences of peripheral autoimmune neuropathies. The earlier treatment begins, the better the prognosis for the affected individual.

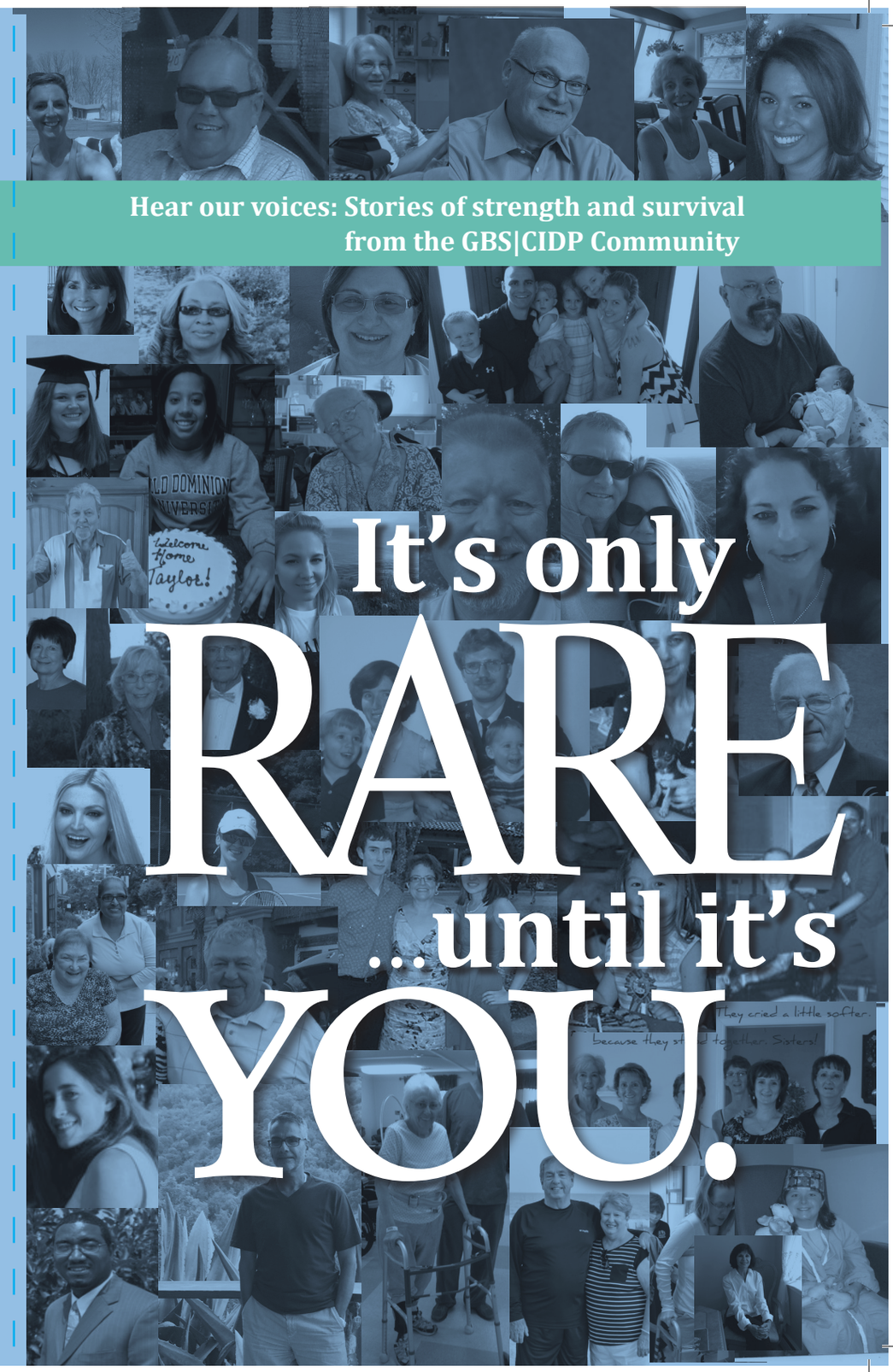
GBS|CIDP Foundation International brings leading scientific minds, patients, and other stakeholders together with the goal of advancing our understanding of these conditions and improving care for affected individuals. For more than 35 years, the *Foundation* has provided a way for anyone suffering from GBS, CIDP, and variants to have access to someone who understands. Someone they can reach out to when their world is turned upside down.

I extend my sincerest gratitude to the many GBS and CIDP patients and their family members, who, like mine, have shared their very personal and heartfelt stories with *GBS|CIDP Foundation International* in this journal. Stories that make clear that ***it's only RARE…until it's YOU!***

John Garamendi, US Congressman

GBS|CIDP
Foundation International

It's only RARE...until it's YOU.



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GBS|CIDP Foundation International is the preeminent global nonprofit supporting individuals and their families affected by *GBS, CIDP,* and related syndromes through a commitment to support, education, research and advocacy. The *Foundation* has more than 40,000 members throughout 47 countries and has a 26-member *Global Medical Advisory Board* comprised of the world's leading physicians in peripheral neuropathy research and patient care. Since its inception, *GBS-CIDP Foundation International* has been closely aligned with the *University of Pennsylvania Medical Center*, and is a member of the *National Organization for Rare Disorders (NORD.)*

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Published by *GBS|CIDP Foundation International*

This book is dedicated to patients, their families, and their caregivers around the world who have experienced Guillain-Barré syndrome and variants.

For the last 30+ years, we must have received thousands of stories from patients—some handwritten and mailed, then those which were faxed and then those sent by e-mail—the most recent way we tend to communicate.

In this journal, *"it's only RARE...until it's YOU,"* are many of these stories. Although we could not include every one we received, we want to share with you, those that may, *"ring a bell,"* or *"touch your heart."* If your story does not appear, we are certain you will find your tale in someone else's! So many have commented, *"that's exactly what happened to me!"*

Thank you to everyone who shared your deep, and very personal, story with us.

Estelle L. Benson

Founder, *GBS|CIDP Foundation International*

"My battle with this illness has taught me some very useful things."—SD

Alan Cate's Story

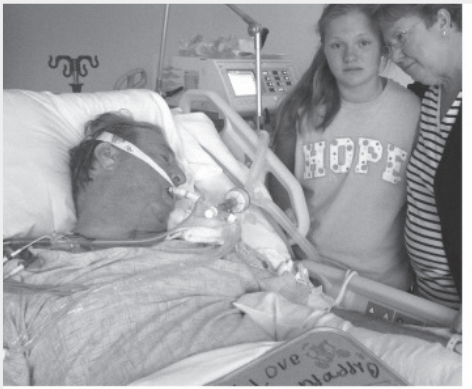
I am not sure where to start with my Guillain-Barré (GBS) journey, so I will begin when my family's life was changed forever—Memorial Day weekend 2013.

I had just returned from a week's vacation in Florida. I was sitting on my dock watching the grandkids ride their jet ski. I was talking with my daughter and told her my feet felt funny—like they were asleep. Neither one of us thought about that becoming a life changing sign.

Tuesday, May 29, began as any other normal day. I woke up, fixed my coffee, grabbed my newspaper and kissed my wife goodbye as she left for work. Sitting on my screen-porch enjoying my morning, I was planning on babysitting our youngest granddaughter and working with her in our garden. I didn't really notice anything different at the time but within a few hours, things really began to change.

We routinely care for an elderly neighbor and had someone doing repair work at her house. The repairman stopped over for payment and that is when I noticed that something was *"very wrong,"* I couldn't hold a pen to write him a check.

I immediately called my son to ask him to take me to the hospital fearing I was having a stroke. We met my wife and daughter at the hospital where I was able to stand and then transfer into a wheelchair.



During the several hours I waited to be examined, my blood pressure increased the longer I waited—along with the excruciating pain in my back. I just wanted to go home and lie down! Transferring into a room wasn't much better especially since they dropped me trying to move me into a bed.

I had lost all control of my lower half of my body in only a few short hours. The staff immediately requested a doctor who, in turn, called for a neurologist–Lorin Freedman.

Dr. Freedman examined me and told me he felt strongly that I had an autoimmune disease called Guillain-Barré syndrome. He shared with us that most cases are not life threatening but that it could cause me to be on a ventilator if symptoms presented higher than my waist.

Sadly enough, within a few hours, mine took over my whole body and I was on a ventilator scared for my life and unable to communicate. My family, all there at my bedside, were as scared as I was and I could hear them speaking.

From there it all went black. I was told I was given immunoglobulin (IVIG) treatment for five days. IVIG plasma treatments replace your bad plasma with good plasma.

My next nine days—I'm told, were bumpy ones—and were what my family called "Locked In." They struggled not knowing whether I was able to hear them when they talked to me. The doctors ran all kinds of tests and found that I did have brain activity, which meant I WAS STILL IN THERE and gave the family hope. I, of course, had lost all track of time. Once I regained real presence of mind, I was then able to make sense out of what everyone was saying.

From that point I thought I couldn't live like that, and I will just shoot myself. Then I thought *"how could I do that? I can't even hold a gun!"*

I began to talk to the Lord and said, *"Lord, I have followed you all of my life. If you will just help me get through all of this, I will*

continue to follow You." I knew that only God, Himself, could see me through this.

My daughter documented my journey with pictures and videos and captured the first movements of my head on my tenth day in the hospital. That exercise was her way of sharing the hope of me coming back to my family. From then on they would notice little changes every few days. By the end of my thirty-day stay I was able to open my eyes and move my head.

Still on a ventilator, it was time to leave the hospital for a long-term-care facility. This was yet another challenge because there are so few hospitals that accept vented patients. Let's just say that the lack of good medical care for these types of patients is sad. My family had to hire sitters for me every day—night and day—because I had no way to communicate.

My wife was so very strong through this all the while being diagnosed with breast cancer two weeks after me being admitted into the hospital.

I stayed in that facility for another thirty days and then transferred to yet another nursing home that offered less than stellar care. If it were not for my family insuring I received the best care, I am not sure where I would be today. I feel so bad for those who go through this kind of thing without the support of family. I stayed at that facility about four months and while there I was able to finally be weaned off the ventilator, able to communicate, and learn how to swallow all over again.

Every day was a challenge, but I thanked the Lord that He had brought me this far.

Finally, on October 5, 2013, my journey took a positive note and I was able to move to *Siskin Rehabilitation Hospital*. I knew the only chance of me having any type of successful recovery was for me to have the most aggressive therapy available. *Siskin Rehabilitation Hospital* is amazing and I cannot say enough great things about it.

Doctors and therapists at *Siskin* were eager to begin helping me and made me feel like I could conquer the world. I worked from 4- to 6-hours a day doing all different types of therapy which may have been the hardest and most rewarding thing I'll ever have done. There were days I was so tired and wanted to give up. But between the Lord, my *Siskin* family and my own family, I made it through.

After two months I was able to go home. I was still in a wheel chair but I could talk… and sleep in my own bed! It was still a hard journey but I continued with outpatient therapy at *Siskin* for another year. I also joined the gym and was able to work out on my own time. I was even able to swim, which was wonderful.

Siskin Rehabilitation Hospital now has a separate wing for vented patients—a lifesaver for some people. At *Siskin*, therapy can begin as soon as you're admitted.

My life is now a *"new normal."* I have graduated to just a walker and am working just as hard to move to hand canes. My hands and feet are not 100 percent but I am working very hard to get there, as well.

I am not going to say any part of this was easy. But, with the Lord's help, and the help of my supportive family, extended family and friends, I have begun to live a full life again.

All I ever wanted to do was enjoy retirement with my family and grandkids. I am slowly becoming able to do just that. *Bless the Lord for His love and mercy.*

it's only RARE...until it's YOU.

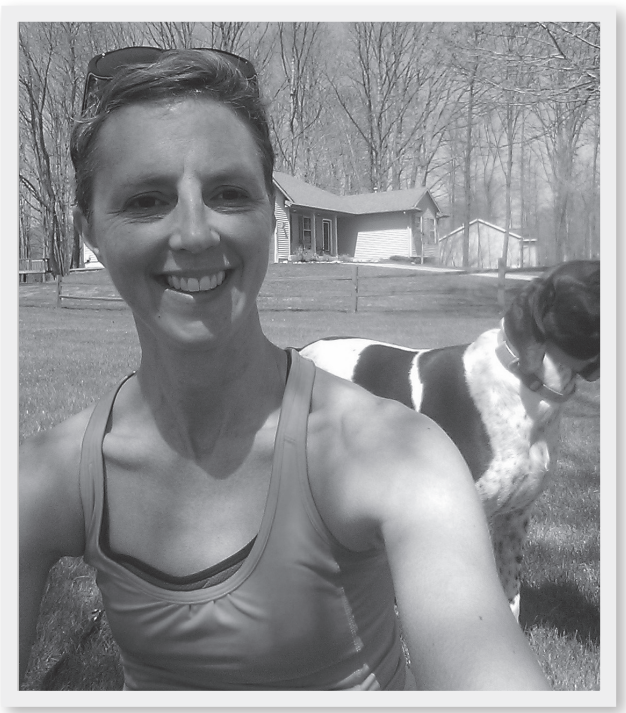
Alethea Mshart's Story

In 2011, I was stronger and healthier than I had ever been in my life. My youngest son, Benjamin, had been diagnosed with leukemia late in 2009, and by mid-2010, I had stress eaten myself to my highest weight ever. My husband and I decided that for my health and well-being—starting an exercise routine was the path I needed to take. I embraced the workouts, finding that exercise lent organization and order to my over-taxed mind, and strength and shape to my frame.

I kept up with the workouts, reaching the pinnacle of my accomplishments by running a half-marathon in the fall of 2011. The week of the half, my son had been quite sick with a diarrheal illness, which affected me as well, so my race performance was disappointing, but I was able to complete the distance, which was an enormous accomplishment.

As time went on, Benjamin kept having tummy trouble, and sharing it with me, until we finally discovered that he was fighting Campylobacter, which his puny immune system was unable to combat. After a stay in the hospital and a hefty course of antibiotics, Benjamin finally recovered from the infection.

In the mean time I was fighting my own battle, having been diagnosed with mononucleosis that winter. Though it didn't suit me at all, I rested and recovered.



In April of that year, my husband had his second back surgery, and even though I wasn't yet 100 percent healthy, I rose to the occasion, and managed the house, including our child who was still battling cancer, while my husband recovered.

On Mother's Day, I was sitting in church, and kept noticing my feet were asleep. I became entirely distracted, able to focus only on my tingling feet, that I couldn't alleviate no matter what position I moved into.

Time went on, and my tingling feet became tingling legs, which I stubbornly attempted to ignore because of the weight of responsibility to my family. Finally, in June, I went to my doctor, who referred me to a neurologist.

By the time I saw the neurologist, the tingling was joined by weakness, and had taken over my legs, was affecting my arms, and I struggled with bladdercontrol. He ordered a battery of tests, all of which returned with normal results.

As a last resort, I submitted to a spinal tap, which again, failed to yield information. Then, one afternoon, in late July, while I was sitting in the oncology clinic with my son, I got a call from the neurologist, who admitted that, to his chagrin, the last of the results from the cerebrospinal fluid had returned, and indicated that I had Guillain-Barré syndrome. At this point, well over two months from the start of symptoms, there was little hope that therapy would be beneficial, so I set about resting my body, and doing the best I could to recover.

As months went by I gained strength, with the goal always being for me to return to running. The goal proved elusive for nearly two years, but in spring of 2014, I was able to run a 3-mile stretch, and was able to continue to run. I made gains, and trained my way back up to the half-marathon distance. In the fall of 2014, I applied to be a *Road Warrior*, a sponsored runner, for the *5th Third River Bank Run,* a 25k race. I was accepted as a Road Warrior, and enjoyed six months of training with the team, and successfully completed a few 5k races, a 4-miler, a 10-miler, a half-marathon, and then the 25k in May of 2015.

After that, I set the goal of running a full-marathon in Grand Rapids. I trained through June, then in July, I started feeling poorly and struggled to keep up with my running schedule. I changed my running plan to the half-marathon distance, as I was unable to envision completing the full-marathon. My illness persisted throughout July, then finally in August, I began feeling better—with great relief—and resumed my efforts to train for the half-marathon. The training was short-lived. By the second week of August I was experiencing tingling in my feet again. I contacted my neurologist, who made arrangements for me to be seen that week.

After my physical evaluation, it was determined that I was having a recurrence of Guillain-Barré syndrome (GBS.) The doctor made arrangements for me to receive in-home therapy with IVIG, as my symptoms were not yet mandating hospital care. After a week of waiting on insurance approval, we found out that my insurance did not deem my symptoms worth the cost of the IVIG.

Disappointed, I called the neurologist, who recommended that I go to an ER, reporting progressive symptoms of GBS, which is an admissible diagnosis. By that time, the weakness in my legs was severe, with little sensation in my feet, so I packed up and went to the emergency room.

Upon arrival, I was evaluated and admitted within the hour. The doctors were surprised by my ability to function with the weakness I was experiencing. IVIG was started a short time

later, and my body responded with a brutal chill, accompanied by a fever. After slowing the drip, I was able to tolerate the therapy. High-dose IV steroids were administered along with IVIG, and I settled into a routine, with many visitors coming to cheer me up.

I spent the rest of the week in the hospital, which included my birthday. By that time, the steroids had me crawling the ceiling, so I asked to have them stopped. The doctors gladly obliged, and I was relieved to have that milestone crossed.

Later that evening, I began to feel my heart beating nearly through my sternum, but in super slow-motion. I was concerned when the aid took my blood pressure, which was elevated, with my heart rate down in the 40's. I asked for a nurse because my chest was starting to feel heavy. After a while, having seen no sign of said nurse, I used my call button. By that time, I had the classic sensation of having an elephant on my chest. The chest-pain team was alerted, and by that time my blood pressure was up to 178/120.

I was given a medication to drop my blood pressure, which worked, and also relieved the horrific pressure in my chest. The next morning, when the neurologist rounded in, we discussed the chest pressure and elevated blood pressure, which he believed to be a rare side effect of IVIG, which likely had been staved off by the steroids I had received earlier. We made the decision to discontinue therapy, after having three of the four prescribed doses, with symptoms having improved by a large margin.

By December, I became and remain profoundly thankful for the therapy I was able to receive. I resumed running in September, and was back to training for a half-marathon coming in April, and a 25k in May. My symptoms were completely gone by October, and my strength, though not what it was in May, was returning. I was optimistic that I would be at full strength soon.

I realize that my case has been at the mild end of the spectrum. I am grateful for that, and for my previous good health which has contributed to my remarkable recovery.

it's only RARE...until it's YOU.

Alexis's Story

Alexis was two-years old when she was affected by Guillain-Barré syndrome a/k/a "GBS."

GBS is an inflammatory disorder of the peripheral nerves outside the brain and spinal cord.

Alexis' symptoms began with an ear infection and a few days later, she was unable to walk. We rushed her to the ER where, after a series of tests, she was diagnosed with GBS. She was transferred to *Texas Children's Hospital,* in Houston, where she underwent further testing to confirm the diagnosis. Alexis was given a series of medications with "no promise" of whether she would ever walk again. After 3-4 days, the medication began to work and Alexis's cries stopped. She was in the pediatric ICU for seven days and when she left, she left the hospital with a walker. Through weeks of physical therapy, Alexis was able to fully recover. The doctors told us she has a 10 percent chance of GBS recurring.

While Alexis was in ICU, we were approached by a nice woman who was there to give us information about GBS and what to expect as well as what resources were available to us. We learned the *GBS|CIDP International Foundation* ("the *Foundation*") helps raise awareness and money to fund projects and help those families in need. The *Foundation* fosters and funds research as to the cause, treatment, and other aspects

of the disorder and directs patients with long-term disabilities to resources for vocational, financial, and other assistance.

Today, Alexis is a happy little girl with a cute smile and bright eyes. She enjoys school and plays with her friends just like any other little girl. We were so scared and lost when Alexis was first diagnosed with GBS, and then later, so thankful to know there are resources available to help us deal with what was happening to her.

it's only RARE...until it's YOU.

Allen's Story

Chapter 1 – 4th of July, No Asbury Park

On the 4th of July weekend in the summer of 2013, I woke up extremely tired with leg pain. Being tired was nothing new to me. I make frequent trips to Asia, typically at least nine times a year, so jet lag is pretty much a part of my life. But, the tired I was feeling was something different, more like desperation than jet lag, and the leg pain was excruciating and something entirely new. The trip to the Jersey shore we were planning for the holiday weekend was out of the question.

As the days passed the symptoms spread to other parts of my body and it became harder and harder for me to understand. The symptoms went up my right side first, then to a lesser extent, followed up my left side. Oddly, everywhere I put my arm felt cold and wet. My skin was sensitive to touch. My fingertips became numb. Waking up every day was a horrible adventure as each day brought a new symptom. I couldn't go to work and I didn't understand what was happening to me.

I did not have many doctors at the time. I had a long-term relationship with my endocrinologist to treat diabetes, but I saw no other doctors with any regularity. I called my endo to see if the symptoms could possibly be related to diabetes or perhaps thyroid disease. He said no, so we didn't set up an appointment He recommended that I see an infectious

disease specialist, as Lyme disease is not uncommon here in New Jersey and the symptoms were similar. A number of Lyme tests proved to be negative, as did all of the other tests he performed. The infectious disease guy didn't seem too interested after all of the blood tests were negative and he sent me on my way.

The days continued to pass and every day the symptoms progressed. I lost my sense of taste and smell. I tried to keep up with work email but I couldn't feel the keyboard because of the finger numbness, and as a result, I couldn't type except by an excruciatingly slow hunt-and-peck.

As long as I could still hunt-and-peck I thought I might as well try an on-line health site. I did a search on 'lost-taste" and "everything feels wet." The first two hits were cold/flu and endometrial cancer. I was pretty sure I didn't have either of those. **Note to everyone:** The web is not an MD.

I was becoming increasingly desperate as the pain went from place to place without relenting. When the symptoms became overwhelming I went to the Emergency Room where the ER physician diagnosed me with kidney failure and admitted me. Finally, I thought, some progress. Well, the nephrologist was quite sure that I didn't have kidney failure. Since I hadn't eaten more than a half-slice of dry bread a day for a week or two, my blood chemistries were completely out-of-whack. I suppose the emergency room guy could have figured that out but he didn't bother to meet with me or ask a single question before making a diagnosis.

I spent some time in the hospital but they couldn't figure out what was wrong, and although the symptoms didn't improve, they sent me home. My wife pulled the car into the driveway and, as we walked from the car to the house, my right leg collapsed and I fell into the shrubs. It wasn't just some leg weakness; I had no strength whatsoever. My leg might as well have been a piece of wet rope. I could no longer walk.

Back to the Emergency Room again where they took x-rays of the leg and said they were negative, and I should have the kidney failure addressed (the ER records still showed that I had kidney failure.) They gave me crutches and a leg brace and sent me on my way. I still have not met the doctor. **Note to self:** *Find a new Emergency Room.*

It occurred to me that the doctors I visited had never seen me before. I was wearing sweat pants, a hoodie, and winter

house slippers in the 90-degree New Jersey summer. Why was I dressed in this odd garb? For one thing I was freezing, and for another, I couldn't manage to dress myself in anything requiring any level of dexterity. So elastic waistbands and house slippers were the order of the day. Further, I couldn't get in and out of a shower or hold a hairbrush. My hair looked something like Einstein's, and the rest of me looked like a madman. I suspect that the physicians I was seeing, in addition to being faced with a number of seemingly unrelated and bizarre symptoms, suspected they were talking to a crazy person. **Note to self:** *Dress better if you want to be taken seriously.*

Finally, I had an appointment with my endo, who took one look at me and reacted as he walked through the door, *"What happened to you?"* I explained the madness that I had been going through and the series of dead ends I had experienced. He looked again, checked my reflexes (it turned out I had no reflexes) and said that I was going to see a neurologist tomorrow. He picked up the phone and called a neurologist and the next day I started *Chapter 2. The Diagnosis.*

Chapter 2 – The Diagnosis

My endo, and new neurologist, both suspected immediately that I had Guillain-Barré syndrome (GBS.) Finally, I had a name to attach to the symptoms. This was a relief as I had started to believe that I had lost my mind, or at the very least, I was Patient No.1 with something new that might be named after me, although probably posthumously. I mentioned

that I was starting to get desperate, right? After all, I had a series of bizarre and seemingly unrelated symptoms that were evolving every day as body system after body system was affected. Clearly, the emotional low-point was falling into the shrubbery, although watching my arms and legs lay flaccid as I failed the reflex test was gut wrenching.

The new problem was that there is no way to perform a direct test to positively diagnose GBS. As a result, the doctors perform a series of tests to show that you don't have anything else. That is to say, that if the tests are all negative (positive for nothing else), they may then diagnose GBS.

So I had a few questions. How did I get this? How is it treated? Why couldn't anyone else figure it out? How do we find out if I have the acute or chronic form? What do we do now?

Chapter 3 – What do we do now?

It turns out that the first thing we do is go into intensive care. I wasn't in immediate need of intensive care but there was the possibility that I could stop breathing. If that happened I would not have time to get to a hospital. By the way, I was in a new hospital now. No sense having my kidneys treated.

How did I get it? Like many people in this predicament, I had a preceding infection. An upper respiratory infection in my case. No different than those I have had in the past. Why did this one result in GBS? No one knows but there are some interesting theories.

How is GBS treated? Oftentimes, it is not. In my case, the doctors thought that it would resolve itself without treatment, but, it was lingering and finally was treated with intravenous immunoglobulin or IVIG, to shorten the duration. IVIG is one of the two typical treatments used to shorten the duration of the symptoms.

Why couldn't anyone else figure this out? First, there are only about 2,000 to 6,000 (depending on your source) cases of GBS a year in the United States. Many doctors will see a case only very rarely in their careers, if at all. Second, if you are relatively healthy, you probably do not know if your doctors are talented or not. Most of us only find this out after you need some care that challenges their abilities. As a result of GBS, I discovered at least three doctors and one Emergency Room that I won't visit again. Lastly, I think there was a bias against believing a list of bizarre symptoms reeled off by an unfamiliar patient who looked something like Doc Brown from *Back to the Future*. Too many doctors allowed me leave their care without either a solution or a direction.

Do I have the acute or chronic form? Sorry, again there is no test. I found out I had the acute form after about a year, when it didn't come back. To this day I walk on eggshells when I recover from a cold.

What do we do now? One day, my doctor simply said, *"go back to normal activity."* I still have some numbness and tingling in my lower legs and feet; it is probably permanent, but I'm walking again and have no restrictions or lack of strength. I

went back to work, continue to travel far too much, and so far I can keep up with my grandson. He's only three and will undoubtedly outrun me one day but it won't be because of GBS. All in all, it could have been worse. I'll take it.

it's only RARE...until it's YOU.

"'half-empty' can be more optimistic than 'half-full' if the glass was half-empty."—LH

Amanda's Story

My name is Amanda Guerrero. Back in 2011, I was 24 years old and living in an apartment in Santa Monica, CA. Just starting my career as a neonatal intensive care nurse at *UCLA Medical Center*, I was in the prime of my life. That was all about to change. On November 6, 2011, I started having a terrible backache. I struggled through two night shifts at work, while at the same time, having tingling sensations in my arms and legs and losing the sensation of hot and cold.

On Tuesday morning, November 8th, when I left work at 7:00AM, my legs were so weak, I could not climb stairs. I called my parents and they told me to walk directly to the emergency room at *UCLA*, but instead, I was stubborn and started to drive home. I kept telling myself that this was probably only the flu and I would be so embarrassed to go the Emergency Room if that were the case. By the time I arrived home, I knew something was definitely wrong so I went to the nearest Emergency Room in Santa Monica. They released me after drawing blood and referring me to a neurologist who couldn't see me for ten days. They told me I was probably just stressed and tired. I immediately went to bed as I was exhausted from working two night shifts.

I called my mom early the next morning since I couldn't walk unassisted, still had the backache, and was now

nauseous. She picked me up and took me to the Emergency Room at *UCLA*. After countless tests (including an MRI and lumbar puncture,) I was tentatively diagnosed with Guillain-Barré syndrome (GBS.) The doctors gave me of all possible scenarios (brain cancer, MS, etc.) With GBS being the most treatable, they had high hopes for a full recovery. However, they also told me that things were going to get worse before they got better.

I was admitted to the hospital. The next morning a dozen or so doctors (*UCLA* is a teaching hospital) evaluated me and came up with a game plan—five courses of plasmapheresis. By this time, I had very little feeling in my arms and legs. I could walk a few steps with assistance, but it felt like my legs

were bricks. I also had a terrible headache, loss of bladder control, and worsening back pain. They took me into surgery to insert the intra-jugular PICC line which is how they would administer treatment. I came out exhausted.

They started my first treatment on November 11th, after which I had a horrible headache, my blood pressure dropped and my heart rate skyrocketed. I was immediately put on a heart monitor and not allowed any pain medication stronger than *Tylenol* because GBS is a neurological disorder.

After my second treatment, I again had a terrible headache, couldn't keep any food down, and fainted. They thought I had a seizure or stroke, so they immediately took me for an MRI of the brain. Thankfully, there was no evidence of a stroke or seizure, but now I was losing the feeling in my face. They took a day break from the treatment. After the fourth treatment, blood was drawn and I was told I needed a blood transfusion because my clotting ability was non-existent. I did not want the fifth treatment but the doctors insisted treatments were helping. I was so afraid of losing my ability to speak, eat, and breathe because both sides of my face were tingling now. I also had an EKG since my heart rate was, at this point, way too high. The EKG results came back okay, too, so they told me that it was just part of the disease. Just sitting up for a few minutes made me feel like I had just run a marathon.

After my fifth treatment, and another nerve conduction test, it was decided I should start a series of four IVIG treatments.

At this point, the doctors did not like the results of my blood work and decided I needed another lumbar puncture. I had lost twenty pounds and was down to 100 pounds in weight. Meanwhile, the doctors kept taking vials of blood because they wanted to make sure I didn't have any other virus. I was also placed on anti-viral medications. Everything kept coming back negative. I had not been sick, so after weeks of tests, the doctors believed I contracted GBS through my recent flu shot.

Over the next couple of days, things continued to worsen. I now could not pronounce all sounds and people had trouble understanding my speech. I was tired, sore and exhausted. Fortunately, I have very supportive parents who cheered me on every day. In fact, either my mom or dad was there night and day with me the entire stay at *UCLA*. They would encourage me to eat and would run all over Westwood to pick up anything that sounded good to me to eat. Gradually, I was able to sit up for short time periods without my heart monitor going crazy.

After a couple of weeks, I was transferred to *UCLA's* inpatient rehabilitation center where I had physical therapy, occupational therapy, speech therapy, recreational therapy and frequent massages. Slowly I began to see the light at the end of the tunnel.

On Thanksgiving, I was able to go outside, using a wheelchair, and I made a goal with my therapists that I would be discharged from the rehab center before my 25th birthday on December

14th. Thankfully, I did make this goal, although I did have to give up my apartment and move back home with my parents. I began outpatient physical therapy and was away from work for about six months. Gradually, I began to feel like my old self and, now, have just a few residual effects.

I know I was one of the lucky ones as I was diagnosed and recovered relatively quickly and never had to have a feeding tube, tracheotomy, etc. I also had access to the best medical care.

The infectious disease physician at *UCLA* had Guillain-Barré when he was a medical student and now looked perfectly healthy. He was definitely a source of great hope and encouragement. My advice to anyone who is suffering from this frightening disease is to find a recovered GBS patient to talk with about your experience.

I've heard doctors and nurses make the worst patients. This could not be more true than in my case. As a nurse, myself, I knew how to take care of others and being in control. This was a very difficult and humbling experience. I had no control and completely lost my independence. Every day, I would ask God, *"Why did this happen to me?"* I realize now that having had Guillain-Barré has made me a much more compassionate nurse. I strive daily to be the best neonatal intensive care nurse I can be.

"I try to live one day at a time, but sometimes several days attack me at once."—KH

Anita Joy's Story: Nurse practitioner becomes Guillain-Barré (GBS) patient

My life changed dramatically in a just a few days. I had been described as the *"Energizer Bunny,"* by several of my cohorts, having held in Emergency Departments, Intensive Care Units, and many other registered nursing positions for several decades. Prior to, I completed my masters' degree in nursing and became a nurse practitioner, all while working and raising two amazing daughters.

I also walked my dog very early in the morning, each day, before heading to work in a busy family practice office.

I continued figure skating, and I ordered what I thought would've been my last pair of skis for my upcoming 60th birthday. My husband and I had actually been snowshoeing the day prior to my realizing that something was wrong.

I had mentioned that I felt weak but didn't think it had anything to do with an illness. Instead, I thought I wasn't exercising enough....it was the holidays and I had just started a new job that required me being away just before Christmas and then returning home to find my in-laws staying with us… and all the usual preparations for the holidays.

The night after we went snowshoeing, I had such odd

discomfort in both of my legs that I actually couldn't sleep or even remain in bed...the next night it was worse, so much so that I agreed to go to the ER.

My husband, who is also in health care, knew that if I conceded to go to Emergency, that the pain was more than I could manage. I don't give in to pain easily...I had been an athlete since childhood and I was accustomed to painful over-exertion injuries.

In the ER, they did blood work and gave me pain medicine. They offered hospitalization for pain control, but no diagnosis. I opted to follow up the next morning with one of the doctors I had worked with. He provided additional pain meds and advised that I go to the ER if the problem continued. I asked him if he thought I might have Guillain-Barré syndrome (GBS)... He said, *"no, GBS doesn't have pain."*

That is when my real learning about this disease began.

The pain in my legs, and now in my back, had worsened. I felt horrible, maybe due to the pain and/or the anxiety of not being able to take care of myself and/or not knowing what was happening to me.

Again, my husband took me to the ER, where I was greeted by a very seasoned nurse. She said to me, *"what did you expect? That it would get better in a day!"* She was referring to my complaints of pain. I hope she has learned, since then, that not everyone complaining of pain is searching for drugs.

I was admitted, and diagnosed, with possible viral meningitis, and my education continued. I learned that just because a lumbar puncture doesn't show protein... yet... doesn't mean it ISN'T GBS.

Hospitalization continued with many exams including MRIs, that were very uncomfortable with unrelenting, bizarre, pain in my legs and back.

One morning, a neurologist came in to examine *"the patient with supposed meningitis."* He asked me to stand on my toes. I couldn't do it... which brought me to tears. I couldn't believe I was unable to even stand without assist... a very frightening experience. My learning as a patient continued.

I learned that electromyography and nerve conduction testing are not comfortable when positive. Mine were both positive and I was then diagnosed with GBS. My husband and I had only seen GBS patients that required intubation since

we both had ICU experience. However, after several days in the neuro ICU, and frequent breathing evaluations, I didn't require treatment for respiratory distress.

Again, I learned something I hadn't known prior to my personal experience as a GBS patient; not all patients with GBS require ventilation. I received treatment with IVIG, steroids, and narcotics.

I truly became a patient, unable to even sit on a toilet seat by myself. My husband held me in place like I was a rag doll.

Today, I barely remember not being able to stand or walk. Some memories are just better off forgotten.

I learned to walk again with the help of a physical therapist. I learned that recovery from nerve damage is not like my overuse injuries in the past.

I learned to be patient with myself and continue to practice patience daily.

I began eating foods that were suggested for improving myelination and continued my anti-inflammatory, healthy diet.

I contacted Dr. Gareth Parry and he wrote back regarding his article *Pain in GBS* (helpful and appreciated.) I tried many of the suggested medications for neuropathy, including narcotic analgesics, antidepressants, anticonvulsants and several topicals… and, experienced numerous side effects.

I continue to be challenged with significant pain and contractions in my toes, feet, and lower limbs. I'm working on my pain management. I tried massage, as nice as it was, but it didn't provide me with long-term benefits. Not being able to work like I used to, I have to be frugal. I learned Reiki which I continue to use for myself, mainly my feet. I get acupuncture treatments that do provide me with a better sense of overall wellness and I do have faith in them... another lesson learned... faith in your treatments matters.

I am so blessed to have a loving and supportive husband. He is my Rock! We enjoy going for hikes with our chocolate Labrador.

I'm looking forward to attending the *GBS|CIDP Foundation International* Conference in September, 2016. The *Foundation* gives me hope for the future.

One last lesson: Everyone's story is different and I learn from them all. Thank you.

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"…GBS actually stood for 'getting better slowly.'"—JC

Ann's Story

Things in the world of Guillain-Barré syndrome (GBS) have changed since my adventure in 1996-97. I had been grading papers all afternoon, rubbing my neck and right shoulder every few minutes. Thinking I needed some exercise and time away from my desk, I set out on a brisk two-mile walk. The pain only intensified. That night I woke up with searing pain in my shoulders and back. No amount of *Advil* helped.

The next night, my husband took me to the ER where I received a blessed shot of morphine. And so the routine began. Going from doctor to doctor back and forth to the ER in a desperate search for answers. And for relief. Neither were forthcoming. After three weeks I had amassed a supply of strong pain killers—from three different doctors—none of whom had answers. My legs were becoming more unstable and I slogged through the days in a semi-conscious state. I dreaded the night when all was still and I was left alone with the searing pain.

After the first couple of weeks my husband had taken to sleeping downstairs while I waited for the dawn upstairs—two flights dividing us. One night everything came to a head. In my sleep deprived state, I must have taken a large dose of everything and anything in my home pharmacy. All was

still until I heard a thumping sound, followed by a loud bump. Then I felt myself being lifted up, and put in the car. At the ER again, white-coated figures, a needle jab, and someone asking me silly questions: What year is it? Who is the president? The white-coated figures seemed to be more out of it than I was. My answers were less than polite earning me a black mark in patient-hood. I still have the hospital report that recorded me as a "narcotic overdose" …and aggressive! I was 64 years old at the time.

Eventually, my husband and I found a neurologist familiar with GBS. He consulted and after some persistence, I was admitted to our *University Hospital* just before midnight on Christmas Eve. I would have no attending physician. Treatments during my twelve days in hospital were primarily maintenance only—with just enough medication to keep my pain from rocketing out of control.

Upon my release early in the year 1997, I received a brochure in the mail from *GBS|CIDP Barré Foundation International*. Many of my family members had been researching, praying, and keeping track of my travails.

Fortunately, my experience with GBS did not include dependence on a ventilator. Thank God. After reading the experiences of Sue Baier and many others, I know how fortunate I was. Recovery went well and I returned to teaching in August—eight months after my pain presented.

No one should ever have to go through something like this—no diagnosis, no treatments, no one to talk to about what I was experiencing. In 2001, I, and some others, held the first support group meeting in the Denver area. Sixty people attended—patients and their friends and families.

For nine years, I visited patients, listened to their stories, organized meetings, procured speakers, wrote news releases… all in an attempt to bring heighten public awareness. The greatest pleasure was seeing the look on another patient's face when I walked into his or her room and stated, *"I had what you have."*

I am much older now and still write a bit about this odd disease. People want to know how GBS affects us in later years. I answer that, *"everything that happens to us brings scars of some kind. We should wear these scars proudly because we are survivors."*

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"Put one foot in front of the other. You just never know where it might get you."—KD

Bob Doherman's Story

After suffering with aching calf muscles in my legs that led to not being able to walk within five-days, I was taken to the ER, experiencing cranial nerve involvement, and looking much like a stroke victim since the left side of my face drooped.

An excellent ER doc put me through a series of tests and eliminated stroke or a brain tumor. After a spinal tap, I was diagnosed with Guillain-Barré syndrome (GBS) on September 9, 2001. I was admitted to the hospital at 2:00AM on Sunday morning and had my first IVIG infusion before noon.

The GBS progressed up my extremities, effecting both my legs and arms, but stopped just short of my diaphragm. All four quadrants of my body were paralyzed, but I could still breath on my own. I could do almost nothing without assistance. I could not feed myself, brush my teeth, or roll over in bed.

Because the cranial nerves were involved, I had to manually hold the left side of my lips together to drink using a straw. I could not close my eyes for several weeks. I was lucky in that I made a rapid and good recovery. I spent nine days in the hospital and 21 days in an acute rehabilitation hospital, walking out to go home using a straight cane. After my release, I had several weeks of outpatient therapy and went on my way.

During that period, my family was very much involved. We had no understanding of Guillain-Barré syndrome and the anxiety for all of us was high. My daughter was at my side 24/7 during my hospital stay. My family was with me on a daily basis during rehab and recovery at home.

I was employed as a manufacturer's rep in sales. Needless to say, I was not working during my hospitalization or recovery. My income was reduced by 80 percent for the first few months. Following release from therapy, I made some local sales calls by telephone. I progressed to making client visits (with friends or relatives at the wheel.) It was six-months before I was recovered sufficiently for travel to clients by myself on a state-wide basis.

Today I am fully recovered. I still have tingling in my feet and have not regained all of my hand strength.

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Bob Pinney's Story

My name is Susan Pinney.

On February 10th, 2008, my husband, Bob, was diagnosed with Guillain-Barré syndrome (GBS) at the age of 63. Although we had no idea at the time, Friday, February 8th would be his last day at work.

Bob had been experiencing sporadic leg cramps for the last week as well as a nagging backache while out to dinner that Friday night. I walked up the steps to the parking lot behind him and noticed that he appeared to stumble slightly on the step but thought nothing of it. In bed later that night, his back was hurting and Bob couldn't find a comfortable way to sleep. Spending most of the night awake tossing and turning, he woke me around 4AM complaining of the backache as well as a feeling of pins and needles in both hands and feet.

Within the hour, we arrived at the Emergency Department of our closest hospital in Cary, North Carolina.

The doctors seemed to be mainly concerned with the back pain and gave Bob narcotic pain killers. He was given a CAT scan which showed nothing out of the ordinary. After several hours, we were sent home with a prescription and no diagnosis. Throughout the day, Saturday, Bob needed my help to maneuver from room to room. His feet were

feeling numb, and his balance seemed to be off. We originally thought that it was the effect of the pain killers he was given at the hospital. Later that afternoon, when attempting to sit on the couch, Bob's legs gave out and he fell to the floor. His legs could no longer support his weight. At that point I called EMS, and Bob was transported back to the hospital.

None of the doctors who saw Bob were able to pinpoint the cause of the strange symptoms he was having. He had an MRI and was finally admitted that night.

The next day we noticed more, and worsening, symptoms. Bob said his legs felt heavy, and he now needed a catheter. Hand/eye coordination was not good, and his blood oxygen levels dropped. Bob seemed to forget to breathe. It was late in the afternoon before a doctor came to the room to examine him.

My stepdaughter had asked for a hospitalist to be paged since her dad seemed to be getting worse rather quickly. We were all so scared, not knowing what was happening. Fortunately, the hospitalist on call that day happened to be a neurologist. When she checked for reflexes and found none, and asked Bob to raise his eyebrows, shrug his shoulders, smile and frown, she soon determined that he probably had GBS.

That night Bob was transferred to a hospital in Raleigh because it had a neuro-ICU unit. He was admitted to ICU that night and remained there for 102 days. Bob started receiving plasmapheresis treatments the very next day.

During one of his treatments, four days after being admitted, Bob stopped breathing. The paralysis had reached his diaphragm. He was intubated immediately and put on a ventilator. Bob had a tracheostomy six days later. At some point, a feeding tube was inserted into his stomach so that he could receive nourishment. Bob also had a course of IVIG after the plasmapheresis.

Therapists came to Bob's room to perform range-of-motion exercises. During his stay in ICU, he suffered from pneumonia twice, a blood-borne infection, MRSA, a bowel blockage, and hallucinations due to ICU psychosis. Bob was unable to communicate due to total paralysis and being on a ventilator. Attempts to begin to wean him off the ventilator proved unsuccessful.

By early May, as he became medically stable, it was determined that Bob needed to be moved to a LTAC facility. There he received physical therapy and soon began to breathe on his own.

On May 20, 2008, Bob was transferred to *Select Specialty Hospital* in Durham. While there, he continued physical therapy and further breathing treatments. He was completely off the ventilator by Father's Day and soon did a swallowing test in preparation to begin eating solid food.

Being able to breathe on his own meant also being able to begin to speak again, first through a valve in the trach and then with his own voice. On July 3rd, Bob was transferred

back to Raleigh to *WakeMed Rehabilitation Hospital* which is part of the same facility where he was in ICU. With the aid of some assistive devices, Bob learned to feed himself. Physical therapists worked with him to resume the strength back in his legs and arms. Eventually he was able to sit for long periods of time in a wheelchair. I was trained in transfer techniques and how to care for him at home.

Bob was discharged to home on August 30, 2008, leaving in a wheelchair and still unable to stand, or use his hands and arms.

Outpatient physical and occupational therapy started on September 2nd. Bob continued outpatient therapy for another 13 months. He graduated from a wheelchair to a walker. Strength, and small motor function, returned to some extent. In October of 2009, we took our first long-distance car trip, a 9-hour drive to see my son and daughter and their families in Ohio.

Today, Bob is able to walk on his own inside the house. He uses a footed cane outside as well as holding someone's arm for balance. He is able to perform all personal grooming by himself and no longer needs constant supervision. Bob has remained involved with friends and organizations using the phone and a computer.

Bob and I have been on five Caribbean cruises since December 2011 as well as many trips by air to Wisconsin and Ohio to visit relatives.

Bob still has no reflexes or feeling in his legs below the knee. His hands are affected by severe muscle atrophy and he has trouble performing small motor functions. He remains unable to drive and fatigue is always an issue. Bob has learned to listen to his body and takes short naps when necessary. Nerve pain is controlled by medication.

We are very thankful for the level of recovery that he has attained and for all the things that he is able to do. It has been and continues to be a long process, but the focus is always on not what has been lost, but what we have gained!

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"I was stunned. They'd said this could happen… but I hadn't really expected it. It was awful."—WK

Bob Shea's Story: Breaking Open

Life can break you or it can break you open. That is one of my favorite sayings, and it is refers to something everyone who has suffered from Guillain-Barré syndrome (GBS) knows well.

I was diagnosed with GBS on September 19, 2002, and I endured a series of physical challenges: total paralysis; placement on a respirator; vision loss; pneumonia; bacterial and urinary tract infections; and a pressure sore at the base of my spine.

However, those maladies were not the worst of my experiences with GBS. The combination of the disease and the morphine had contaminated my mind. I no longer was able to see the line that separated delusions from reality. There would be many evil and ugly delusions. My wife told me she was leaving me for another man: my children were in trouble and I was losing my family; the staff at the hospital hated me to such an extent that a nurse was planning to kill me. All of these delusions are as real to me today as sitting at this desk writing this story. Of all my experiences with GBS, losing my mind was far and away the worst.

Unfortunately, the bad news would continue. A few days after Christmas, we received notification that our health insurer

was going out of business. I had hundreds of thousands of dollars of unpaid medical bills. We were financially devastated and sure to lose our home.

Then, a dark cloud descended on my mother. She had taught eighth grade children in the *Chicago Public School System* for 40 years and was a force of nature. She visited me every day for the seven months I was in the hospital. The neurologists were terrified of her and the nurses loved her. The bright and powerful woman that was my mother was diagnosed with vascular dementia. She would eventually move in with my family and we would begin the long goodbye.

The dark cloud would then move to my wife. She was diagnosed with an aggressive form of cancer that had spread to a second location. She would have surgery, and a month later, begin the horrors of chemotherapy. I now would have to take on the role of caregiver for my mother and my wife.

What is it that brings you back? What enables you to break open rather than being broken? Physically, when I was going through eight months of physical and occupational therapy, I was like a brand new baby starting over again. But psychologically and spiritually, it was the care and compassion of one person who showed me a new life.

When I was transferred to another—the third—hospital, I was assigned a speech therapist named Sarah. Sarah helped me learn how to speak and swallow again. I had not been

able to eat or drink, and was nourished through a feeding tube, for the previous four months. As we worked together, Sarah would talk and laugh with me. One day she asked what would be the first thing I would eat or drink when I passed the swallow test. My answer was orange juice. It makes me sound boring but I could have died a happy man for one glass of orange juice.

On the day of my swallow test, Sarah accompanied me to the lab. She went in with the technician while I was given the test. When the test was completed, I was alone and praying that I had passed. The door opened and Sarah was looking at me with tears in her eyes. The second I saw her tears, I knew I had passed. We celebrated because we knew I was successful. Sarah took me back to my room. What I did not know is that prior to, she called he nurse's station on my floor.

Shortly after I returned, three nurses appeared at the door of my room. They all had big smiles on their faces and one was holding a tray. They announced it was a lunch time. There was some broth, a bowl of *Jello*, and in the right corner of the tray… a glass of orange juice! It was a miracle. The taste, the smells and the textures were miracles. I now have a glass of orange juice every day. Every day it remains a miracle and everyday it reminds me of Sarah.

The dark night of the soul is painful, but ultimately a blessing because, it is what allows the soul to grow. It is our choice, however. We can allow life to break us, or, "break us open."

Now, I am the person bringing the orange juice. I volunteer full-time at *Rainbow Hospice* in Chicago. The pain of my dark night of the soul has meaning when I can help a person or their families when they are facing death.

Guillain-Barré syndrome broke me open. It can be a gift if you allow it.

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Bridget's Story

On the night of November 16, 2012 I was driving an hour south of my hometown to a Carrie Underwood concert. During the drive my feet began to feel tingly, like they were falling asleep. The entire night through the concert I tried to wake my feet up, but no luck. Foolishly, I thought this was a pregnancy symptom, as I was ten weeks pregnant at the time. When I woke up the next morning, the tingling had spread to my hands and arms. It was the second day I woke up and was unable to walk up my stairs, my legs were too weak. It was that day I was admitted into the hospital and would spend the next 84 days away from my three young children, Lauren, Sophia, and Michael… all under age 5.

By evening, I was diagnosed with Guillain-Barré syndrome (GBS) and would start my first round of plasmapheresis the next day. By this time, pain had taken over my body. My husband was carrying me to the bathroom and repositioning me in my bed just about every 10 minutes.

I went into surgery first thing the next morning to have a port placed. That procedure was very scary for me, not only because of the procedure itself, but because I was pregnant and needed to be awake for the procedure.

I still had no clue about the road I was soon to take. The port placement would be only the first of multiple surgeries

to come. Because I was in my first trimester, the only pain medication I was able to take was *Tylenol*—and it was not managing the pain. *Tylenol* was also ineffective during my plasmapheresis treatments.

I struggled to keep a consistent blood pressure during plasmapheresis treatments to the point that during the second round, two days later, as I returned to my room, that my numbers dropped to sixty-over-thirty. My husband and twin sister were with me and I remember hearing them yelling at me to stay with them; yelling at the nurse to help me; and my sister running out to the hall for help. By evening I was in the ICU. My breathing was more labored and my blood pressure was still unstable, so much so, that they airlifted me to the *University of Iowa Hospital* where I would be admitted into the medical ICU. I am glad they did, because it was just four days later when my lungs collapsed, I was intubated, and ultimately placed on life-support.

I spent fifty days in the MICU before being transferred to *Mercy Hospital* in my hometown for five weeks of inpatient rehab. While in the ICU, I celebrated Thanksgiving, Christmas and New Year's. I missed my son's first birthday and my daughter's third. After about a month, I finally began the process of being weaned off life support. My heart rate dropped several times, one time stopping for 8 seconds. Doctors contemplated inserting a pacemaker, but I was able to show enough progress to avoid that. The pain

was excruciating—the type of pain that makes you want to rip your arms and legs off. My body temperature was never consistent. I remember days when I had the room temp down, a portable fan blowing on me and a cool washcloth on my forehead, while my sister sat by my side wearing her winter coat, a hat and wrapped in a blanket!

Dealing with the seemingly never-ending pain was a struggle, especially when I was intubated, then trached, unable to communicate beyond mouthing things. However, nothing was worse than the emotional toll. Days when my children could come visit were both my worst and best days. My husband and I first worried about how it would effect them—seeing me with so many things hooked up to me—but their presence was great therapy and motivation for me to give everything I had to improve. The hardest part was after they left, not knowing when I would see them next, worrying about how scared they were, and not being able to do one thing to support them. Because I was in such a serious state, my husband never left my side, how scary for them to have us both gone.

This may sound surprising, but the last five weeks in rehab were the most difficult of hospital stays. The physical struggles, like only being able to sit on the side of the bed for a few seconds, seemed never ending to me. While the emotional part was taking a huge toll on me. Even though I felt everyone else's lives were "back-to-normal" because they could sleep in their own beds, and I was confined to a ten-by-ten room unable to

move my legs, needing to call for assistance just to roll to my side, I was wrong. They weren't.

My room was covered with pictures of my family. Yes, these pictures were my motivation, the most recent picture of my three little ones was taped right on my bed so I could see them and keep myself motivated. But I also became sad at times looking at those pictures. They were pictures of me, healthy, playing with my kids, carrying them, having them sit on my lap. At that moment, my legs were so sensitive, my bed sheets couldn't even be tucked in at the end and I couldn't even lift my own arm, let alone my child!

I can say that I had superior physical therapy support, and the much need support for my emotional struggles. About half way through my five-week inpatient rehab, I was still to have my twenty-week ultrasound. I was just a nervous wreck about it. Once I was put on life-support, no one spoke of my pregnancy. I had fetal heart rate checks every few days, but that was it. You can imagine the relief and joy my husband and I felt when the technician gave us a good report on our daughter. Everything seemed to look good.

I was amazed at the progress I was able to make during my five weeks of inpatient rehab. I had learned to eat, talk, dress myself, and even walk short distances during my time there. There was no happier day then the day I was discharged and, FINALLY, could be home with my family!

Home was difficult. My living room was my new bedroom because I was unable to maneuver stairs. Three kids under age four is a lot of work, and my husband added another one… ME!

Within a month, my outpatient therapy had improved and I was walking with a walker—soon a cane. Seven months from my onset of GBS, my daughter was born a healthy baby girl. At that time, I was walking independently. We joked, because it was a contest of who was going to walk on their own first, mommy, or Michael, my one-year old. I won!

By summer, I had a much better handle of, and outlook on, things. Instead of being sad that I couldn't hold my sons hand as he walked unsteadily, kick the ball with the girls in the yard, or teach my oldest child to ride her bike, I appreciated being alive and being able to watch my husband play that role for the time being. I am three years out now and there isn't anything stopping me from playing with or caring for my children. I am enjoying my role as a liaison for *GBS|CIDP Foundation International* and hope I can support other families stricken with this scary disease.

I must say, the quick diagnosis and fabulous healthcare I received, along with my amazing physical therapist, are all the reasons why I have recovered so well.

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"Nerves grow back about a millimeter a day."—GK

Chris's Story

One morning in June, I woke up and the last two fingers on my right had were numb. Like most people, I thought that my fingers would *"wake up."* The next morning, the last two fingers on my left hand were numb. Again, I thought they would *"wake up."* Unfortunately, they did not.

I called a neurologist to make an appointment but she could not see me until September 28th. While waiting, my hands went completely numb and so did my feet. I could not feel anything in one hand—nor could I hold anything. My balance was shaky and walking was pretty difficult. My speech was jumbled.

When I was finally seen by the neurologist, I was given an electromyogram. The neurologist knew right away what is was—Chronic Inflammatory Demyelinating Polyneuropathy (CIDP.)

The neurologist explained what that was but I just could not wrap my brain around it. How did I get this? How is it treated? Will it go away? I was told, *"don't worry, there is a treatment and it is top of the line."* The treatment? Intravenous Immunoglobulin or IVIG. I asked her how long I will be undergoing treatment? She said, *"you may have them for the rest of your life."*

I made an appointment for a follow-up visit and left the office. Once in my car, I drove home and remember none of it. All I could think of was, how do I tell my wife? How do I take care of my family? My 90-year old mother had just come to live with us because she could not be alone. What if this gets so bad that my wife would now have to take care of both of us? I was devastated. When I arrived home and shared the news with my wife, she could not believe what she was hearing!

I started my IVIG treatments in November. It took that long to go through all the tests before any treatments would begin. And, I was still trying to understand what was happening to me. My birthday is in December and just my luck, my IVIG treatment was on that day. Happy Birthday!

I had a wonderful career, one that I enjoyed immensely. I traveled to places like France, Italy, Mexico, and Brazil. I was now unable to do what I've loved to do for 20 years. So now what?

At church one Sunday, I was sitting quietly before the service started and prayed. I am a man of strong faith. While sitting, praying, and thinking, I thought, OK, if God gave me this illness it must be for a reason. I did not know what that reason was, but there must be one.

So, I went home and I began an internet search to see if there were any kind of support groups for CIDP. I came across the *GBS|CIDP Foundation International.*

Another day I was just sitting, kind of feeling down, when I decided that I would not let CIDP define me. I do the treatments and just keep moving forward. I am trying to be an example to the young people that I mentor that no matter what you are dealt, you can still have goals and they can be reached. So I keep doing everything I love to do but I make sure that I take care of myself in the process. I am doing my best to live my life to the fullest. I have a great support group in friends that help me when, and if, I need it. They don't look at me as a disabled man. They know me as their friend Chris, who happens to have a rare illness.

It has been four years since I was diagnosed with CIDP. I continue to receive my IVIG treatments, or as a lot of us call it, "getting juiced."

My hands and feet are still numb. I still have difficulty walking. And, I still have problems holding on to things. My speech is still jumbled from time to time. And, I live with pain all the time. However, I do not allow any of those issues stand in my way.

With God's help, I just keep moving forward.

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"I had to mentally place myself in my 'happy place,' if I had any chance of getting through this. Hours felt like days and days felt like weeks."—MM

Christina Garamendi Aliende's Story

My heart was pounding with excitement as I boarded the plane in Sacramento. The first Garamendi child to join the *Peace Corps,* and I was on my way to Ecuador. Having just graduated from *UCDavis,* I was filled with hope and expectation. Months later, I found myself paralyzed, and in intensive care, at a hospital in Quito. A spinal tap had confirmed that I had Guillain-Barré syndrome (GBS.)

I was medi-vac'd to *Georgetown Hospital* where I began the long journey of treatments to bring me back to life again.

Helplessness and depression hit hard, however, calls from survivors like Ralph Neas, and others, gave me hope. My younger sister bathed me, and my Dad carried me around the house in his arms like he did when I was a baby.

When I was finally able to return to California, my fiancé, Eugenio, taught me to walk again, diligently working with me for months.

At the family ranch, when I was finally able to walk down the aisle on my wedding day, there was not a dry eye. Dancing with my father for the first time since GBS, I whispered in his ear*, "Daddy, I can't believe I'm dancing."*

As they say, *"the wounded become the healers,"* and before I even completed my recovery, I began my studies to become a

nurse. After graduation from *Johns Hopkins*, I helped establish a Women's Clinic in a poor, rural, area in northern California.

I am blessed with two children and, of course, my wonderful husband, Eugenio.

it's only RARE...until it's YOU.

D. Alexander Holiday

In 1971, I was ten years of age and in a second foster home. One morning, I was attempting to get out of bed, shake the sleep from my eyes, stand and walk to the bathroom—customary, like I had done for most school mornings and especially since I was beginning to like my new foster parents, my new friends, and the new school. I felt a little light-headed, dizzy, and maybe even slightly nauseous. I stood at the sink, holding onto the porcelain frame and trying to shake away both the dizziness and the weakness in my bones. I was having trouble standing without holding onto something. My legs felt as though they were too weak to hold up my body.

Somehow, having used the bathroom, washing in the tub and even getting dressed into the clothes my foster mother had placed on the bunk bed were I slept, (under my new, older, foster brother, I made my way downstairs to the kitchen and took my place at the table. I waited patiently for my brother and foster sister to join me for breakfast before going to school. As my foster mother helped me into a light coat, she noticed how unsteady I seemed trying to stand and get dressed. She asked if I was alright, even touching my forehead to check my temperature. Although unsure of what was happening to me, –but guessing that whatever it was it would pass, reluctantly stood at the side door and said goodbyes to us, handing us our lunches before retreating back into the house.

I met up with my friend from across the street and another from down the block, and we proceeded to journey off to the school. I recall holding on to fences in front of houses, too weak to take steps before first doubling over and almost bringing up my breakfast, but also too weak in my legs to walk any further. My brother went back to the house and shortly returned with both my foster mother and my foster sister.

I sat in the living room while my foster mother stood over me, both feeling my head and talking on the phone to my foster father. She asked him to return home so that I could be taken to the hospital. I did not know what to fear more, my large, overbearing, new foster father or the hospital. Both had managed to frighten me during the brief time I was in this new home, and with this new family, as well as the time I dropped a bowling ball on my foot and broke my big toe. Before I realized it was happening, my foster father was home, bundling me into a coat, carrying me over his broad shoulders, out the door, placing me in the back seat of the car and speeding us all off to *Jamaica Hospital.*

Due to space, the remainder of my story can be found in my book, *In The Care of Strangers: The Autobiography of a Foster Child: A Memoir.* In my writings, I speak openly about my life and about my experiences as a Guillain-Barré survivor. Remember, it was 1971, nine years before *GBS|CIDP Foundation International* would be founded. There were no miraculous cures like IVIG or plasma treatments to expedite

recovery, so today I have to wear AFOs. I have other residuals, as well. However, I received the education I dreamed of as a young boy, two college degrees and I have published my writings. I am also blessed and honored to be a liaison for the *Foundation.* It's been a hard life… but one I wouldn't trade with someone else. Good luck to all of you on your journeys.

An exerpt: *He believed that he had done something bad, again, getting sick like this and having to be in so many hospitals. There he was, bringing all this trouble to the Pleasants and his social workers—this new one having to come and drive him to the hospital.*

He felt mad and angry with himself for not being able to use his hands and arms and legs anymore. Maybe that was why they were sending him away to another hospital. His social worker told him that he was going to get plenty of physical therapy at this hospital, and if he worked really hard, he might be able to walk again one day.

He didn't understand what she was saying. What did she mean, that he would have to work hard? What were they going to do to him at this new hospital? Were they going to hurt him, too? Why did everyone want to hurt him?

First, Ms. Blackwell, that mean woman with her beatings and bad food. Then he was taken away from her and brought to the Pleasants' house, only to be beaten by Mr. Pleasant because of some lie that the schoolyard lady told about him. Then he had to go to the hospital because someone tripped him in the schoolyard and he blacked out when his head crashed onto the concrete.

He dropped a bowling ball on his foot, and he had to go to the hospital again. He was such a klutz, always having to be in hospitals for being so clumsy. And, here he was again, being taken to another hospital because he had done something wrong. He was sick and unable to use his hands and legs. He was being sent away.

Debbie's Story

My name is Debbie Buckley and my GBS story began in February of 2010. I was a very healthy, active, 53-year old mother of three grown sons. I exercised on a daily basis, ate healthy and really worked hard at trying live a healthy lifestyle. I always assumed that if you took great care of your body it would repay you by not getting sick. That was not the case this year.

My husband and I took my youngest son, Tyler, a high-school senior, car shopping as he was off to college in the fall. It was a beautiful, sunny, day but I just wasn't feeling right. I felt achy and malaise—as if I was coming down with the flu. So, I thought, I just needed extra rest and went to bed a little earlier that night. A few short hours later, I woke up with a very strange burning pain in the kidney area on both sides of my back. Unlike anything I have ever experienced before. As the pain intensified with every passing hour, my husband thought I might have had a kidney stone, so off to the ER we went. After blood work and a urinalysis, I was told I did not have a kidney stone and that I probably pulled a muscle in my back and just couldn't remember how, or when. I have had pulled muscles in my back before however, I knew this was something different. My husband agreed, as he, a chiropractor, has helped me before with muscle strains and sprains.

The hospital sent me home with *Oxicodone* which only took the edge off the pain. With each passing day and sleepless nights, the pain and burning continued to intensify until it was so excruciating that we both knew it was time for another trip to the ER.

P.S. I was given the same pulled muscle diagnosis and was sent home once again!

By Friday night, I did not know how I could possibly survive a fifth sleepless night so I didn't even bother trying to sleep. I paced through the house for hours to try to allow my poor husband to get some sleep since he also hadn't slept all week. Now Saturday morning, I was in excruciating pain not to mention exhausted from lack of sleep, so my husband decided to take matters into his own hands and make some

calls to a several doctors he knew. Within an hour I was admitted to our local hospital. We thought *"thank goodness, we'll finally get some answers!"*

Since we do not live close enough to a city large enough to have a teaching hospital, I spent six days on morphine and had very little testing being done. Needless to say, I was going downhill fast.

On the sixth day, I developed *Bell's Palsy* on the right side of my face. My husband and son's knew I had to be transferred to a hospital better equipped to diagnose me. Our eldest son, Jason, is a Pediatric Cardiologist who attended medical school in Tampa three years prior. Ryan, our second son, was a medical student that year in Tampa, so the contacts they made while interning were able to help me be admitted to *Tampa General Hospital*. Off we went, all drugged up with morphine, to make the two-hour trip to Tampa. That trip turned out to be the best thing for me. Four-days of tests were ordered and preformed around the clock. By the fifth day I started complaining that my toes hurt and that they were very numb.

My neurologist ordered a spinal tap which led to finally solving the medical mystery—I was diagnosed with Guillain-Barré syndrome (GBS!)

I had never heard of any such disease but my husband and sons had. So, of course, they were relieved that there was

finally a name for what was happening to me. But, we were still very nervous about the possible outcome. Because I had a mild case—with atypical symptoms—it was a very difficult situation, and hard to diagnose. I did not have the initial numbness, paralysis or weakness in my legs that I learned many GBS patients experience. Weeks later during my re-cooperation, I did recall, that as I was out walking for exercise with my husband months prior to getting sick, my feet kept getting numb and that numbness traveled up one leg a few times.

After finally being diagnosed, I had to continue on morphine around the clock because it took two days for my physician to receive authorization from my insurance company for IVIG treatment. I received the treatment for four days at four-hours a day and after the first round of treatment I felt amazing compared to how I had felt the previous two weeks and thought, *"Yay,"* I was ready to go home!

I was one of those impatient, determined, patients who thought as long as I'm feeling good I can walk by myself to use the bathroom—I was so wrong! I fell twice and was very lucky not to have broken a hip, or worse, hit my head, so I realized I better chill out and listen to the nurses, my husband, and my sons who were all so amazing and patient with me through it all. I didn't realize that after being in a hospital bed for two weeks my legs would be like rubber and that it would be very difficult for me to walk.

I'm a petite, small-bone, woman who before this illness, was a very healthy, 104-pounds, losing 8 of those pounds and a lot

of muscle tone. I knew then I had to do what I was told but was also very determined to begin using a walker and start my slow laps around the nurse's station. With each lap the nurses cheered me on and gave me the incentive and drive to keep pushing.

Within a few days, my doctor told me what I wanted to hear. He said, *"you can go home,"* which was two days before my 54th birthday. Of course, I was very happy, but I also knew it was not going to be a quick or easy road to recovery. Nonetheless, I was so ready for my two-hour trip home with the little bag of meds I would need to manage the pain.

Today, my only residuals are permanent nerve damage in my toes and in my back. I feel pain and numbness off and on every day in my toes and muscle pain in my back as it was explained to me— that the nerves attached to the muscles are damaged therefore the muscles in my back are not receiving the proper nerve supply making them very weak. I've been able to manage pain with *Gabapentin*, a low-dose muscle relaxer. Before GBS, I was always into fitness and exercised almost every day. That said, I decided to try hard to get back into exercise and, hopefully, take less meds. I'm happy to say that, although I do live with residual pain on a daily basis, exercise provides great relief. I'm back to walking 2-3 miles per day, practice yoga—great for my back muscles, and for fun, I do Zumba.

It took a while after GBS to build up my stamina for exercise, but I find the more I do, the more I can do!

When I returned home from the hospital, I thought my life as I knew it was over. Although I was lucky enough not to have a severe case of GBS, I still could not imagine being able to do all the things I wanted to do and enjoyed doing, like going to work, caring for my home, gardening and exercising. But, I also knew not being able to do these things was not an option for me. I still have to remind myself not to overdo it as I find fatigue presents more easily then prior to GBS. Now, I just go with it, and take more breaks. If you're reading this, chances are you are also a recovering GBS patient. Please don't lose faith and do your best to fight your way back even if your life has to be altered in some ways.

I feel very blessed that I'm here to share my story, and also extremely grateful to have a wonderful family that was such an awesome support throughout my ordeal. I think, when a loved one gets sick, it is vital for a person's recovery to know that they have the understanding, love and support that they desperately need. I also want to say how wonderful the doctors and nurses were at *Tampa General Hospital!*—such and amazing team of professionals!

I also want to thank the staff at *GBS|CIDP Foundation International* for all the work they do! I look forward to each newsletter that arrives in the mail. It is informative but also inspiring. It gives me the support and strength that I need to continue to move forward with my life.

it's only RARE...until it's YOU.

Donna Mlady's Story: Destination Unknown

My name is Donna Mlady, I am 57 years old, and I'm definitely not a newbie to Guillain-Barré syndrome (GBS.)

I came down with GBS back in January of 1983. I was only 23 years old, and had my dreams and a future all arranged. I was a professional musician, 12 years of voice, piano and guitar.

It took four trips to the ER, one to a chiropractor, four to my primary care physician, and all I heard was *"it's a viral infection."* The flu? It was in my head? Hyperventilating? (This really floored my mom.)

The doctor actually told my mother the reason was because of a previous abortion—which went bad! I about fainted. They never even had a OB-GYN examine me!

I went to stay with my parents. The next day, I woke in my mother's bed and was unable to move my legs or feet. I stared at them and my brain would not connect.

My mother brought me a popsicle on her way up and stayed to rub my fee and legs, trying to help me move them while I ate my popsicle. All of the sudden I began choking. Mom did not know what to do. We met my doctor at the hospital.

Unable to get into a bed, I was given a soda and, once again, choked. Four doctors rushed into my room.

I overheard a nurse telling the doctors she felt it looked like

a case of ideopathic Guillian-Barré syndrome.

A lumbar puncture showed my protein levels were "a mess," and up to the ICU I went. On my way, I sang my very last song, *"These boots were made for walking."*

I lived at the hospital for 14-months, then to rehab, and then lost my voice due to the intubation. I survived double-pneumonia and a 107-degree temperature.

I was doing great until 2-years ago, when I, again, became very ill. I needed surgery within 6-hours or I was told I would die. That was in June of last year. In January, I was back in the hospital… and almost died, again! OK, so I may have been a cat in a past life.

A 10% chance of making it with GBS. Almost no chance last June, and another 30% chance in January.

Today, I'm battling two more issues. Chronic Inflammatory Demyelinating Polyneuropathy (CIDP,) AND Chronic Myloid Leukemia (CML.)

I enjoy the family I have grown to know and love in my GBS support Group. In my present state, I may not be able to attend any functions. So, I would love to hear from you all. Just knowing you are there would really be special for me.

I was able to attend the Philadelphia symposium and it was the best time of my life

With that, I hope you enjoyed a day in the life of Donna Mlady.

Elizabeth Coleman's Story

Dear Mrs. Benson,

I received the Fall/Winter *Communicator* with much pleasure. In it, I found, *"A Fact Sheet on GBS for the General Practitioner/ Primary Care Physician*. The piece is very interesting and informative. I have met so many laypersons who have not heard of Guillain-Barré syndrome (GBS,) including most of my friends.

When the question is asked, *"What's that?"* I give a presentation about my experience with GBS. Last year, I had an appointment with a physician who had never heard of it so, I sent him some material from *GBS|CIDP Foundation International.*

In my past correspondence to you, I stated I had learned of the *Foundation* through library research. At my request, you sent me the booklet, *"An Overview for the Layperson,"* and now I receive the *Communicator* newsletters. I always look forward to each new issue and I have started my own GBS library.

Mrs. Benson, I would now like to share the experiences that lead up to my *"full blown GBS—the most severe form"* (as stated by my doctor.)

In December, 1998, I suddenly came down with an intestinal disorder. It felt like something was scraping up and down my intestinal tract, continuously—no relief.

I saw a doctor in the urgent care department of the HMO I belonged to at that time. He gave me a rectal examination, a chest X-ray, and a prescription for pain. Then he sent me home. *"Come back in two weeks if you're not feeling better,"* he said.

I returned in less than two weeks with the same problem and saw a different doctor who had me undergo a sigmoidoscopy and a barium enema. He stated that, if the tests were negative, further tests would be needed. The tests were, in fact, negative as well. However, it was at that time I decided to withdraw from my HMO and enroll in a private healthcare facility.

In February, 1999, I saw my new doctor and explained to her about the scraping up and down sensation which settled in the lower abdomen. She administered additional tests and more blood work with the last examination being in August of 1999 (including the use of an endoscope.) In September, I still did not feel well. I couldn't balance very well. I felt as though I was coming down with the flu and sort of stumbled when walking. If I sat down, I could barely get up without help. I saw the doctor on an emergency visit but was sent home to rest. She also felt I was coming down with the flu.

On October 23, 1999, I found myself unable to walk and had to support myself by holding on to a chair, wall, table, etc. just to keep from falling. I gradually came to the point where I could not open or close doors, could not turn on the faucet, and dropped whatever I tried to hold with both hands. I thought I had a bad case of flu. Somehow I crawled into bed.

The next day was worse. My daughter, who lived next door, came over. Thank goodness she had a key to my house because I could not open the door.

She found me crawling around and felt strongly I had something other than flu.

I was taken to the ER by ambulance. I was examined and sent home. I was told to return if there was further weakness, shortness of breath, bowel or bladder changes, fever or worse. My condition worsened. I returned to Emergency by way of the same ambulance and attendants. I couldn't even sign the admission slip. My whole body was like jelly. I could not hold my head up. I was unable to move.

This time, I was seen by a different doctor who asked my permission to do a spinal tap. The tap proved his suspicion—that I had Guillain-Barré syndrome.

He showed me an image of the middle of my back; between two vertebras was a *"fatty piece of protein"* with what looked like stems festering from underneath out toward both sides of my body. The doctor stated, *"We'll keep you here for a couple of days. You'll be fine and thank goodness there's no paralysis."*

My condition worsened. The paralysis began about a week later. At that point I was told I would have to be air-lifted to a hospital that was better able to treat me. My transfer diagnosis was Guillain-Barré syndrome (Post Infectious Polyradiculo-neuropathy,)

At Emergency, I was started on intravenous hyperimmune gamma globulin and a course of methylprednisone. I was transferred to another hospital for plasmapheresis. I was unable to get out of bed without assistance, unable to ambulate and unable to sit in a chair or wheelchair.

When I arrived at my final destination (another hospital) I was met by a doctor (a neurologist who is "an expert in GBS".) He explained my illness to me and stated I had ''full blown GBS."

He also said I would recover and, hopefully, begin to reverse toward recovery sooner than expected. If I hit bottom, recovery would take an estimated three to six months. His words were, *"you are a sick lady."*

I was hospitalized for five-and-a-half weeks. I was in the intensive care unit the first week, but did not have to be placed on a respirator; my breathing was monitored every four hours throughout my hospital stay. I was moved to the observation unit the second week and remained there for about two weeks or more and then finally to the hospital's skilled nursing unit. I had six days of two hours daily of plasmapherisis. That did not help me. The second treatment did not help either.

At that point, my daughter was told I may not survive. There was one more treatment available that might help. An expensive intravenous medication was flown in immediately.

I began to improve. Facial paralysis began during the plasmapheresis treatment. The right side of my face was so distorted the doctors thought l had a stroke.

l was given a brain scan. Results were negative—no stroke.

I was in rehabilitation during the last three weeks of my hospital stay and discharged on December 22, 1999. I had a home-health team (speech-occupational-physical-therapists and a nurse) for a month, and outpatient therapy for three months.

My discharge diagnosis was Campylobacter Jejuni (bacteria with diarrhea) Axonal Guillain-Barré syndrome.

I still have some facial paralysis and eye damage (the muscle behind the eye) from bruising during several falls. There's a little residual sensation on my left side (hand and foot) but I have resumed my favorite activities—ballroom dancing, fashion design and usual home-type activities. I do try my best to rest when I feel I need it.

Although my neurologist stated GBS is acute, and progresses suddenly, I still feel my GBS began with a gastrointestinal disorder I contracted in December, 1998.

As for the flu shot, I had the injection October of 2000 or 2001 and was very fearful; however, my neurologist and my primary care physician stated that, due to my age (78,) diabetes, etc., I'm at high risk and should take the shots every year.

I did have a very mild GBS-type reaction but I'm fine now.

Mrs. Benson, I'm enclosing a check to help with the *Foundation's* research, I will contribute as I can. I am very interested in the *GBS|CIDP Foundation International* and the wonderful work being done.

Sincerely,
Elizabeth Coleman

Elizabeth Garamendi Kann's Story

Paralyzed from the chest down, I lay in the hospital bed and realized my life had changed forever. I had traveled all night from Tegucigalpa, Honduras, to the *University of California at Davis Medical Center,* during which time I felt the paralysis slowly work its way up from my feet towards my lungs.

My dream of becoming a *Peace Corps* volunteer had dissolved before me, and all of my aspirations became focused on the pinpoint hope that I would survive. Just one month after graduating from the *University of California at Berkeley,* I joined the *Peace Corps,* hoping to serve for two years promoting health and well-being in a small community in Honduras, where I was to be stationed.

Unfortunately, my stay as a volunteer came to an abrupt end as I was stricken with Guillain-Barré syndrome (GBS.)

I remember the day so clearly. I was in training in a town just outside Tegucigalpa. The training center was nestled along a mountain side with stairs to climb in between classrooms. The stairs were once easy for me to climb, but as days passed, I found myself having more and more difficulty climbing them.

One day, I went out to play ultimate-*Frisbee* with friends. When I returned to my host family's home, I took off my shoes to

find my toes numb. I thought, maybe, my running shoes had been tied too tightly. When I woke up the next morning, the numbness had encompassed both feet. I knew something was wrong.

The story was much too familiar, as I recalled my sister's GBS diagnosis just 10-years earlier. Could it be that I, too, had been stricken with this disease?

I remember the call to my parent's home in California. It was on the next flight out that a physician accompanied me back to San Francisco. I was evacuated to *UCDavis Medical Center* where I was treated for ascending paralysis and respiratory distress.

For six long months, I worked tirelessly to recover from GBS, eventually regaining my ability to walk and go about the daily activities that most of us take for granted.

Over ten years have passed since my diagnosis. Today, numbness in my toes is my only daily reminder of my bout with GBS. And, for that, I am extremely grateful.

It was the incredible diligence, knowledge, and care of the team of physicians, nurses, and therapists at *UCDavis,* who inspired me to pursue a career serving those in need as a physician. I owe those who gave me that opportunity, a debt of gratitude.

GBS also changed me in a profound way, opening my mind and emotions to what a patient encounters when dealing with the heathcare system.

Upon entering medical school, I found myself excited about having the chance to integrate my personal story, experience, and insights into the practice of medicine. Seeing illness through a patient's eyes is a strength that I feel allows me to care for the sick with more compassion and empathy.

Today, I am blessed with a fulfilling career in medicine, an amazing husband, three beautiful daughters.

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"I've never seen anything like it."—HC

Gail's Story - Heel Strike

"Gail, today you are going to try to get heel strike," said my therapist. Heel strike is when you take a step with your foot and your heel strikes the floor first. I tried with every fiber in me but my toes go down first on every carefully placed step. Learning to walk Again, at age 56, after a bad bout with Guillain-Barré syndrome (GBS,) was one of my many challenges.

I call Guillain-Barré Syndrome my trip to Hell and back.

It all started with laryngitis—then, my immune system would not shut off and attacked my nervous system. It nibbled through the myelin sheath that protects the nerves, and had a feast. The results leave you paralyzed. The trip to the Emergency Room at *Beaumont Hospital* confirmed my GBS.

I was administered plasmapheresis, and IVIG. After fourteen days in ICU, and in extreme pain, I was transferred to a step-down unit. I was very lucky to have avoided being given a tracheotomy.

My neurologist came in and said *"therapy–therapy–therapy, and you will be fine."*

Now, there I was, flat as a fritter. I couldn't close my eyes so, the nurses taped them shut at night. To call for help, I had

to blow into a specially-placed tube, because I couldn't move my head… or anything else for that matter. I even talked like Elmer Fudd.

The next round of doctors came by, after a bunch of EMG nerve tests, and said I probably wouldn't walk again. Immediately I thought, *"I going to prove you wrong."* When you're scared, put on a brave face. A quote from John Wayne comes to mind about courage. "When you're scared to death, you saddle up and ride."

The first time I was able to sit up, I lasted 3-½ seconds. WOW!!! Was I proud. Significant progress was going to be a real challenge. Be brave Gail, God will give you strength, I reminded myself.

After four and a half months in the hospital, I arrived home in a wheelchair. I could not walk. Another challenge would then be learning to walk without the use of my arms. Heel strike, heel strike, where are you, I said? Finally, one fine day, I did it. However, walking without the fear of falling was hard to overcome.

Hands, hands, where are you? Telling myself, you need to be feeding me, washing and wiping me. You need to come back. I prayed to be Gail again. She needed to paint pretty pictures and hug people. O look, my little finger moved a little bit. It had been seven months since my hands moved at all. Nerves grow back about a millimeter a day, so it takes a long time to reconnect.

Nineteen months of therapy and many stories to tell. Thank you God for putting me back together.

it's only RARE...until it's YOU.

"The stairs leading to the exit never before looked so formidable."—WK

Gil Rumsey's Journey with GBS.

My name is Gil Rumsey. I am 68 years old and I have been a professional artist for more than 45 years.

On August 14, 2013, I noticed a tingling in my fingers. Three days later I was in Intensive Care and was, for the most part, paralyzed from the neck down. A ventilator, tracheotomy, and pacemaker we're necessary to keep me alive.

Hello Guillain-Barré syndrome (GBS)!

My road back home took 91 days of intense therapy, including learning how to talk, walk, breath, and feed myself. Of course, my strong will to survive and working harder than I was asked to, made a huge difference.

My physical therapists, occupational therapists, and respiratory therapists and I bonded, to say the least. One of my main concerns was regaining full use of my hands. And, after about 10 weeks, I was able to handle using a pencil. All in all, I created more than 30 pictures while still in the hospital. Art and fine motor skill activities are fantastic motivators for recovery.

I returned home a week earlier than expected (using a walker) continuing to work hard to regain my strength and mobility.

I am now playing golf, doing heavy yard work, and enjoying my grandchildren… life to the fullest. I've been called a miracle—but in my mind, I am just a survivor of a relentless illness.

Read more of my story at my website, gilrumseyart.com

it's only RARE...until it's YOU.

Glen Barbour's Story

As I shoveled snow for about four hours on a day during the blizzard of 1996, I felt tingling sensations in my lower extremities. As a matter of fact, it was January 7.

After working so hard I decided to go inside to warm up from being in snow that was up to my waist at times and because I thought that I might have hypothermia since the tingling sensations were worsening. Once inside, I relaxed on the couch and fell asleep. I awoke about twenty-minutes later unable to stand. There tingling sensations in my feet and hands remained. Alarmed, I cried out to my wife, Felicia. Responding to my beckoning calls, she helped me up to stand and assisted me to the bedroom where I laid down and went back to sleep. After another hour of sleep, I tried once again, and was unable to stand. We realized it was serious enough to get to an ER.

As we arrived at the hospital, the ER docs performed the usual exams resulting in a misdiagnosis of high-blood pressure. They prescribed blood pressure medication and instructed Felicia and I to return if things got worse.

Two days later I was back in the ER. During this visit I was wheeled in. This second visit was pretty strange in that the same doctors that diagnosed me two days prior were on shift again. My physical appearance was different and I could not

speak for myself. Felicia was doing all of the talking now. After the doctors performed their diagnosis they were about to send me home once again, diagnosed with the same result—high-blood pressure—even though, as I stated earlier, my appearance was obviously different.

Felicia protested the diagnosis. I will never forget her questioning the doctors. She asked them *"How is it that I can tell that there is something 'seriously wrong' with my husband, that it's not high-blood pressure, and that the both of you are trained physician and can't recognize it? There is something wrong here."* You could have heard a pin drop!

Felicia then asked them to alert our family physician that they have a patient of his in the ER with unusual symptoms. As she assumed he would, our doc asked that I be transferred to ICU.

I was in ICU for two weeks before being diagnosed with Guillain-Barré syndrome (GBS) after a lumbar puncture indicated elevated levels of protein and electrical nerve and muscle function tests were performed. Doctors and nurses kept a close eye on my breathing until I was finally stable. Given high doses of intravenous immune globulins—about 40 vials—to help me regain feeling in my extremities, I was stable enough to be transferred to a rehab center where I resided for the next month.

I would like to thank all of the physicians, nurses, and rehab specialists who had a hand in my recovery.

Of most importance, however, is that I cannot forget to make clear my faith in God who brought me through this ordeal. He was beside me every day as I walked through my journey with GBS. I continue to encourage others who are struggling with GBS to not give up and to continue to fight for their well-being.

It's only rare...until it's you.

"I have to pee—you want tea?
I have to pee—you want to read?"—LH

Hailey's Story

"I've never seen anything like it," my daughter's pediatrician said. I was at once both shocked and frightened by what I heard. Testing was inconclusive, but a neurologist had a hunch.

When your trusted family doctor doesn't know, anxiety can stop you in your tracks, or it can push you to action. For me, I relied on all my energy and sprang into action.

Right before my eyes, I could see that something–something the doctor couldn't quite put his finger on–was rapidly overwhelming Hailey. *"I really got scared when she couldn't even open the car door."* I knew Hailey was in trouble.

"We had never heard of Guillain-Barré syndrome. We couldn't even pronounce it. And it was getting worse. The nurses had so much trouble inserting an IV and I was panicked that they wouldn't be able to give her medicine."

That was in March. Hailey relapsed four times in the next six months. Finally, she was referred to a doctor in Denver, Colorado, two states and eight hours away. The whole family drove through the night, arriving at the hospital before it even opened.

We made three trips to Denver that summer and I was angry and confused. *"We met several doctors who suggested plasmapheresis, chemotherapy, steroids and IVIG. I was always upbeat in the*

hospital. I needed to be strong for Hailey. But then, I would go home in despair, and cry. I was rundown and emotionally paralyzed."

Even though the doctors in Denver made the right diagnosis—CIDP, Hailey's problems persisted. So, what was next? It was Hailey's grandmother who made the first contact with the *GBS|CIDP Foundation International.*

"After reading every word of every document the Foundation *sent, I found mothers on the Forum who literally saved Hailey's life and gave me hope. They had experience. They listened and shared. They already walked my path."*

In October, Hailey and our whole family traveled 13 hours to the *Mayo Clinic* in Rochester, Minnesota. *"We were all so drained,"* The entire family felt the strain. *"My heart broke again. Kolin, Hailey's brother, just fell apart. He was so scared for his sister. He needed me, and I just didn't have much left to give him.*

That was heart-breaking. Of course, I love them both, but Hailey was sick and needed me differently."

At *Mayo*, I finally found a doctor who understood my anxiety. She recognized that I would make any sacrifice I had to for Hailey. *"You're her mother,"* she told me. *"You see Hailey every day. You understand her reaction and you know what's best."* With those words and the support of the mothers on the Forum, I turned my anger and isolation into acceptance and resilience.

With the correct diagnosis, it was clear that Hailey needed regular IVIG infusions. With the closest infusion center several hours away from our Montana home, I was determined to acquire the skills necessary to administer the IVIG. *"I kept turning back to the mothers on the* Foundation *Forum. They understand the treatment regimens necessary to serve each child individually."*

"…if one way isn't working, try another."—MM

Isabel's Story

We had to rush Isabel to the Emergency Room early Christmas morning. She had lost the ability to use her legs and had lost movement in her face. It was terrifying. The doctors performed an MRI and a spinal tap and Isabel was diagnosed with the rare autoimmune disorder Guillain-Barré syndrome (GBS.)

While GBS is truly a rare disease, oddly enough, some of you may remember that two of my sisters, Christina and Elizabeth, both had it. They were, each, paralyzed for 12-6 months respectively. Fortunately, both made full recoveries. So the good news is that at least we knew what we were dealing with. And, we have been so lucky to have both Auntie Liz, and Auntie Tina, as our resident experts in this journey. They truly have been a rock for us with their positive attitude and inspiration.

Isabel was at *Children's Hospital Oakland* for a month and received two treatments of IVIG. The treatments worked to stop the progression of the paralysis. She couldn't walk, stand, or move her legs. Her face, on one side, was completely immobile. Her arms were functioning and her diaphragm and lungs weren't affected. This, in itself, is a blessing.

We took the situation moment by moment and now Isabel is finally at home. She is making great progress in rehabili-

tation—learning how to walk again and regain her strength. Isabel's facial paralysis is lessening and her big smile is coming back. There is no doubt that she is on her road to recovery. We feel confident that she will be fine.

As a junior in high school Isabel is anxious to improve and return to school and to her friends. She is our hero and has been so positive and determined.

Zack and Miranda have been so loving and supportive of Isabel, which has drawn us all closer than ever before. Marty and I count our blessings for our wonderful family and friends who have been right beside us as we walked this adventure with Isabel.

it's only RARE...until it's YOU.

Jerry Koering's Story

In December of 2014, I was a normal, healthy, 70-year old retired professional having had a career in education and educational publishing. My wife, Cathy, and I have a condominium in St. Paul, MN, and a lake home in rural Wisconsin—about 1 ½ hours from our home in St. Paul.

Cathy and I have been married for 46 years. We have four children, Adam, Jacob, Sally and Nate. We have been blessed with 10 grandchildren whom, in 2014, ranged in age from 4 to 13.

We were spending our December at the lake with our families. We have family activities in the snow, on the ice rink, on the lake, and just have fun during the Christmas holiday.

Than a life changing event began.

I had recently had a slight intestinal flu. I was never very ill, just tired and wanting to sleep during the day which is unusual for me. I also had diarrhea, but ended up with severe constipation. By December 30th, it was so severe I had to have hernia surgery. Fortunately, by December 31st, I felt terrific and left the hospital.

January 1st... my balance and strength were very weak. I also noticed the inability to stand up. My family and I assumed that was from the surgery and the meds. I stopped taking

all of the pills. On January 2nd, my balance was worse in the morning and I had little, if any, strength to stand up or even walk. *"What is wrong with me?"* was my concern!

I fell several times. In the early afternoon, I had a severe fall and I could not move my legs. I was rushed to the local hospital where I had the hernia surgery. They listened to my story and blamed it on post-surgery issues.

I was sent up to a room for overnight observation. That evening, and the next, I fell several more times and noticed my hands were losing their strength. By January 4th, I had no ability to move my arms and legs. The medical staff blamed it on my age, size and the recent surgery. I was becoming less excited about my future, depressed, and about to give up on life.

I had no pain at all. Nothing hurt.

On January 6th, a doctor returning from outpatient work reviewed my case. He suspected neurological issues and immediately called an ambulance for *Region's Hospital,* in St Paul. He asked for breathing support for the travel.

Upon arriving at *Region's,* I was comforted and provided many hours of MRI's, a spinal tap and several other diagnostic reviews.

By noon on January 7th, I was diagnosed with Guillain-Barré syndrome (GBS.) The head of the Department of Neurology began my plasmapheresis regimen. I had five treatments in the next 10 days. After treatment I was sent to the *Acute Rehabilitation Center* at *Region's Hospital.* I was provided physical therapy, occupational therapy, and speech therapy through my stay ending on February 10th.

During that stay, I concentrated on betting better and focused on methods to learn to move around, dress, sit up and start to regain my body strength. It was like beginning life all over again. I carefully observed ads on TV. Viewing one-year olds learning to walk actually helped me learn to walk again!

My care was direct—and strict—but always kind. I relearned how to hold things and always think about safety. My strength was really at "0." I had little ability to do much of anything, for example, I was unable to even push down the button on an electric toothbrush!!

The therapy staff encouraged me, kept me focused and most of all, became my friends. They helped me feel like I could do it!! And, they were right. They were TERRIFIC!!

Also, my family was wonderful! Cathy was there for me at every time and any time I needed her. She supported, advocated and just showered me with love, care and concern. My four children and their kids were there for me, as well. Daily visits from the kids meant so much to me and more than I could express at the time. I had many relatives call, and visits from friends. I must mention my brother-in-law, Bob, as he visited me, called me and provided me with support routinely. Without all of them I am sure I would not have felt the drive to succeed.

Their love and positive vision for me helped so much.

I received so many cards, emails and phone calls from work friends, high school classmates and college friends. I had one friend, Don, who himself was suffering from cancer, who routinely visited me, called me, and provided me with the strength to continue on a positive journey. His unselfish care for me provided me with strength the days when it seemed like they would never end.

I mention this in my story simply because I believe that support was the key to my successful recovery. You have to work hard when so many people provide you with so much strength and support. I think your ability to show resilience

motivates them as much as their care motivates you.

On February 10th, I was sent to a rehabilitation center in St. Paul. I stayed there until April 24th, and then went home to continue outpatient rehabilitation until mid-October.

During my entire hospital and rehab stay, I received care, support and was provided the focus to learn all about my body and how I must work hard to succeed. I must say, I never took a negative approach or got frustrated with the slow reaction my body had to constant rehabilitation therapy.

At times, I could have felt tired and hopeless. I believe the positive attitude of the staff, and all my family and friends, made a great deal of difference.

I must also mention my friend, Bill, who passed away in 2013. He suffered severe rejection from a bone marrow transplant. His journey, and all the suffering I knew he had endured, ended up being a motivator for me.

"Thank you Bill! Knowing how hard you tried and worked to endure made my endurance possible."

I also watched a movie that gave me strength, *"The Theory of Everything,"* the story of Stephen Hawking's battle with ALS. My thought was, *"if he can climb stairs"…I sure should be able to"* thus I focused on making it up stairways. He is still a model for me to remember as I struggle with stairs.

I am not back to normal. I likely have a good year or two

before I will know the extent of the damage to my body from GBS. On the positive side, I am close to normal because of all the hard work and support I received. I am walking, driving, and able to *"get around."* I still cannot walk stairways without good strong railings, go up any high steps without support, and I must always be aware of objects and safety issues.

My hands still shake a bit and I get tired easily. Sometimes I wish I could just twist caps off bottles easily.

I sometimes call it the *"happy disease."* A doctor friend, who has multiple sclerosis, told me this, *"You started where I will end"* ...how fortunate I am, that I can recover!!

This journey has given me a new lease on life. I have more appreciation for support from my family and friends, a sense of the importance of relationships and most important, recognizing the gift of life and the joy of the "now."

Thanks to all for helping me on this continued journey. You are my inspiration to continue the battle to recover and stay healthy!

it's only RARE...until it's YOU.

Jim Crone's Story

Yesterday marked another important milestone in my recovery. I headed back to the office for the first time since the stemcell transplant process began. In the same way parents take pictures of their kids on the first day of a new school year, Jenny felt the need to grab a pic of me on the way out the door.

I had been doing some work from my home office for some time. Yesterday, however, was my first adventure back into office life. I'm easing back into things by doing a few hours a day and gradually working up to full-time. I am still easily fatigued so this arrangement allows me to work as I feel up to it and then rest when my body tells me it's time to do so.

Cooper (our dog) is having to readjust to the new arrangement. He has gotten used to having me around 24/7 lately. Now he must get back to the normal routine and keep tabs on the house by himself.

A couple of random time-related facts:

- Yesterday marked 12-weeks since my stemcell transplant on June 17, 2015.

- I've now gone three months and five days without an ounce of IVIG being infused into me. Previously, I was getting injections every ten days to stay on top of my CIDP. That

means I've already been able to miss nine infusions (soon to be ten) thanks to the transplant. Pretty remarkable.

In general, the recovery overall, continues to move along at a slow, but fairly steady, pace. The numbness is lessening. The nerve regeneration pain is still around. I still have labs drawn frequently and I am in touch with the team at *Northwestern* as they continually monitor my progress.

All in all, not too shabby!

Recovery continues:

First, let me apologize for not posting updates more regularly during the past couple of weeks. I intended to update about once per week, but haven't been able to keep up the pace. The good news is that no news is good news at this point. It means nothing abnormal is happening other than what is to be expected with human stem cell treatment (HSCT) recovery.

I was reminded the other day of a special motto by a friend. When I was initially diagnosed with Guillain-Barré syndrome (GBS) 9-1/2 years ago, the motto was that GBS actually meant *"getting better slowly."* When the diagnosis changed to chronic inflammatory demyelinating polyneuropathy (CIDP,) six months later, the motto still applied. I think it is also very applicable to HSCT recovery.

I still continue on with PT/OT. We're working on a lot of strengthening and endurance-related things. On days when

I'm not at a scheduled appointment, I'm doing the home exercises they instructed me to do. After all, it wouldn't look good if the husband of a physical therapist didn't follow orders!!!

The fatigue and pain continues. Remember, the pain is a good pain as it means the nerves are healing. The fatigue is also normal after all my body has been through. Let's take yesterday as an example. I had to take two naps and slept like a rock all night. Apparently, a thunderstorm came through and our two little girls crawled into our bed out of fear. My body was so tired I slept through everything! The bottom line is, I have to listen to my body and not overdo things.

Even though I am not in Chicago, I am still being well taken care of by the team at *Northwestern*. Not a week goes by when we do not exchange several emails or phone calls. They'll routinely just call to check-in and make sure everything is OK, talk through the week's lab results, etc. I will be forever grateful to Dr. Burt and his staff for all they've done (and continue to do) for me.

Happy (1 month) Birthday!

Just a quick post today to mark a significant milestone. Today is my one-month stem cell birthday! It's hard to believe that exactly one month ago today, my stem cells were returned to me and added a second birthday to the calendar each year.

Looking back, it's been a long road of ups and downs with

more recovery still ahead, but I do not regret the decision to do the transplant one bit.

Day 26, week 2 at home.

I've now completed my second week recovering at home after being discharged from the hospital. I haven't had any IVIG infusions since just before the transplant. Normally, I would have had three treatments (quickly closing in on number four) in that span of time. Prior to the transplant, IVIG was my magic juice and kept me going. Without regular infusions, I would go downhill fast. I'm keeping my fingers crossed as this continues!

Both physical and occupational therapy is now in full swing. Even when I'm not at a therapy appointment, I'm being a good patient and doing my home therapy program in between sessions. I'll have to say it is quite a workout when your body is recovering and adjusting to its new normal.

I also have the assistance of a home therapy assistant, Cooper. He makes sure to keep my bald head cool while I do things on the floor. He also decided to add some extra weight while I was doing bridges and sat on my stomach. An extra 100-lbs. is not something my body is ready for yet!

Last Friday, I had a check-up with my neurologist here at home who seemed very pleased with how things are going so far. He also saw me just before the transplant and noted some initial improvement in my exam this time compared

to pre-transplant. He's going to check me over again at the three-month mark to see how things are progressing.

First week at home.

The feeling of exhaustion and fatigue continues. From what I've heard from previous patients this is normal and will continue for a bit. Frequent rests and naps are a necessity. Jenny caught Addy and I catching some ZZZZs together on the couch this weekend. Addy's excuse was that she only got six hours of sleep at a friend's sleepover the night before.

The nerve pain is also hanging around. As I've mentioned before, this could be around for some time as the nerves heal. It is good pain (if there is such a thing.) Every once in a while I'll also feel a little jolt in a nerve as the electrical signal reconnects and leg will jerk. It's a weird thing, but I know things are repairing themselves on the inside.

My new immune system and body temperature are still getting to know one another. I run low-grade temps on an off. I also get frequent hot flashes and sometimes break out in a sweat for no apparent reason.

I can also attest that "chemo-brain" is a real thing. Hopefully, that will get better with time (although Jenny says my brain is always messed up.) With all that being said, the recovery and side effects are well worth it when I look to the future and my life with CIDP in remission.

BTW… for now my plan is to post updates weekly, but I'll be

sure to break in to regular programming with an update if anything significant happens.

A belated Happy Independence Day everyone!

I've been recovering at home for one week. It is definitely good to be home! I certainly don't miss the middle of the night blood draws, vital checks, IV pumps beeping, etc. Hospitals are important, but they are not the place to rest and recover.

On Monday, my big adventure was a trip to *OSF Saint Francis Medical Center* to have my weekly labs drawn for Dr. Burt. Any trip out in public means hot facemask time and frequent squirts of hand sanitizer. It is quite a fashionable look.

I have to have the labs drawn weekly for the first month, then every other week for two months, and finally monthly for three months. That takes me to my six-month check-up with Dr. Burt. Labs are all done in Peoria and then sent up to the team at *Northwestern* for review.

On Tuesday, I woke up and Jenny asked, *"What's wrong with your lips?"* It turns out, they were swollen and the inside of my mouth had what looked like cold sores all over it. I was also running a low-grade temp. So, we headed off to see my primary care doc and consulted with the team at *Northwestern*. They said a reaction like this one can happen after a transplant, and does sometimes. A medication to swish around in my mouth was prescribed. It had that nasty, cough-

medicine taste… yuck. I was drinking out of a straw for a few days because it hurt too much to put glass to my lips. It has, pretty much, by now. Just a bump in the road.

Looking back: Days 9, 10 and 11.

The rest of the week I've been adjusting to my new normal for a while. Things like having to rest for a while after simply taking a shower. Any energy is quickly depleted from the tank. I tested my limits on Friday and realized I'd done too much. I certainly felt it on Saturday, and rested most of the day. I've also been known to fall asleep on the new hammock Jenny bought for the backyard.

I've been experiencing pain on and off. Some of it was the *Neupogen* bone pain subsiding. Dr. Burt also said CIDP patients can expect to have pain for a few months, post-transplant. It is actually good pain as the nerves are regenerating and healing. The thought of CIDP no longer wreaking havoc with my nervous system and my body now in a position to heal itself is certainly exciting!

Looking ahead to this week… On Monday and Tuesday, I begin physical and occupational therapy. I'm sure Jenny will be keeping an eye on me.

Finally, thanks again everyone, for your continued thoughts, prayers, and words of encouragement. I certainly could not have gone this far without a tremendous cheering section behind me.

Day 9, 10 and 11, recap.

I wanted to take a moment to recap the events of days 9, 10, and 11, to fill in the gaps between my day 8 update and the post that I was home.

Day 9

Day 9 started out pretty normal. Dr. Burt and his team came by for rounds. I knew it would be one of the last times we'd all be together so I grabbed a group photo. The rest of the morning was pretty normal, too.

I was tired most of the afternoon and napped in the guest bed in the big picture windows in my room. Later in the afternoon I woke up with a headache. We tried *Excedrin,* but that didn't do anything. The headache and bone pain were getting worse. It really hurt to move an inch. By early evening I was practically in a frozen position in my hospital bed with IV pain meds coming regularly.

Just when we thought enough was going on, my nausea friend decided to show up, as well. We didn't catch it soon enough with medication so, I vomited two times. They were now starting to get a little concerned that something else might be going on internally. Maybe bleeding because of my platelets being so low. A hospitalist arrived and did an exam to rule things out. After talking with Dr. Burt, they agreed that everything checked out OK.

It was a long night of short naps with IV pain meds in between to keep me as comfortable as possible.

Day 10

Dr. Burt came in first thing and asked, *"What's going on? I know you had a rough night."* We talked through everything and he said it was mostly a bad case of a *Neupogen* reaction. He said some patients have no symptoms and others can get it really bad, like I experienced. The good news was that I had technically engrafted overnight. The stem cell transplant had worked and my new immune system was coming online. I was also, theoretically, OK to be discharged, but Dr. Burt said he didn't want to discharge me if I didn't feel up to it yet. We agreed that staying another night and seeing what the headache and bone pain did would be a good idea.

Most of the day was spent with me in bed sleeping and receiving pain meds while Jenny binge-movied by my bedside. Dr. Burt even called in two times to talk with me to see how things were going. He gave me a migraine medication at one point just trying to find something that might work better. As the day went along, we could tell things were slowly subsiding as the pain number wasn't getting as high in between doses of medication.

Jenny and I closed out the night by catching our final *Navy Pier* fireworks from the comfort of my Presidential Suite.

Day 11

The next morning I woke up not feeling 100%, but not so bad off that I needed to stay in the hospital. I was ready to go

home! I took a much needed shower which, by itself, made me feel better.

Dr. Burt came through and I told him I was ready to recover in the comfort of my own home. He smiled and agreed to process my discharge orders. Jenny began taking loads of stuff I had accumulated to the car. Meanwhile, nurse Regan gave me one last dose of IV meds for the road then pulled my PICC line. That was pretty uneventful. It probably looked worse than it actually was.

After that, Jenny went to retrieve the car while Regan escorted me to the discharge waiting area. I told her *"thanks for everything,"* and gave her a quick hug. She's one of the special ones that took extra good care of me and had me 5 of the 18 days I was an inpatient. Then I got comfy in the car for the ride home. Amazingly, we had zero traffic and made it home pretty quickly.

When we arrived, I was greeted by two little girls and a big dog, that were all happy to see their daddy. We had Facetimed quite a bit, but it's just not the same as seeing someone in person.

I also received by stem cell birthday present, a customized *Chicago Cubs* jersey. The #17 is in recognition of my June 17, 2015 stem cell birthday.

Needless to say, I am happy to be home and resting comfortably in my own bed. Two little girls and a dog are also happy to have me here!

Jim Wickert's Story

I was one month away from turning 60 when I sold my Ohio business and retired to Florida in November, 2002. Six weeks later, after settling in to a retirement community in Florida to begin retirement life, I awoke one morning feeling that something wasn't quite right. By that I mean, every now and then, the world seemed to tilt, or spin slightly, but only for a minute or two at a time. I thought I must be coming down with something. Otherwise, I felt fine and felt even better after a few hours. At some point during the day my fingertips started to tingle—the same tingle a person feels when their fingers fall asleep. But, it was more than that. I can't say it was painful, but it was so irritating that I continually found myself banging my fingers on any hard surface I happened to be around trying to wake them up. However, the tingling simply would not go away.

In the early afternoon I couldn't help but notice that my left leg wasn't fully cooperating. It kept kicking out to the side when I walked and it could still hold my weight. There was no pain. The lateral movement of my left leg wasn't very good to begin with but, try as hard as I could, I couldn't stop it from kicking outward when I walked.

I decided to take a short nap. My earlier disorientation, coupled with tingling fingertips, and now an errant left leg, convinced me to, basically, give the day another chance by

going back to sleep and waking up again. Other than the irritating tingling in my fingertips, I felt no sensations of pain at all. I did fall asleep and when I awoke I felt fine. The tingling in my fingertips didn't seem nearly as bad as before, but it was still there. However, when I got out of bed and took my first step I wheeled left, right into my bedroom wall. My left leg could barely hold my weight and the way it had been kicking out was now much more pronounced. But, by concentrating and focus, I could still walk, but very slowly and carefully.

Now knowing something was very wrong, I drove myself to the ER. This was only possible because it was my left leg having the problem and not my right leg. I went into the first entrance I came to which happened to be an "ambulance

only" entrance. A nurse came walking toward me and I could hear her telling me that I cannot come in using this entrance. It was for ambulances only. When she finally stood directly in front of me, more or less blocking my way, I took another step and, once again, wheeled face-first into the corridor wall. In that instant I could no longer walk straight, but my left leg could still hold my weight. I told the nurse what I was experiencing and she immediately yelled for the Stroke Team. I told her I didn't believe I was having a stroke (I don't know why I thought that except I was still clear-headed, so to speak) but she said it was very important to find out as quickly as possible.

With the nurse's help we made our way into the MRI area and the Stroke Team performed their work. The nurse returned and said she had some good news and some bad news. The good news was that I did not have a stroke. The bad news was, she thought I might have something called Guillain-Barré syndrome (GBS.)

I had never heard of Guillain-Barré syndrome before that. The nurse went on to say that she had more good news and bad news. The good news was, if I did have GBS, the odds were very good that my condition would improve. The bad news was, I would more than likely be in for a rough road ahead and a "challenge" before things would start to get better. A neurologist was called in to perform a spinal tap, looking for the elevated level of a certain protein that would confirm, or dismiss, GBS.

I am ashamed to say that I cannot remember that nurses name. As rare as GBS is, I still think it was truly amazing that the nurse's diagnosis (after eliminating a stroke) was absolutely correct. She went on to explain the paralysis to come saying that only time will tell how far it would progress. And, the spinal tap finally did confirm GBS. In the short time I had been at the hospital I could no longer stand up on my own. It had taken less than twelve hours to go from normal upright to abnormal flat on my back for the next three months.

I did get, "The Mother of All Headaches," later that night that the neurologist predicted. It seems that's not an uncommon affliction after a spinal tap.

The next day, other than having a headache, I was still in no pain at all and couldn't help but find it interesting that both of my legs were now paralyzed. It was a condition that I thought I could surely overcome with a little will power. Aaah, no! The nurse had been right. My challenges had just begun. And, one of those challenges was getting over, what I took to be, my own weak will power.

It was my bad luck that the small hospital in my retirement village where I was admitted did not have the necessary equipment to do a plasma exchange. Perhaps I should have been transferred immediately to a larger facility that did have such equipment, but instead I had to wait for three days before the equipment was brought to my hospital.

While waiting for the equipment—and since I was in no pain—I thought I'd test the strength of my legs. Paralysis had only effected my legs and I was able to sit up in bed and still move my arms. I manually moved both of my legs until I had swung them over the side of the bed. I had decided to slowly slip off of the bed, but not totally, just to put some weight on my legs in order to gauge their strength. That was a big mistake. I crumpled to the floor with my legs folding like an accordion under me. It was my first initiation into a world that would very soon become filled with pain. In the process, I twisted an ankle but otherwise did no damage to myself. My yells for help caused two nurses to come running. With great effort they helped me back into bed making sure that the side rails were kept up from then on. That wasn't necessary. I wasn't about to do it again.

I was scheduled for the surgery necessary to implant the valves needed to perform the plasma exchange tubing. They do that so the chest area doesn't have to be punctured to find the necessary veins and arteries each time they do an exchange. I had three sessions three days apart. I did seem to be improving and the neurologist came in one afternoon with two male therapists to see if there was, in fact, any strength improvement. There was… but it was only slight. Nonetheless, the neurologist was encouraged and predicted that I would be walking out of the hospital in approximately three weeks. The upcoming events did not seem to reflect his optimism.

It was the very next day that I crashed. For the next six weeks, I had no idea of time. I had crashed to the extent of unconsciousness and when I came back into the world, the world was the last place I wanted to be. A feeding tube had been placed directly into my stomach.

Everything hurt to the extent that the word "agony" seemed like a euphemism. The only relief from the continual pain were opiates, but in a strength that put me back to sleep. I don't want to sound maudlin, with *"poor me"* overtones, but I will truthfully say that I would have rather been dead than awake. Over and above all of the pain caused by short-circuiting nerves, it had felt as if I was lying in bed with a stone between my shoulder blades. As some measurement of time passed, that stone turned into the tip of a knife and the knife then began to very slowly push deeper and deeper into my back between my shoulder blades. Since I could not move at all, there was no way I could even try to lessen the pain of the imaginary (and yet very real to me) knife blade. I learned later that this kind of pain is not uncommon with GBS.

Opiates gave me relief from pain but also relief from consciousness... until they had to be withdrawn to see if my diaphragm was going to be affected with paralysis. Continuing the opiates would make that more difficult to determine. That period of time was the most agonizing and seemed to last forever. I felt extremely hot, even though afterward I was told that I felt exceptionally cold while complaining about it.

My children brought a fan and, whether I was actually cold or hot, the breeze felt wonderful.

The paralysis did get to my diaphragm rather unexpectedly and that was my first "code blue." It is no fun to try to take a breath and have nothing happen. The closest I can come to describing it for those who have never had that experience, is simply and deliberately, try to hold your breath and then try to breath without moving, or expanding your chest. I can remember struggling for breath (mostly in my mind I suppose because physically struggling by this time was impossible) and then consciousness leaving me. When I awoke I had been incubated.

As I've already mentioned, time became meaningless. Every time I regained consciousness I wanted no parts of it. The pain associated with some cases of GBS can be unimaginably intense. But those readers who have ever had sciatica, may want to try imagining it by thinking about that same kind of unabated nerve pain, but throughout your entire body.

Time passed and the intensity of my pain began to weaken.

My second "code blue" was when it was thought that I had, once again, recovered to the extent I could nearly do my own breathing. I had improved, but the thinking was somewhat premature. My breathing machine was turned down and the nurse left the room. I was still totally paralyzed with one side of my face drooping and one eye not able to be closed.

Since I was incubated I couldn't talk. But, I couldn't breathe either when the machine was turned down to only help me with two breaths a minute. Once again, the panic of helpless suffocation swept over me. I heard a buzzer. I think I saw a nurse hurrying into my room, but I'm not sure. Everything went black. Did a minute or two pass or was it an hour? I had no way of knowing.

Since then, I have a renewed respect for simply breathing. I discovered what a "pleasure" being able to draw a breath really is.

The peristaltic action of both my throat, and my bowels, were victims of paralysis. Nothing could be naturally moved along through those internal canals. Input was managed by a feeding tube placed directly into my stomach. Output was another matter altogether.

It is neither pleasant to write about, or read about, and this is the only time I have ever written about it. And, I'm mentioning it simply to say, yes, it is both embarrassing and humbling, but it was also a "no choice" situation. Like the paralysis itself, it is a thing that you must come to grips with… and you do!

This is a good place to expand on the "acceptance" of paralysis. I've heard the same from others who have had GBS. I still do not understand it myself, but when you are suddenly totally, or partially, paralyzed the mind seems to accept it in some

ways. It simply is what it is and, mentally, it was not nearly the nightmare that one would expect it to be. That doesn't mean it was accepted as something permanent, or unalterable. But when you ask your mind to move a leg or a foot, and then nothing, absolutely nothing happens, it is not something that the mind tends to dwell upon. I was never angry that I was suddenly paralyzed, as strange as that might seem. I'm sure the continual encouragement that it would pass played a big part in that. I believed it because I wanted to believe it.

Being moved while in bed was torture. There's no other word for it. I only hope that hospitals now understand a lot more about GBS to help improve that part of the recovery process.

One afternoon, a nurse wanted to smooth the sheets at the foot of my bed so she lifted my right leg and crossed it over my left leg at the ankles. I had no way of telling her how much that hurt. It was agony. But, I can see why nurses wouldn't think that could possibly be the case. I'd now like to make it clear that IT IS the case. I was so frustrated by things like that, that I learned to talk (well sort of and almost) while still being incubated. I managed to croak out my complaint about how I was being moved and it did get better after that.

I spent two months in the ICU at the first hospital, before my daughter transferred me to another—much larger—hospital after I had begun to improve. Another month went by and I began PT. My thyroid gland stopped working and has never recovered. I take regular meds for that. My left foot

splayed outward (but fortunately not severely) and I now walk somewhat like a half duck. It has done this even though I wore corrective boots every day for more than a month. I have intermittent reflexes in my left leg—the first leg paralyzed. I still have paresthesia in both feet, the sensation of "rug burn" on top of my left foot and flashes of heat in both feet. I can feel imaginary "bugs" landing, or crawling up, my legs at times. It also feels as if I'm walking on the bones of my feet to this day. It feels as if I have no "padding" on the bottoms of my feet. Both feet are still "numb," but not really. It is only a feeling. If I stuck a pin into my foot I would feel it. I take *Lyrica* and *Percocet* every day, which does mitigate these residual problems, but never quite takes them completely away. But that's okay. While I might not have recovered as well as the majority of those with GBS, I still feel fortunate for my recovery, having had the opportunity to pass through many "challenges" and come out alive and on the other side.

The takeaway: Small things are very important when treating GBS. 1) Continual encouragement that things will improve. 2) Visitations—which I cannot over emphasize. 3) Careful handling and touching while in the full grip of GBS. 4) Pain management. 5) Do exactly what your PT tells you to do—because they will make you do it anyway. :)

And one last note… there is no visible cause for GBS pain. In that way it's much like a headache. If a person complains about a headache, others might be sympathetic, but that

sympathy is mitigated by no visible evidence of pain. Unlike a stab wound, for instance, where the cause of pain is clearly visible.

Speaking personally, I often had the impression that hospital staff somehow doubted that I was in as much pain as I often (and quite often) said, or indicated, I was in. I will always be grateful for my sisters' visits. They knew me well enough to know when I exaggerated things and when I didn't. They insisted on better pain management and, after that, things did improve. Once again… Visitations...with emphasis!

it's only RARE...until it's YOU.

"I sometimes call it the 'happy disease.' A doctor friend of mine, who has MS, said this to me, "You started where I will end."

How fortunate that I can recover!" —JK

Jim Yadlon's Story

November 17 is a day that will live in our lives forever. 42 years (1973) ago, my wife, Rachel, and I went to the Englewood Hospital ER and for the next five weeks, I lay in the ICU, totally paralyzed.

I want to attempt to tell our story through, what I believe, would be my wife's eyes. I can never truly understand how Rachel felt and thought during these weeks and months, but I will give it a try.

I came down with Guillain-Barre' syndrome (GBS.) My peripheral nerves were attacked by my own immune system for some unexplained reason. I was totally paralyzed—including my diaphragm—unable to tell, or signal, anything to anyone. Rachel, my bride of three months, and only 19 years old, took over my life.

The hospital that I was in did a pretty good job of keeping me alive. There was no IVIG or plasmapheresis in those days, so keeping me alive was the only thing that could be done to make sure that I recovered.

There were many decisions to be made and Rachel made all the difficult decisions that affected my life. She had to decide whether to keep me in this hospital and most importantly, what to do with me when it came to rehab. Only one physician recommended that I be sent to *Columbia Presbyterian*

Hospital in New York City that had a full-time physical rehab floor. After thinking about it, Rachel decided that it was the best place for me. Everyone else wanted me to stay where I was and rehab, which would have been many less hours per day. Not everyone agreed with her, including all but one of the medical team watching over me. I heard stories about battles that Rachel had with the lead neurologist that occurred in the hospital elevator. But Rachel did what she thought was best and off to the city I went.

We both cried the night that I was moved. Rachel, because she wanted to be sure that it was the best move. Me, because I would be alone in a big, cold, city and scared out of my wits about not being able to do anything for myself.

After a few days there, we both knew it was the best place for me and her decision was absolutely correct. The visiting

hours at *Englewood Hospital* were brutal on a loved one. Rachel was only allowed in for five minutes every two hours. She was also holding down a full-time job. Rachel would come before work and visit and then again at lunchtime and then, after work, she would stay until midnight. This went on for five weeks. Her job was near the hospital which was a small blessing. She worked for a Neanderthal of a man who had no empathy for her situation. He made crude comments to her and humorless jokes about my being ill. When visiting, Rachel had to sit in a very small room and wait for the clock to hit that 55th minute before the hour.

I spent 23- of 24-hours each day alone in my head and locked in a body that didn't move in any way. With my vision impaired, I am nearsighted, I was seeing double at the time due to paralyzed eye muscles.

But when the visiting five minutes came around, I was so happy to see my new bride. When the ICU door opened every two hours for five minutes at a time, my heart jumped and I was so happy to see her come to my side. She never let me see her cry at my awful appearance, she always carried a smile and only let me see her confident side. I cannot imagine what was going through her mind when she walked through that door.

Rachel would never let anyone in to see me who would cry, or show sadness or shock, at my sight. One of her father's friends wanted to visit me. My wife's family is old world Italian

and very emotional. When this, very emotional, Italian, man entered the room, he got very upset and started crying. Out the door he went in a flash. Rachel ushered him out and he was banned from returning until I was much better.

Christmas Eve was a quiet night in the ER. Staffing was light, but something miraculous happened. Rachel was allowed to stay longer and we just hung out trying to find some joy in a normally wonderful time, our first Christmas together as husband and wife. A group of Christmas carolers came by the bed and sang. It still makes me weepy after 42 years. Then, suddenly, my pinky moved. We rejoiced as it was the first sign of the recovery. We realized that we had turned the corner and were on the road to recovery.

Rachel, I can never thank you enough for staying by my side and being my caregiver during those horrible days. We made it. Today, 42 years later, we are a blessed family of 12 and we truly know that the most important part of life is—family and love!

Thank you, I love you so much, Jim.

PS: Caregivers need much more recognition. They give of themselves to the patients who are indeed helpless and incapable of caring for themselves. I honor and recognize caregivers at every liaison meeting. I hope that all of us can remember to honor them at every opportunity. Bless them, they are truly *Angels sent from Heaven*.

Joel Steinberg's Story

Monday, January 4, 1982, started out for me like most weekdays. I met with my fellow internist at our office in Philadelphia, reviewed our hospital patients and then drove to the *Frankford Division of Frankford Hospital* (now called *Aria Health System*) *Frankford Division* and rounded on patients. I noticed that I was pulling on the handrail of the hospital's stairs to climb it. Since I have a smallish, 5'5" and agile body, I often used the stairs rather than elevator to get around the hospital. When I drove back to the office something peculiar happened. I just about collapsed onto our doctor's room sofa rather than gently sitting on it as I would normally do. My associate, a rather astute internist, suspected that I was coming down with the flu or some virus. He drove me home. I felt like a whipped puppy.

Over the next day or so I became progressively weaker. My wife, trained as a rehab nurse, noticed my waddling duck-like gait, calling to my attention that, *"You have a neurologically deficient gate, like in GBS."* Of course I shrugged off her comment. By Wednesday I could not walk up stairs and had to sit down on a step, and push myself up, to raise my rear and sit on the next step up. By Thursday, about 2 AM, my gums were tingling, what we docs call paresthesis.

"Something is seriously wrong." What disorder causes symmetric, rapidly ascending weakness with paresthesia? GBS of course.

I cracked open my neurology text book. Guillain-Barré syndrome (GBS) was not in the index! A quick turn of pages. There it was, *Landry-Guillain-Barré-Strohl syndrome*. A quick read. Yep, that's me. No point in calling my buddy neurologist that I consult for patients at this hour of 2 AM. At 7, I called him and described the patient. He asked the patient's name. My response, *"It's me."* His response, *"Oh, an oriental patient."* *"No, you're talking to the patient,"* I replied.

By 10 AM, I was at his office. A quick exam. No deep tendon reflexes, and neuro-muscular electrical testing. Yep, GBS. What now to do? The consensus with my wife and I: if I stabilized I would stay at the local community hospital, *Frankford Hospital*. If it looked like I was rapidly deteriorating we'd ship me to the local medical mecca, the *University of Pennsylvania*.

Into the intensive care unit (ICU,) wired up, intravenous line inserted. My wife and our neurologist were discussing care

plans. He wanted to respectfully take a minimalist approach. My wife, one sharp lady, admonished him clearly to treat me like any other patient, not like a doctor. Wise words.

By the time I reached the ICU, my lungs were a tad congested but were clearing by the next day. Normally, I'm pretty healthy. A non-smoker, rarely use alcohol, no chronic med problems. So I had good protoplasm on my side. (So here's a suggestion: If you're going to get GBS, better to get it when you're young and otherwise healthy.) About 10 days later, on Friday, I was discharged to home. Tried to walk up one step, from our family room to our kitchen. The legs gave out and down I went, uninjured but annoyed.

The phone range. It was Estelle Benson. My wife was panicking on the phone, what to do about, and with, me? *"Is he hurt?"* asked Estelle. *"No." "Then don't worry. He'll be ok. Just help him up,"* was Estelle's response. At the time I did not know it, but that phone call was likely only the second time in world history that the soon-to-be-formed GBS Support Group, now the *GBS|CIDP Foundation International*, had helped a patient.

That Monday, into *Moss Rehab Hospital*. The rehab doctor, a great guy, could not believe I had survived at home with my profound weakness, a compliment to the team effort that my wife and I used. And of course the internal medicine and other consultants at *Moss "knew"* this could not really be GBS. After all, doctors don't get GBS. The medical facts enlightened them of my reality.

Rehab was great, because somebody up there likes me. I made steady rapid recovery. Eventually I was allowed to sleep at home, and was taken by a special van in my wheelchair back to the hospital each morning for rehab.

Soon I could cut meat, triggering the first time in my life I cried with joy. Eventually I had enough stamina to work for an hour a day in the office. My associate internist fully appreciated my very limited stamina and fatigue that would cause me to collapse. Oddly, it was not until several years later, at a meeting of the GBS Support Group in the United Kingdom, that the audience kept asking about dealing with fatigue in GBS and their medical advisory board perked up its ears to register and recognize this important issue.

I was still attending the *Moss Day Hospital* rehab program when Estelle called and invited my wife and I to her home. It seemed that her husband was just getting over a worse case of GBS than I—upsetting her enough to want to start a support group. We met Dr. Arthur Asbury and his trainees, David Cornblath and Gareth Parry, and talked. As he put it, we neurologists know how to diagnose and treat GBS. But when it comes to patient support, that's just not part of our repertoire. *"So maybe you can help us."* And the rest, as they say, is history.

Some weeks later Estelle realized she had no written educational material to give to new patients she would meet in hospitals. She asked if I could write something. *The Overview*

for the Layperson resulted. We realized the most likely type of doc to initially see a new GBS patient is an ER physician. So I created our poster for ER docs, alerting them of key features of GBS. We quickly realized that CIDP patients did not have representation; and by then Glennys Sanders of the UK had approached us to help her start a support group. Plus, one of our board members explained the value of raising funds if we became a foundation. And so our name changed.

I was able to return to full time work in about six months. But it took about two years before I no longer had to anchor my right wrist with my left hand so I could right smoothly. And it took about six years before some residual tingling in my right little finger finally went away.

A few years ago, when I began my full-time hospitalist position, it became apparent that there was no literature explaining the nuances of treating the newly hospitalized GBS patient. So, I wrote the *Foundation's* booklet, *GBS: An Acute Care Guide for Medical Professionals.*

Where are we now? Seems that there is still so much work to do. Fortunately, some of the world's top researchers are investigating the cause of GBS. Perhaps this activity will lead to better treatments. The number of support group chapters is growing as more people come forward to serve as liaisons. Bless you. We are always looking for better methods to alert new patients of our services.

GBS|CIDP Foundation International has had growing pains—part of the normal human experience. But we have never lost our focus as put forth by our founder, Estelle Benson. PATIENTS FIRST! And no membership dues. Experiencing GBS, CIDP or MMN is enough dues. So, we continue to grow, looking for better methods to build upon our proud and strong heritage and brand, and reach out to more patients, families, and caregivers, sooner.

it's only RARE...until it's YOU.

Julie's Story

My journey began in October, 1967—the year I was born. I was the child of two college students who wanted nothing but the best for me. Their love for me allowed me to be put up for adoption. Twenty-eight days later, I had a permanent home.

My life with CIDP began in December of 1995, at the age of 28. I was living in San Antonio Texas and flew home for Thanksgiving. I was walking through the airport when my dad (a pediatric radiologist) noticed that my gait was off. I attributed it to being a "post-pregnancy" thing. I did tell my dad that my hips were sore. He advised me to see my primary-care doc and get a referral to see an orthopedist. My doctor ran some tests and asked me to stand on my toes which I could not do. I was a dancer through college. I did not realize I had lost function. I left his office with my referral. The next day I received a call saying that I had a 1:00 appointment with a neurologist. At this point, I remember that I was in a panic. I had hip pain and I thought I was seeing an orthopedist, not a neurologist.

I arrived at the neurologist's office to find out that a blood test for muscle inflammation came back elevated. The neurologist wanted to conduct tests of his own. I began to refer to these tests as the "push me, pull me" tests. I had EMG's done, a spinal tap, and a muscle biopsy. The physician had narrowed

his search down to multiple sclerosis, muscular atrophy, multiple myeloma, or chronic Guillain-Barré syndrome. After Christmas in 1995, we received the results of all the testing. I did in fact, have chronic Guillain-Barré syndrome. The doctor said to look at the bright side… chronic GBS is treatable. Yeah. Easy for him to say, he was not the one dealing with the devastating news.

After the initial diagnosis, I was very depressed, angry, scared, and mad. Why me? That is what we all say at one point or another. Lucky? No way! I had my pity party. I was scared. I cried and I screamed. I am a young mother with two children, what am I going to do? At that point, my husband and I "took the bull by the horns" and we began our research.

Treatment also began. I was sent to another doctor. I saw a hematologist/oncologist. I began my marathon rounds of plasmapheresis. I went every day for 28 days in a row. I remember being so cold when the plasma was being removed. The tool for measuring the effectiveness was me. How did I

feel? It was at this point that I began to learn to listen to my body, and began to work on being in touch with how I was feeling. I also began massive amounts of steroids. Eliminating as much stress as possible was strongly recommended by all, so I stopped working full-time as a special education teacher.

In my research, I found *GBS|CIDP Foundation International*. I gathered information about this rare disease. I contacted Dr. Richard J. Barohn, who was on the medical board, and made a visit to Dallas, where he was practicing. Dr. Barohn was a great doctor. He confirmed, and agreed, that chronic form of GBS, (CIDP,) was what I was dealing with. A second opinion, from a doctor familiar with the disease, helped me come to terms with my situation.

I continued on my journey as a patient with a rare disorder. The next several years were spent battling this monster. I had flare ups that would cause me to go backwards. Each time I recovered, I never made it back to where I once was. I soon found out that this monster would flare its temper and would strike back the next time with more vengeance. And, that this would be my life. I soon adapted to this pattern, slowly losing functioning in my arms and legs. I still stayed in touch with the *Foundation*. I looked forward to seeing the newest updates in treatments and progress. I made copies of the *Foundation* letters and took them to my doctor's offices. I became the expert of my disease. I became the educator of those around me.

Nine years into this disease, now named CIDP (Chronic Inflammatory Demyelinating Polyneuropathy,) I faced an even bigger battle. In October 2004, my husband, Phillip, was diagnosed with Pancreatic Cancer. How lucky we are… we sat together in the Hematology Oncology office, dripping together. I was getting IVIG and my husband chemotherapy. I knew my disease would not kill me, but as I sat by cancer patients—and my husband—I knew they were not as lucky as I was.

I became the care provider for my dying husband, my 15-year old daughter and our 10-year old son. In August of 2005, 10 months after the initial diagnosis, my husband lost his battle with cancer.

Dealing with a tremendous amount of stress, I continued to push on. At this point in my life, my condition worsened. I developed drop foot in both feet. The functioning in my hands deteriorated. I began to use ankle foot orthotics on both feet. As an adult, my choices were limited for "age appropriate" looking AFO's. I began to embrace the face that looked so very different in the mirror. I chose to make the best of the situation and I began buying crazy knee socks. I switched neurologists and began my infusions at his facility.

Along this journey, I met another individual who had this disease. We became drip buddies. We made it a point to have a "girl's-day" on infusions days. We would order lunch for delivery. We brought chick-flicks and made popcorn. Instead

of being depressing, we made it a fun day.

Children are great. Their innocence is wonderful. They will ask, *"What is wrong?"* After answering questions and dealing with insensitivity I began to say to people, *"I have been blessed with a chronic inflammatory disease that affects only 1.5 persons in a million."* I soon discovered that this was the best phrase for people. They either ask for more information, or they are speechless and don't say anything.

In April of 2012, I had a major setback. I slipped at home and severely broke my left ankle. I needed to have surgery. I am now the proud owner of an L shaped plate and about 9 screws. I experienced life in a wheelchair and did not enjoy the experience. My drive was to become as mobile as I possibly could—as fast as possible.

The *Foundation* helped me feel like I was not alone on my journey. Over the years, I had read about, and attended, the symposium in Fort Worth, Texas. It was a life changing experience for me. I felt like I was with family. Everyone understood. They got it. I realized at the symposium that many people were unaware of the daily living aids that were available. I began a new mission: to help others with my disease discover modifications and tools that exists to help with daily function. I left the symposium with such drive that I knew I needed to become a liaison so that I could help others. I have learned to advocate for myself and want to help others advocate for themselves.

In March of 2013, I tried a new device for drop foot. It is a neuro-electric stimulation system. I passed the screening and this electronic system would work for me. I soon found out that it was not covered by insurance. I knew that this system would keep me active and help me keep my leg muscles functioning. I began searching for alternative funding. $8,000 for each leg was way out of my budget. I discovered the Department of Assistive Rehabilitation Services, (DARS.) I met with a caseworker and ten-months later I was fully funded for bi-lateral *Bioness*.

Today, I work full-time as a special education teacher, completing 19 years of teaching. I have regained and maintained my health and I still receive IVIG infusions every 2 weeks.

I hope to continue to help others on their journey. If you look at where I have been, and then the things I have endured, my life is truly a blessing!

it's only RARE...until it's YOU.

June Prance's Story

My name is June Prance. I am 87-years old and this is my story. In early 2003, my life was full of work that I loved and traveling to wherever my job, volunteering or my adventures took me. Even though I had retired in 1991, I continued to work as Executive Director of Exhibits for *Hillsborough County Schools*, a part-time job that allowed me time to continue my long-time secondary love of interviewing interesting people and having my articles published around the world. I was 73, in good health, and enjoying life with my family.

Then, in early-March, 2003, my life came to a full stop—suddenly and painfully. I had been experiencing lower-back pain for a few weeks during the annual *Florida State Fair*. I had supervised 27 school exhibits and had increasingly worse pain daily. On the last day of the fair, I went home early due to the pain.

Two days later I was in the emergency room at *Brandon Hospital* where I was given *Cortisone* shots to relax my muscles. Two days later, I couldn't get out of bed—my legs wouldn't move. About 5AM, I phoned my daughter, Cathy, and my son, Bill. They both arrived about one hour later. They called an ambulance when it became obvious that I could not use my legs.

Leaving out many of the details, it took nearly three days

for me to be correctly diagnosed as having Guillain-Barré syndrome (GBS), a rare reaction to a recent flu shot. (I had a flu shot annually because I worked with school children.) I was given a spinal tap and then began plasmapheresis every other day. Soon, I was moved to the ICU, and within 36 hours, I was on a ventilator.

About a week later, my daughter had to sign for me to receive a tracheotomy because the doctor thought it was not safe for me to remain on the ventilator. I was completely paralyzed from neck-to-toes, couldn't even move a finger. I communicated by blinking my eyes—once for yes, twice for no. Then, I began losing my hearing and questions for me had to be written down.

In July, I was moved to *University Columbia Hospital* (now *Florida Hospital*) in Tampa. The rehab department there was considered to be one of the best in the area and I found that to be true. The nerves in my upper body had started to recover and I was provided physical and occupational therapy, plus respiratory therapy and lessons on how to speak with a trach. My lower body, however, was not making much progress. And, my daughter, Cathy, had weekly fights with my insurance company to be able to keep me in rehab. Cathy was a tiger, and thank God she was successful.

More than once during the next two weeks, I threw blood clots in my arms, and almost catastrophically, to my lungs. This caused me to be transferred to the cardio-pulmonary ward

for treatment. Cathy was not able to get me transferred back to rehab (for reasons we could not determine.) However, the rehab techs knew I needed their treatments and they agreed to come to get me every day and take me to their wing. I will be forever grateful to that small group of physical and occupational therapists who went above and beyond their job requirements for many months on my behalf.

In September, I was told by my pulmonologist that I was not trying hard enough to wean myself off the tracheotomy. But, I WAS working diligently with the techs who were training me, and coughing as hard as they asked me to. During one session, I coughed so hard I blew the trach out of my neck and coded! It was determined that my inability to wean off the trach was because my wind pipe collapsed during the original surgery (which only happens in about 1% of those procedures.)

My doctors said that I wasn't strong enough yet to undergo surgery and I would have to wait a little while longer. Thankfully, I was still in the hospital and my condition was being carefully monitored. Physical therapy continued and I gradually, and painfully, was able to walk with the help of a walker. And, because I lived alone, I received plenty of special training in how to do things to help myself.

I was finally released for home, just before Christmas. My eldest daughter, Marilynn, and her husband, Arnold, visited from Canada to stay with me for six weeks while I adjusted to

life at home. I also had in-home physical therapy three times a week. In two months, I was walking with a cane.

In the spring of 2004, I had to have all my teeth pulled because of nerve damage—a tricky procedure due to the tracheotomy. I must admit I was very afraid. Marilynn flew down from Canada to hold my hand throughout the entire ordeal—a huge blessing. I have to say, I never thought that I would ever have false teeth because I've always taken great care of my own. Depressing, but life goes on regardless.

I continued to have residual pain in my lower legs and feet but was able to walk with my cane, drive my car, and manage most of my own affairs. I needed help with housework and a few other things, but I faithfully cleaned my trach twice a day and did my exercises using the kitchen counter for support.

Finally, in December of 2004, a year after leaving the hospital, my ENT doctor scheduled me for surgery to remove my trach and have windpipe reconstruction at *University of South Florida Hospital*.

Having neck surgery from ear-to-ear was another trauma. Walking around with my chin on my chest made it difficult to talk and eat. Eventually, my windpipe (from which 2-1/2" had been removed) stretched enough for me to hold my head up again.

Over the years, my ability to walk lessened and eventually, I had to begin using a walker. By 2014, I was in a wheelchair if I

had to walk any distance to, or from, my car, or if I wanted to go shopping. I stopped driving altogether in August 2014 and have required more assistance getting around since then. I also require more assistance at home. Pain in my legs was now above my knees and into my thighs. I have lower-back issues which causes sciatica and am on low-dose *Fentanyl* patches. These do not help manage my 24/7 GBS-related pain, however.

Finally, in December of 2015, I won the jackpot again when I was diagnosed with CIDP. I was prescribed IVIG treatments, beginning with a treatment every two weeks for three months and then a maintenance treatment three or four times a year.

Unfortunately, I could not afford the $3,000 co-pay for each IVIG treatment ($18,000 for the first three months alone.) So, my neurologist prescribed 40mg *Prednisone* for one month, reducing the dosage 10mg per month for three months. I am now on a 5mg maintenance dose. As far as I can tell, the *Prednisone* has not been beneficial. The pain level has not been reduced and I have several side-affects like swelling of my face and ankles, indigestion, blurry eyesight, etc. I was told the IVIG treatments would improve my quality of life. And, they did in 2003. But now, the co-pays are outside my retirement payscale reach.

This is my story, and it seems impossible to me that my life, a full and productive one, could be brought to a complete stop, simply because of a flu shot. In 2003, it was.

"Oh, what we take for granted."—KM

Kara Dunford's Story

It was a scene I had watched play out many a December throughout my childhood.

The *Winter Warlock* learned to take things step-by-step, coached by Kris Kringle, as part of a musical number featured in the 1970 stop-motion classic, *Santa Claus is Comin' to Town.*

One December, of 2010, things were different. It was no longer the *Winter Warlock* needing to "put one foot in front of the other." It was me.

During the fall semester of my sophomore year of college, my mind buzzed with anxious anticipation of final essays and excited expectation of the upcoming holiday season. But, something felt off.

My fatigue reached levels beyond that of a college student facing the end of semester crunch. A bout of back pain sent me to the hospital—though the trip proved inconclusive. Perhaps I was coming down with the flu. The aches and yawns being standard symptoms of a viral infection. My best course of action: get some rest.

I slept through the majority of the next day. Upon waking the following morning, a Friday, I made an attempt to return to my regular schedule. But soon, anything beyond a slow shuffle exceeded my ability. Another trip to the hospital was in order.

The onset of a tingling sensation in my feet, countless insistences that I felt as if elephants were sitting on my legs. Over 24-hours later, the medical team gave me a diagnosis. Guillain-Barré syndrome, (GBS.)

And, so my journey began. I had never heard of it, but soon I knew of its characteristic weakness plaguing my extremities. The days in the hospital, first in the neurology unit and then in the acute rehab unit, blend together. But certain moments do stand out:

- The first time I wheeled myself to the physical therapy gym, rather than my physical therapist pushing my wheelchair
- The initial sight of my roommates leading a giant Bugs Bunny balloon into my room, only to have the scene

repeat every so often when they brought the balloon back to the gift shop for more air.

- Celebrating my birthday surrounded by friends, an ice cream cake, and one enormous cake knife.
- The first time I successfully ascended two stairs.
- My sister standing on a chair to string green and red paper chains across the room, in preparation for Christmas.
- The first time I traded in my walker for a cane, my legs wobbling, fear coursing through my mind, excitement soon appearing on my face.

These moments served as signs of hope, emblems of progress, and above all, reminders that the positive is oftentimes there, waiting to be found.

As I continued to progress from wheelchair to walker to cane, a familiar mantra ran through my head. While Dory may have said *"just keep swimming"* and President Bartlet, *"what's next,"* I had a saying of my own, with a tip of the hat to my friends from the land of televised holiday specials.

Sure, there were many days when living these words was about the last thing I wanted to do. There were days when the seemingly simple act of swinging my legs off the side of the bed felt like I was running a marathon. Days when holding my feet up to test my strength left me feeling like Atlas shouldering the weight of the world. And days when I honestly couldn't bring myself to take one more step, feeling crushed by the forces of fatigue and disappointment.

It was in these instances, when my support system of family and friends sensing the pain on my face (and oftentimes seeing the tears in my eyes) rose to the occasion. Sometimes, the simple reminder you're not alone can melt away the trepidation taking root in your heart. For this, I'll be forever grateful.

During the five years since Guillain-Barré first entered my vocabulary, in the midst of setbacks, more hospitals and additional physical therapy, the lessons behind those words have become clear.

"Put one foot in front of the other" is a reminder to have, and to keep, faith in the big picture, but also to persevere in the routine task. I couldn't lose sight of the path, but my primary focus had to be on just the next step, the one in control and the one that ultimately would bring me to where I was going.

While I continue to navigate residual effects, I've also continued to move forward, completing the studies put on hold and finding a new love of stand-up paddleboarding.

It turns out Kris Kringle's advice was loaded with wisdom: Continue to put one foot in front of the other. You just never know where it might get you.

It is this advice, coupled with the everlasting encouragement of my family and friends—and the inspiration provided by fellow members of the GBS and CIDP community—that propels me toward the next step each and every day.

Katrina Hartman's Story

My name is Katina Hartman and I live in sunny South Africa. I am now 60-years old and my recovery from GBS has been ongoing for 3 years.

The symptoms began on the morning of May 14, 2013. The Guillain-Barré syndrome (GBS) diagnosis was confirmed two days later, after I could no longer swallow, and a second nerve conduction test showed that the nerves in my legs were no longer receiving messages from my brain.

It all started with tingling and numbness in the tips of the middle fingers on both hands—progressing to my thumbs and index fingers by the end of the day. I could still type, drive and cook, and I initially thought the numbness was due to pinched nerves in my neck. By 3AM the next day, my hands were floppy and my fingers were extremely weak. My husband dressed me, and drove me to the hospital where I was admitted after my legs started getting weak, and x-rays of my neck and spine showed no abnormalities. By lunch time I couldn't walk. I collapsed onto the floor when I tried to stand up from the bed.

The fear of becoming quadriplegic was indescribable. As a former nurse, I was viewing myself objectively and subjectively. My training in the 1970s had not included GBS. I feared a brain tumor. Was I going to die? Would it be quick and

painless? At age 57, I wasn't ready to say goodbye to my husband and children.

Breathing stopped on day 7 and I was resuscitated and hooked up to a ventilator. My family was told to expect the worst. The nightmare of surviving from one day to the next over the next few weeks, until my condition stabilized, is covered in detail in my blog at *louisehasgbs.wordpress.com*. The blog includes tips that I learned along the way as well as updates on my progress.

Four months in ICU were followed by four and a half more in a rehabilitation clinic; very long, homesick, months. I missed my family and I missed our pets, too. By the time I left rehab my arms and legs were still useless, but I could sit in a wheelchair for up to two hours. During those months away

from home and work, my family, friends and colleagues were extremely supportive. Their love and support still carries me through each week of my recovery. The stress that my illness had placed on everyone was huge, but my friends and colleagues rallied around my family and helped take care of them, which I so much appreciated. I can never fully express my gratitude to them. They were, and are, all truly amazing.

Yes, I am still recovering. I cannot climb stairs, yet, but I can walk short distances while holding onto a *Rollator*. And, I can walk unassisted in a swimming pool. Hydrotherapy has been very helpful in strengthening my legs and core muscles. My fingers and hands, which I was told by my doctors and therapists would probably be the last to recover, are becoming stronger but are still too weak to properly hold a full mug or glass. BUT, I did write my name for the first time since GBS, on 7 March, 2016! This was so exciting and just the beginning of a stronger future.

Early on, during my time in rehab, I truly learned the meaning of the word… YET!

My mind refuses to accept that I must be satisfied with the recovery I have attained thus far. My lack of independence, inability to drive, cook, comb my hair or dress myself is terribly frustrating. And, there are the odd days when the slowness of recovery is too much for me to cope with. To quote Ashleigh Brilliant, "*I try to live one day at a time, but sometimes several days attack me at once.*"

After a "pity party"-for-one (i.e. a big cry,) I remind myself that it could be much worse; that there are people who are living with, and in conditions, far worse than mine; that I am improving (even though it's too slow for my liking); that I am able to do things to make my days more bearable; that every day is a new day, and my future progress is in my hands.

To other recoverees out there: No matter how insignificant an improvement is, it's the start of progress which becomes exponential over time. Push yourself but don't overdo it. With GBS, pain is not gain, recovery is not measured or consistent. Never give up!

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Kay's Story: A Story of Six Sisters.

Six Catholic girls born into a family of nine—raised in Nova Scotia. All but two of us girls remained in the Maritimes. Mary Catherine, aka Kay: city life. There, she lived in a high-rise apartment, worked for banks and investment firms, traveled by subway, and enjoyed all the diversity and opportunity living in a large city could offer.

Our sister Kay made annual visits to Nova Scotia for weddings, funerals, graduations, baby showers, or summer vacations. Seldom did we venture to Toronto.

September 16, 2013 all that changed.

A mysterious, sudden and serious case of Guillain-Barré (GBS,) had turned her world upside down… and ours too. A call from her good friend Edna, who had provided care in the preceding days, informed us Kay had been admitted to *Toronto East General Hospital.*

Needing family consent for treatment, our oldest sister Ann flew to be with Kay. Little did we know how scary the months ahead would prove to be. Daily communications with all family members was crucial, and we promised to keep it off social media sites, choosing to use email instead.

With Ann by her side, Kay's condition continued to worsen. Within days she was placed in the ICU, trached, ventilated

and helpless. Collectively we read articles on GBS, cried and prayed for God to help her through this ordeal. As the days turned into weeks without any improvement, it was obvious Kay would need one of us there continuously. It was as much for us as it was for her.

We soon developed a plan for a rotation of sister visits. Some of us, still working, had to secure time off. Others were able to go for longer periods. During the most critical stage we overlapped visits. Kim arrived from Alberta, later Betty, then Dorothy from Nova Scotia.

Kay remained totally paralyzed and ventilated in ICU for three long months. We anxiously watched and talked to staff while they cared for her. Our eyes were glued to the monitors as her blood pressure and heart rate fluctuated for months.

Numerous infections and a heart attack complicated any

progress. The *TEGH* staff did their very best to keep Kay alive and comfortable, for which we are grateful. They too, had to endure five different sisters, with various personalities, viewing and questioning every procedure, sometimes even disagreeing on the plan of care. Some staff, neurology, respiratory, and PTs, who had GBS experience, were wonderful in caring for her and us. Others required constant reminders of her needs.

Coping with Kay's illness was difficult. But being so far from our home and adapting to the city life she had embraced for years was yet another challenge.

We were ill prepared to travel to unfamiliar locations using public transit, often in the dark. The extreme winter weather added more difficulty. Coming home to her empty apartment exhausted and emotionally drained often involved crying with each other via *Skype*.

Our saviors were Kay's good friends and neighbours. They provided drives, meals, advice, and much needed comfort in a big unfamiliar city. These were folks we heard stories of for more than 20 years, but had never met. Suddenly we became deeply connected in our effort to see Kay through her illness. One friend in particular, Wendy, secured our contact with the *GBS|CIDP Foundation International*.

Without seeing any improvement in Kay for months, we challenged the staff to consider another IVIG treatment.

Shortly after the second treatment we saw what we considered a miracle. Kay had very slight movement in both arms. Everyone in ICU celebrated the good news.

Throughout November and December, Kay continued to show signs of healing. She gained more upper body movement and some ability to breathe. Kay had a visit from two women from the *GBS|CIDP Foundation International* who offered support and encouragement. The best Christmas gift we received was a video sent by Eunice of Kay's visit to the hospital lobby to see the Christmas tree. There she was sitting up in the wheelchair with the trachea tube closed off! It was only then we began to believe the GBS was finally leaving her body. Eunice spent five weeks with Kay over the holiday season, away from her husband, coping with terrible weather and a very bad cold. We are grateful for her commitment.

Early in the New Year, Kay transferred to the respiratory unit to be weaned from the ventilator and various other apparatus attached to her body. Betty had the pleasure of being with her while the catheter, PICC line, trach, and feeding tubes were removed, all in one week! She was thrilled to be eating real food and having her voice again. Soon afterward Kay asked to visit the ICU to thank the staff that took such good care of her. Although it was an emotional visit, the staff was overjoyed to see the new Kay.

Plans then began to secure a suitable rehabilitation facility, hopefully one with other GBS folks. Leaving *TEGH* was both

exciting and frightening for all of us. We were familiar with the staff, location, and they knew our sister Kay so well. But starting over someplace else meant her physical rehabilitation could begin. We all wanted that badly. Word of the move came to us on a week when none of us were with her. She transferred to *Baycrest Hospital* with the support of a devoted neighbour and friend Terry. Only after Ann arrived did we realize it was primarily a geriatric centre with little or no GBS experience. A quick call to Donna Hartlen of the *GBS|CIDP Foundation International*, assured us that Kay was in good hands. After some initial bumps, it turned out to be a perfect location with good PT/OT programs. While there, Kay resumed more control of decisions and choices in her own care and rehabilitation planning. We are relieved and happy for her. Kay now owns an *iPad Air*, a family Valentine's Day gift. With this tool she *Skypes* us daily, emails friends, reads the paper, listens to radio, watches movies, reads books, etc. Having time on her hands has allowed her to stay connected with the world beyond *Baycrest*.

Kay's determination to regain mobility, starting with the most basic things such as using a fork or pulling on her shirt, has been an inspiration to us. At times it was overwhelming and she needed to let the tears run. Being with her then was important not because we could say anything to help, but just to hold her hand to get through that moment.

We sisters appreciate everything that has been done for Kay;

for us, by the medical system. We will continue to support her as much as needed until she regains her former life.

As a family, we are now closer than ever. Our one and only living brother, Bob in Florida, has been in constant communication, providing a sounding board and gentle advisor. Each of us has brought their own perspective and attributes to the situation; all of these helpful at different times. We did truly rely on each others strengths and are forever grateful for having each other.

In reflecting on what we've been through, we'd like to offer some advice for caregivers in similar situations: Establish Power of Attorney for medical and financial reasons. Frequent communication was needed with Kay's physicians, employer, bank, insurance company, etc.—all requiring proper documentation along with photo identification before allowing us to act on her behalf.

Please talk to, and reassure, your family member. Let them know you are there even when they appear unaware. Our Kay has few clear memories of her early weeks in ICU, but she remembers us speaking to her and assuring her that we were taking care of her.

Appreciate the fact you won't always agree with medical staff decisions. Don't be afraid to question it, but accept that some decisions are made for the right reason even if you don't fully understand.

Let the little things go. Not all staff performed procedures the same way. Nurses had different dispositions, as did we. In the end, every one of them aided Kay's recovery in some way.

Accept the support offered by friends and neighbours. It is important for them to do something constructive to show their love and concern for you and for loved ones like Kay.

Be an advocate for your family member, but do it elsewhere. Assume they can hear every conversation you have in the room. If you are questioning procedures, step out of the room and/or ask to speak to the nurse manager. Our best results came from putting our concerns in writing and having the right email addresses.

Remember the recovery of your family member is not only physical, but emotional and spiritual, as well. It takes endurance unlike anything before in their life.

Some days you have to share their burden to help them survive another day. Prayer may not be a part of your daily life, but it will bring comfort.

Proud siblings of Kay: Ann, Betty, Bob, Dorothy, Eunice and Kim.

"'It's only the common flu,' the doctors said, until three days later."—TC

Kelly's Story

How do you measure the quality of your life? Is it in the experiences, your monetary value or your accumulation of acquaintances? For twenty-eight years, quality of life was not something I measured. I assumed that at a young age, with a steady income, a wonderful partner and the ability to vacation twice a year, that my life was on track. I never felt a lack, a need, or a want for much more…until it was all taken from me.

It began with a weakness in my knees. I crouched to the ground in a store to select an item off a shelf and realized I couldn't stand up. My legs, that once carried me throughout life with resilience, now felt like they were made of lead, that they were constantly wading through waist-deep mud. My hands could no longer grip a pen and my ever-present exhaustion clouded my once sharp mind. I was becoming a person I didn't recognize. I slowly wasted away. Seventeen pounds lost from my small frame. My eyes were now dark and sunken. My inner light extinguished.

I left a position that I was good at but never loved. It was hard but necessary. I always valued my work and my ambitions, but now I saw nothing but uncertainty. The days passed from my bed. The sun would rise to greet me, but I kept the blinds drawn. It would sink at night as I was none the wiser. The leaves on the trees turned into brilliant shades of red and

orange to give their final goodbye before the winter came and I—I didn't notice.

I learned that medical schools must teach doctors to pull up a chair close to you when bad news is in your chart. I have had my hand, literally, held by many, many, physicians. Eventually, I no longer felt hot tears on my cheeks as I slowly shuffled past the waiting room after my appointments in which I was told to expect a lifetime confined to a wheelchair… if I survived! As many others have been along similar journeys, I was told I was either exhibiting symptoms of MS or ALS; both devastating options. I became completely numb. At newly 28 years old I was faced with the reality that the best years of my life had passed by me at lightning speed. I mourned. I had no idea what life had in store for me, or if there would be anything to even fight for.

I was unable to function on my own anymore. One of my most vivid, dark days, was when I had to drag myself by my arms from the bed into the restroom and back; lifting my legs manually with my weakened arms back into the bed that had become my closest friend. I was finally hospitalized in December of 2013, after my primary-care doctor, and my neurologist, petitioned my insurance to have me admitted. *"A healthy 28-year old who can't walk?? What kind of quality of life is this? She needs immediate help. I will not leave until you OK this!"* my doctor firmly announced on the phone while I waited, exhausted in every sense. She was successful… and I cannot thank her enough.

In the ER, my neurologist met with me and described what was next, a week long IVIG treatment. An MRI of my spine did not show any lesions that would be indicative of MS, so if I showed any improvement to this treatment, ALS would also be ruled out. I didn't ask many questions, I just asked to sign my consent form and begin treatment immediately.

Person that I am, I need to know everything, I didn't care about the how, or the why, I just wanted anything at all to work. Five days passed and I squeezed my doctor's hand just a little tighter than before. Sheer delight mixed with relief washed over her face. It was working. I left the hospital just before the ball dropped on New Year's Eve. It was truly symbolic. A new day, and the second chapter of a long journey.

I would be lying if I said it was easy from there on. Painful

therapies, IV's, bloodwork, nurses in and out of my home. I dug deeper into an inner strength I never even knew I possessed.

Eventually diagnosed with Chronic Inflammatory Demyelinating Polyneuropathy (CIDP,) things slowly began to come together for me. When faced with the possibility of having a fatal illness, a chronic one feels oddly less depressing. As the days passed, I slowly started to appreciate the trees for their leaves again. I gradually rose from my bed and entered the world again with my trusted cane. I stopped allowing fear and embarrassment control me or else I knew I would never, ever improve.

From that day on I made it my mission to spread that word to everyone living with this disease. I wracked my brain endlessly wondering how my experience could help me reach that goal and I was at a loss. On one sweltering day in July, my horoscope read, *"your two worlds will collide in the form of a job opportunity"* and on that day I found the *GBS|CIDP Foundation International's* listing. Two months later, I had my first day back to work in nearly two years.

In my role at *GBS|CIDP Foundation International* I have the opportunity to devote myself to patients just like me. With each new person I meet I have a new, instant friend. We are bound by our experience and rarity, and although we are not a monolith, we are still so very similar. I assure us both at once that we can, and will, get through this, and we will do it

together. CIDP destroyed my life, but in return it gave me a new, purposeful, one in which each day is truly the greatest gift. Every time my phone rings, or someone is relieved to simply speak to me and hear from me that there is a life to look forward to beyond the turmoil, I feel like the luckiest person in the world.

This January, I was given the opportunity to travel to California to tell my story as a patient. I stood before 150 eager individuals who hung onto my every word. I was honored—and beyond humbled—to be a voice for so many who may, at present, have none. To be a face instead of a statistic. After thirteen minutes of releasing what I didn't even know still existed within me, the weight of so many months of pain, was lifted from my burdened shoulders. I was immediately a survivor–a title I struggled to accept for so long. After the hugs and handshakes, I made my way down to the shoreline of the Pacific. A promise I made myself when I was laying in my bed; if my health did improve and I could walk on my own two feet again, I would see the Pacific Ocean. Full circle–oh, how I had arrived at you! Tears streamed down my face as I looked out into the infinite beauty, wondering what I can conquer next. Hopefully the sky is the limit.

Tomorrow, and every day thereafter, I will wake up as a person living with CIDP. How I choose to spend that day is up to me and me alone. I will continue to set small milestones for myself and continue to remember that the end goal is my

entire life. The sun rises as I walk on my own to the train every morning—and I make sure to appreciate every second of it. It's not lost on me anymore. Every step I take is for my future, and for the future of all of my new friends living through CIDP. If I never in my life have the opportunity to run again, I still have those steps to look back on, and the ones that will follow to motivate me. I am here. I am surviving. I will live a good life.

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Kim's Story

I was once a woman living a normal, everyday life.

Two weeks after my daughter's 9-month check-up, my arms were so weak I almost dropped her down the stairs. Using a can opener became difficult. Brushing my hair proved to be a task. I went to visit my primary-care physician and explained to him what was happening. He referred me to a neurologist.

After several blood tests, nerve conduction tests, and a spinal tap, I was diagnosed with Guillian-Barré syndrome (GBS.) To be certain, I reached out to a neuromuscular doctor at *Emory University Hospital* for a second opinion.

Since I had never heard of GBS, as soon as I got home, I jumped on to the internet to do my research. Once I read what GBS was, I was horrified. In May, at *Emory,* my second opinion verified GBS. Dr. Hopkins also said, *"I cannot treat you because of your congestive heart failure."* I said, *"what do you mean you 'can't' treat me?"* As much anxiety ran through me, Dr. Hopkins responded, *"every treatment available for GBS will add fluid to the body and your cardiologist will never allow it."* I said *"what am I supposed to do?"* He said *"go home… and if your symptoms worsen, call me."*

My husband and I drove home agreeing that we were in this together.

In October, I began falling for no reason, I could not walk without stiffening my legs to make sure I wouldn't fall every time I walked. Dr. Hopkins prescribed a low-dose of *Prednisone*. My GBS worsened slowly. By January, my legs were paralyzed. My husband would help me in and out of bed and roll me over in bed. He would help me on the toilet then lift me to pull up my pants and carry me to the couch. My arms were so weak I couldn't lift them past my elbow. My husband would lift my arms, stretch my muscles, bathe me, brush my hair and take care of our two small children.

Thankfully, I was granted an appointment with Dr. Ranadive, a neurologist referred by Dr. Hopkins. Dr. Ranadive took one look at me and said I was just days away from being admitted to the hospital… and that my GBS has progressed into CIDP. He then referred me to Dr. Stuart. Dr. Stuart explained that my lack of reflexes explained why I was walking so stiffly. He immediately prescribed *Gammagard*.

Unable to walk or climb, my husband continued carrying me up the stairs for my infusions. After my third IVIG infusion, I was again able to climb stairs by myself by hanging on to the railing.

I haven't looked back since. Fast forward to today…I now live a somewhat normal life again. I can mow the grass, do laundry, vacuum and some other household chores. Best of all, I can walk up and down stairs by myself!!!

There are several things that I still can't do and I have some

residual nerve damage in my hands and arms. I still receive *Gammagard* infusions three days a week every three weeks.

I know having GBS or CIDP can be depressing but, it doesn't have to be. If you believe in yourself, have faith in God and your doctors…there is light at the end of the tunnel. I am living proof! I refuse to allow GBS (now CIDP) to beat me….I beat it. I intend to keep fighting! I never want to be in a wheelchair again!

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"Don't expect an even recovery—it's usually slow with two steps forward and one step back."—SC

Kyle's Story

On the 18th of August, 2013, Kyle was engulfed, suddenly, in a fight for his life. An illness that we could not pronounce laid claim on him, and with a velocity and a determination that numbed us. He staggered…staggered….and descended far below the earth. He came to a standstill. Within four days his lungs, which had sustained him so well for 22 years, ceased to draw breath. His body became immobile; he traveled in labyrinths unknown, and not of his own making.

Fueled with morphine and *Propofol*, the acute phase of Guillain-Barré syndrome (GBS,) sought to do him in as he endured an induced coma. He waged his battle, traversing a twilighted landscape—jungles and deserts and high places, gunshot wounds, dark meeting places in rooms with no windows, ICU psychosis, and dimly lit passageways.

A heart that used to beat at 58, now found its angle of repose at 120 and more. A muscled 185 pounder diminished to 125 pounds in short weeks. A body that could not sustain the basics of life, like blood pressure and a normal temperature. Oh! What we take for granted! The only message he provided us within those first three weeks was a delirious shaking of his head: back and forth, forth and back.

Sitting in his room, that maniacal headshaking was woven into us. Sometimes, we just had to look away. Would he come

back to us? And what parts might be lost forever?

And time went by…slowly.

Four months in hospitals. And then a homecoming on December 23rd, and five months at home with us.

And…many things came back. His mind and his humor (though these had never fully departed), his weight, his will. A couple dozen prescriptions became a dozen, a half dozen, and finally no doses of anything. He kicked it all—opiates, morphine, and finally methadone. Mobility returned, and dexterity. Many things were discarded: Hoyer lift, hospital bed, and his walker.

The boy bares a couple of scars. A stoma from his tracheostomy. A unique puncture in his abdomen where a feeding tube sustained him. And what more? I cannot pretend to know. But maybe this: he came to know what we understand as suffering, but which *"is really only life herself, making him unavoidably unique"* (says Jim Harrison, in "Dalva").

Another nine month incubation under his belt, our beloved Kyle is reborn.

Today he drove north, on a Path of Reclamation. Armed with his Blue Rockers (braces), his hiking poles, his wheelchair, his Dodge, and his dog. He is on his way.

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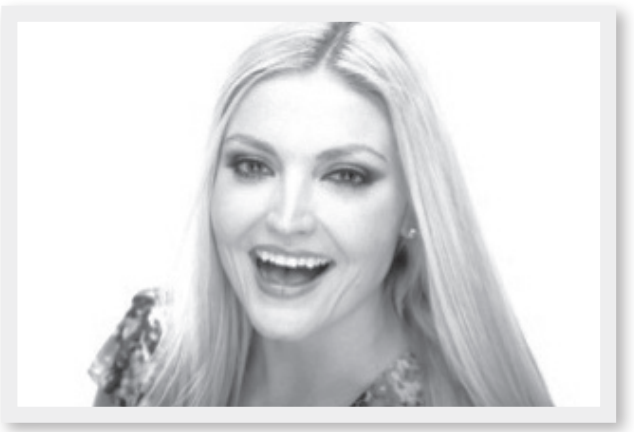
Laura's Story

The old adage, *"when life gives you lemons, make lemonade,"* has been a byline for Laura Dodd almost her entire life. At the young age of 12, Laura was diagnosed with a rare neurological disorder, Chronic Inflammatory Demyelinating Polyneuropathy (CIDP,) a condition similar to multiple sclerosis. The result was several years traveling from a wheelchair, to a walker, to using a cane and finally *"standing on my own two feet"* as expressed in one of her original song compositions. To combat her illness, Laura has regularly scheduled intravenous treatments in an effort to strengthen her muscles. In addition to those medicinal routines, Laura incorporates daily workouts exercises to improve her health.

Laura's vocal and stage accomplishments are quite a few. Some of her more recent performances include the Washington, DC, mall venue for the 100-year celebration of the *Girl Scouts of America;* theatrical and vocal performances at the *JFK Center for VSArts*, the *Strathmore* in Bethesda, MD; for the disability coalition; on the lawn of the White House for the *Miracle League* annual games, as well as many more. An independent film director in Denver, CO, has included three of Laura's original song works into two of her films and a documentary.

Born and raised in Sand Valley, a small Alabama community, Laura now resides with her husband, Joe, in Jasper, AL, and at her home in Nashville, TN.



When asked about her disability, Laura explains, *"My family encouraged me from day one to make this trial a positive one, to grow and become all I have dreamed of." "My dreams have always been big,"* Laura says while smiling, *"but my 5-foot 3-inch frame is dreaming its way to world renowned stages… Carnegie Hall, Grand Ole Opry, and many, many more. Music has truly been the very best medicine for my journey in life."*

Linda T. Hurd's Story

Oct. 26, 2002. *Melrose Wakefield Hospital (MWH.)* I checked in last night. My fever is an aside at the moment as my face was becoming numb and began functioning strangely. I had muscle soreness all week and a pain under my left ear—then my eyes weren't focusing and my tongue became numb. Then my lips.

Finally, I called, *"ask-a-nurse."* The call was after 5PM on a Friday so they said I should go to an Emergency Room. The ER said my CT scan was not totally normal and they wanted to admit me to do an MRI ASAP (not emergency) so the MRI won't be happening 'til tomorrow, Sunday. So, I'm here today to cope with lesser stuff, i.e., get meals, have my bed made, and be able to write in my journal and see a rainy view of trees. I'm missing the lines (while writing) sometimes because when I don't cover one eye, I see double.

Oct. 31, 2002. Woe is woe. Low. I'm at *Mt. Auburn Hospital (MAH.)* CCU. I am glad to have my journal and a pencil since I haven't written since Friday, October 25th. I just did a walk around the room and I'm wiped and dizzy.

Nov. 1, 2002. I'm keeping down my shake/drink since 9AM and it is almost noon.

Nov. 2, 2002 Sometimes a half-empty cup is more positive than a half-full cup. Today I drank a half a cup of juice. So a

half-empty cup is an accomplishment. Meaning I drank the other half.

Nov. 3, 2002 Sunday, Day #5 of the Intravenous Immunoglobulin infusions (IVIG.) I barfed again today. I'm quite good at it. I'm less anxious/overwhelmed, but I am still very affected by everything. Even expecting visitors, trying to make phone calls, trying to eat.

Nov. 4, 2002 My hands are tingly and weak. It is hard to hold a pencil. It is hard to see a singular page

I ate ½ cup oatmeal, some potatoes and chocolate pudding. My legs are skinny and don't work well. They want to buckle under me. Or, I get tipsy and dizzy and feel like falling over.

I was 45 years old in 2002 when this occurred. I tried to recap the days. Some of the dates in this journal are off because it was difficult for me to keep track of simple things like, Wednesday, tongue tingling; Thursday, waiting; Friday, Eye Doctor, *MWH*; Saturday, *MWH* and Dr. Shahrokhi; Sunday, *MAH*; Monday, spinal tap; Tuesday, ICU; Wednesday, PT/OT; Thursday, Halloween and infusion #1; Friday, November 1 #2; Saturday, Nov. 2 #3; Sunday, Nov. 3, #4; Monday, Nov. 4, #5; Ward 3A, ate oatmeal, potatoes, pudding; Tuesday, Nov. 5, RM 803A.

Some names I wrote to remember with gratitude: Tina, Claire, Glenn, Joyce, Hara, Rhona, Dan, Jennifer, Mariah, Deb, Helena, Helen, Andrea, Meredith, Gina, Mary, Dr.

Shahrokhi, Dr. Targino, Dr. Shiftman, Dr. Wang, Dr. Resnick, Dr. Sullivan, Dr. Sarkarati, Dr. Vobert, and Dr. Vemma.

Nov. 7, 2002 Today is a bit brighter. Yesterday, I felt struck by inactivity and I as depressed. I blew breakfast and that was disappointing. I chose to take some *Ativan* to help with anxiety and nausea.

I took some again today and I had a good breakfast so far. I'm sitting and feeling quite tipsy. I guess those nerves are also affected by the disease process. If I can keep up the fluids, I won't have to have I.V.

Nov. 8, 2002 I'm supposed to move to a rehab hospital today. That's progress, but I'm nervous anyway. Thank you, God, for your forgiveness for my inability to relax and rest. 2PM, I just got word that I'll be going to *New England Rehabilitation Hospital,* in Woburn. That means I've improved. I'm nervous, but glad that it will happen today. I ate a pretty good lunch. I hope it stays down. Amen. My back, thighs and hips were up to a 7 on the pain scale. It wasn't a good night.

Nov. 10, 2002 Sunday**,** I fell down in the bathroom last night. Knees collapsed right out from under me. This morning I am also weak and knees still buckling. My hands fell asleep and won't wake up. It's hard to keep track of days. What day is it? I am taking lots of meds: *Ativan; Tylenol;* a blood thinner; some acid thing; a multivitamin; *Colace*, a stool softener; *Sacarot*, a laxative; *Ambien*, a sleeping pill.)

Nov. 11, 2002 Monday, I didn't sleep well. Back pain, hot, too weak to even roll over. I'm afraid of getting worse. Later, 6:30PM. I am wiped out beyond what I thought possible. Actually, I have felt this way a lot these days. I feel like my legs, arms, and what not, weigh 500 pounds. Meals are still an effort to eat. I am getting an egg crate for my bed. I hope I can sleep tonight.

Nov. 13, 2002 I've been totally beaten today. I feel weakened in my legs and arms. I also vomited breakfast and have wanted to sleep all day. I'm going to go back on *Nortriptylene*. Yesterday, I was queasy and weak, too. They are measuring my strength and progress each day. So, to know if the disease is finished moving through.

Nov. 14, 2002 I am weary. I feel like a nap. I can tell my left leg is weaker. I can't pull it up or lift it off the bed.

Nov. 15, 2002 I see how rehabilitation therapists are so necessary for someone to recuperate. I don't feel like moving. I want to stay in bed and rest and feel sorry for myself. I'm going to not have more *Ativan*. It may be why I'm so tired. I'm nodding out all the time. I went into the pool today. I could move. I could float and the therapist guided me. It was nice. I just drank a concoction of stuff with milk of magnesia. I think it contained cloves and molasses. It is supposed to help my bowels move. We'll see.

Nov. 16, 2002 Saturday, My vision is still irritating. With 2

eyes it's often double. With one eye, it's not very clear. Today pins and needles in my feet, knees, hands, back and front abdomen. And, a big head ache when I sit up from lying down. I took pain meds and that helped, but I was freaking out this afternoon because I was feeling so bad.

Some names I want to remember: Alison, Janet, Elsa, Janet, Georgina, Cyrus, Bill, Marie, Chris, Holly, Diana, Maile, Paige, Katie, Kristin, Vicky, Diane, Sue, Paul.

Nov. 17, 2002 Everything to do is a major effort. Dropping stuff is like losing it. Ointment in my eyes makes my vision blurry. I can't walk or stand or move my left leg much. My roommates so far have been able to use a walker. They are elderly but able to stand and walk on their own.

This is day 3 of feeling no progress. I get fearful the disease is not finished with me yet. But I also fear the nurses are annoyed with my lack of effort. It's not lack of effort. It is really, really hard to do this on my own. I am wanting to write, but I can't see well. I can't hold a pencil well and I have little, very little, strength to sit up with my eyes open. I got French fries, fruit, cottage cheese, pocket bread, cheese, root beer, *Boost* nutritional shake and apple juice and raspberry sherbet. I ate cheese, a shake, sherbet, ½ apple juice, ½ root beer, ½ pocket bread, and fries. I am sweating now.

I napped at least 2 times today and felt better this late afternoon and evening. Mark, my husband, visited and we all

(me, the kids—sons ages 15 and 12, and Judy, my sister) ate together in the cafeteria. There was a gentleman playing the piano. His wife is a patient here. He plays improvisation and it was beautiful.

Nov. 18, 2002 I can see I have written a bit more even though generally I don't feel better. In fact, I think I am going to have more IVIG treatments. They should accelerate my recovery. It is hard to think of going back to *Mt. Auburn Hospital.* But, I'm trying to accept, and be in the moment here—not there.

Nov. 20, 2002 *MGH (Massachusetts General Hospital)* Ellison 12 RM 6B. I arrived by ambulance yesterday, was in ER from about 2-10PM with an x-ray and MRI thrown in, a student, junior-resident, resident, senior-resident, each doing the bend-this-don't-let-me-pull-it-lift-this routine. The senior-resident put me over the edge. I was angry at her putting me thought it. I was crying and she still pushed me. When I had to push her away with my biceps, I did it with some anger. Then after she left, the other resident had enough compassion on me to help me to the commode. He was nicer. She seemed like a total bitch.

Nov. 21, 2002 Thursday. One week 'till Thanksgiving. I had round 1 of the IVIG infusions last night. I had anxiety and was having a hard time with the whole thing. Judy, my sister and Deryk, my son, were with me in the evening and we were able to speak about it; I asked to pray in the pattern of *Philippians 4.* I said my plea for the infusion to go well and work well.

Judy prayed, too, and I and she thanked God, too, for what we could—His presence, love, the care I've received. I did feel less anxious and was able to relax and feel more positive. It was a great display of God's fulfillment of His promises. The infusion went well, and I was able to sleep pretty well. I think they are going to do a muscle and nerve biopsy tomorrow. I just spoke with the surgeon. I need to speak with Dr. Venna to understand why.

I can see Boston, the sunrise, the *State House*. I took *Tylenol* at 6-ish today. Less than other days. Days can get long by 6PM.

Nov. 22, 2002 Will this change my treatment now? Can it wait? The surgery (biopsies) are postponed until Tuesday. I feel okay about that. My slow decisions didn't fit the rush of…

Nov. 23, 2002 Saturday. I finished day 3 of the $1,000 infusions. Two more to go (of round 2.) It's sunny today after three days of fog, clouds, and rain. I am a little stronger, but I still feel far off from how I usually feel. I was anxious last night about needing a new IV and that interrupted supper for me. I ate only 2 crackers and a bit of cheese, ginger ale and some cranberry juice. This morning I gagged up some phlegm and I was worried about breakfast. I ate slowly, had some *Boost* drink and a yogurt. I skipped the oatmeal because I couldn't find any sugar.

Nov. 24, 2002 Sunday, 8:30AM. I'm seated in a chair but I just wanted to be back in bed. My body is weak and sitting is work.

The sun is bright and one small cloud just passed in front; relief. It is 8:45AM now. 10:30AM. I had breakfast and then a shower and I'm still in the chair. I wanted to let my hair dry. I could go back to bed but I'm surprised that I had the energy to stay up.

Nov. 25, 2002 Monday, Noon. My respiratory checks have been daily at least 2 times/day. Just now I puffed 3.3 liters, which is good. Thank you, Lord. I stood up in the bathroom and transferred to the wheelchair without a boost. That felt great. With PT, I did 5 stand/sits with the wheelchair to a walker without assistance. Last night I visited with some recovery (12-Step) people and I can see how my physical recovery is, in many ways, the same as 12-Step recovery. Step 1. Powerless unmanageable, 2. Higher power, 3. Surrender will to HP, 4. What's wrong and right, 5. Talk about it—admit to HP and others and self and Thanks, 6. Get ready, 7. Depend on God to work, 8, 9, 10, 11, 12. Then there's *"progress not perfection."* My progress is slow and steady. Very small things I need to embrace as progress.

This is a test. Vocabulary and things I learned:

Boost drink; Boost in bed

Transfer to toilet; transfer to hospital

Demyelization, Demoralization

Progress is progress

I have to pee—you want tea? I have to pee—you want to read?

New wrinkles—a good thing (at 45 years old)

"half-empty" can be more optimistic than "half-full" –I drank half, if it was half empty

When tingling started on my belly and back, I feared my vital organs were going to fail or weaken—lungs heart, stomach.

Plastic-covered pillows make me sweat.

I toss and turn and get sweaty and sore. In the early stages, I was sore with leg pain and tossing fitfully in bed made it worse.

Grateful for: Diane, Elize, Bill, Nanette, Olivia, Alison, Joyce, Lisa, Doreen, Shawn, Cyrus, Gladys, Maggie, Joyce, Maggie, Susan, Sharon, Marie, Alison, Virginia, Pat, Guerline and Nancy.

Sounds of a hospital at night:

Environmental services door opening and closing

Med cart drawers

Nurse/aid laughter

Nurse/aid talking

Someone's telephone

The telephone at nursing station

Loud speaker paging someone

TV in a nearby room

Coughing of a neighbor

Snoring

Rolling over

Legs rubbing in sheets

Call bell

Bed alarm

Repeat #1

Talking patients

Nurse/aid announcing a pill or treatment

Rolling wheels

Nov. 26, 2002 There isn't anything I can do to ensure my recovery will begin or will move fast. I can eat well, work with my attitude by talking and praying, and I can try to exercise and rest. But the actual recovery is something that will be God given. I suppose every healing and recovery is God's gift and not a result of our good work. My disease, being so uncharted, is especially fearsome because no one knows when or how the recovery will come. When you break a leg you expect it to heal in a certain amount of time if it is casted or held still. But what happens to someone with Guillain-Barré syndrome? Full recovery is expected, but when and how? For me, they say mine is not typical.

Nov. 27, 2002 Thanksgiving eve. I am at least as strong as yesterday, but my right eye is not blinking. Tingling, according to Dr. Venna, could mean that the nerves are actually regenerating, so I needn't think it means I'm getting worse. My hands are very tingly and I feel it in my feet, back,

belly, and knees. I had the biopsies yesterday and it was only just tolerable. My thigh and the back of my calf are sore and I'm taking pain meds. I don't know where I'll spend Thanksgiving. Here, *MGH,* or maybe *New England Rehab?*

Thankful for: Eyes that blink, lips that close, muscles, nerves, Myelin, appetite, food, BMs, air, lungs that work, a heart that works, a bladder that works, doctors, nurses, hospitals, IVIG, researchers, donors, blood tests, physical therapists, occupational therapists, speech therapists, Judy and Todd, Steve Charlene, *Calvary Christian School*, Carolyn, Stearns, Pam, John and the kids, Dick and Pat.

Nov. 29, 2002 Yesterday was Thanksgiving. I'm starting my second day of rehab at *NERH* (again.) I was here yesterday. That feels like a big deal to spend Thanksgiving in the hospital. The doctors say I will get better. It's just time. I ate my whole breakfast: 2 pieces of French toast, juice, resource juice, milk, a little decaf.

Nov. 30, 2002 My hands are very uncomfortable, almost painful, very clumsy with so much tingling that I have trouble telling the difference between a pin prick and the dull end of a safety pin. Breakfast is my best meal. I'm on iron, folic acid, *Neurontin, Colace, Nortriptylene,* a multivitamin, *Tylenol.* It's hard to hold the pencil but the eyes are better—not all the way. Yesterday, Judy and Deryk had a day off and Mark had to work. I was here in Woburn. Mark felt guilty to work and I felt guilty to be here. What good was that? People here are

welcoming me back and noticing a big difference in my sit-stand-transfer. It even looks better. I feel like I'm still hanging in—only just. Perhaps better than only just, because now I'm eating and looking toward home as my next stop. My earthly home that is.

OT showed me some toilet and tub options for when I go home. PT helped me walk and did exercises for legs and hips with me.

Guillain-Barré syndrome When my body became completely foreign. My eyes went to seeing double. My tongue went tingly, my face paralyzed. My eyes didn't blink properly or completely so I needed lubricant to keep them from drying out. So, then my vision was double and blurry. Then my arms, legs and trunk went weak. First my hands and feet were tingly. Then there was tingling in my knees and abdomen. My finger tips and toes were tingly as far back as October 12. The tingling grew up my fingers and toes to take hold onto most of my hands and feet. I also had dizziness. The anxiety of feeling so out of control and out of what was normal to me made me also unable to eat or drink properly so I lost weight and needed IV fluids. I think I was unable to keep things down at the beginning of my hospital stay also because of the vision thing. I felt nauseous like motion sickness with vision and dizzy trouble.

Dec. 1, 2002 24 days 'til Christmas. I've wondered what makes a person himself. Like is it your perspective of the outside

world. For me that was important, maybe the artist part of me depended on seeing people and reading their faces and seeing things and nature and sky—all of that contributed to my sense of well-being and the situation with my world. But now that I haven't been seeing clearly for about a month, I'm guessing that this is not really what I need to be me.

My hands also used to be so important in taking in the outside environment, or expressing my visual perceptions of it, through painting and writing. That is now not very possible. I am writing now with a numb/tingling hand that feels like it is not even mine. My legs are also clumsy and unable to set me tall. My back and stomach muscles are also weak and sitting is challenging.

Today I made it to the protestant worship service—which was nice. Rev. Veronica (Ronnie) was there as a patient. I guess no therapy today. I feel tired and lazy.

My condition is supposed to improve. I see people here who are amputees and they will not get better—their limbs won't grow back. That's a permanent loss. My condition is going to get better. Even though for this season, it is sooo difficult to deal with.

Now I'm taking three *Neurontin* per day and only one iron. My poops were getter cement-like and the doctor said one per day was okay.

Today, I had no therapy, but I sat in a chair from 8-10:30AM,

12-2PM and 4PM-? Yesterday, I played some piano. Tough. But good.

Dec. 2, 2002 Didn't sleep quite as well. I had the room too cool, I think. Then my eyes and head ached.

6PM. I had therapies: OT, PT, ST, two times… and pool therapy. So I am beat—beat ready to fall into bed beat. I rested from 4-5PM and from 1-1:30PM but I feel pretty sore, beat. I walked 3 laps of the pool with a dumbbell-type float. I exercised, too. I walked with a walker 15 feet down the hall with Dr. Sarkarati, then around the gym 1 and ½ times, 50 feet, and then I did some step-up exercises onto a small step. That was a work out. About 10 for each foot. They are counting my calories today, tomorrow, and next day. I seem to eat well at breakfast and then get less and less hungry as the day progresses. For supper tonight I ate rice, a vanilla *boost* drink and had some ginger ale and butter. That was it. My roommate is back from Lahey. She is a bit confused I guess, but it is comical that she can't hear well, and I can't speak well.

Dec. 3, 2002 Tuesday I slept okay. Woke up too early and waited too long to ask for *Tylenol.*

Dec 4, 2002 Wednesday I feel so beat at the end of a day. I want to cry and I also feel like crying this morning. I hope I am not overdoing it. I took *Tylenol* through the night. I feel tired and sore. Writing feels like such effort. I have a neck

tightness and a headache a lot. I dropped my pencil and it's under the bed. I am locked up onto the tray table with the leg rests and I can't reach my backpack to use my knife to try and sharpen my OT pencil so I just used the nail clippers to take off some of the "wood."

Today I feel fragile and overwhelmed. I was tearful at PM. OT and PT. I don't know if it is because of sleep, discomfort, foreign feeling, or fear or maybe it is positive movement in my processing this.

Dec. 5, 2002 Thursday My hands make it so I didn't even want to play the piano. The tingling is intense and they are tight so I can't reach an octave anymore. I felt vulnerable and teary yesterday in my afternoon OT and PT. Wrinkles and lines are a good thing for my face's recovery. When we see a new wrinkle show up it is a sign of progress. My face muscles have been paralyzed and flat. Smooth face at 45 years old and it's not good.

Dec. 6, 2002 Friday I am so weary. I can't see this page except for a blur. I just spoke with the family therapist, Jean, cried and spoke about many feelings. I even ignored a phone call.

Dec. 7, 2002 Saturday My back and belly are very tingly. I did eight crunches and eight knee lifts/tucks. I had drawn a stick figure doing each exercise. Also, six head lifts. That was OT with Matt. Then this morning at PT I walked around the 3rd floor rail two times and did squats and tiptoe stretches.

Dec. 8, 2002 Sunday I got to the morning service with Sharon's help. It seemed that I might not. I wished for more hymns or carols, but the scripture and message rang true, clear, and refreshing as much as I could listen. I heard the time is different for us and God. A day could equal a 1,000 years. We don't get it. I feel weary, weary, but the blurry eyes also give me a feeling of tiredness. I want to close them. I finally got my pencil with the OT pad on it sharpened. Pam did it.

Dec. 9, 2002 Monday 11:30AM, time for ST. I'm weary. Met with Dr. Zabar, the neurologist from *Lahey Clinic*. GBS Miller Fisher is caused, perhaps, by an antibody that my body created to attack bacteria in my gut that was similar to the make-up of myelin, the stuff around my nerves.

Dec. 10, 2002 I saw Dr. Zabar yesterday. He thinks we are on the way to recovery and that the second round of IVIG arrested the process of demyelination. Dr. Sarkarati gave a report that the biopsies were normal—or not showing vasculitis or anything other than the GBS. So, I do see progress. All my visitors and therapists have been pointing toward progress. Mark came to walk and do PT and OT with me. He's getting ready to go walking with me on weekends. They project, at this point, that I'd be able to go home by New Year's Day. When I drop something on the floor it seems hopelessly lost.

I find myself wanting to take care of my roommates, Esther at *MGH* and Ruth at *NERH*.

Dec. 11, 2002 Headache when I move my head and neck certain ways. My limbs and fingers sometimes feel like I have them in positions other than they really are. My pointer finger just felt separated and bent from the other fingers that were straight and together. But pointer was just along side the others. Today it is painful to stretch my fingers out straight. Iron and *Colace* must have a delicate balance. I had diarrhea last week and now I'm bound up.

Dec. 12, 2002 Thursday No Pool today. I feel a bit more energetic but am going to rest a bit. It's 3:30PM. I'm wearing thigh-high compression socks and an abdominal girdle thing, because my blood pressure is low and my heartbeat is fast. Pulse 110-120 and blood pressure 104/66 without compression.

I don't know why. The nurse at surgery (the biopsies) said being inactive makes the heart speed up. I hope it's not adrenalin like my mother had.

I'm more active now so I would think it would slow down some. I am having Deryk spend the day tomorrow if he's feeling okay.

Dec. 13, 2002 Friday Progress not perfection.

Dec. 14, 2002 11AM Saturday No one has called yet. I think Mark is better from his stomach bug. He had to stay home Friday. Deryk didn't come here yesterday, but stayed home and vegged with Dad. I hope he can come Monday. I just had

OT and I cooked oatmeal, on a real stove. My knees were jiggling, but I managed—holding on to the counter and walker. I feel weary and bleary. I should probably write in pen. I could probably read it better. I can hardly see this. The right side of my face is tingling. And, my right eye feels worse, but maybe it's just annoying. A group from *Tremont Temple Baptist Church* just came and sang Christmas carols and gave me some fruit.

Dec. 15, 2002 Sunday I just went to the Sunday service and it was good. I am able to do quite a lot for myself now—get dressed including pulling on my TED elastic stockings. I think I might be going home earlier than December. 31st. I've heard of another place called a sub-acute facility that makes for less intensive therapy but more independence. So that might happen before I go home.

Dec. 17, 2002 Tuesday Deryk spent yesterday with me. I think it went well, but he suddenly felt sick during lunch and then we weren't sure if he would make it through to evening. Then he had to decide what to do for today, go back to Judy's, or stay home. Both options meant he would have to spend time alone.

Dec. 18, 2002 Tuesday If today is Tuesday, yesterday must have been Monday. *"Oh, well,"* as my roommate Ruth would say. I have gotten attached to her some. She has some dementia, but is quick witted and really cute in looks and sayings. I'd like to write about this whole experience. I wonder when I

will be able to type. I think sitting up will be the hardest part. I'll write in pencil for now. I sharpened the pencil today with my knife.

Dec. 18, 2002 If today is the 18th, yesterday must have been the 17th and the day before the 16th. Oh, well. I walked 5-6 laps in the pool—not all at once. I pushed hard in OT. I am not feeling good about how much I feel pushed. I have a hard enough time not pushing myself too hard and when it is someone else pushing it is difficult to resist or deal with. I am thinking I need to deal with it sometime or at least I need to deal with it in myself and respect my limits and needs. I had a nice visit with Donna C. tonight.

Dec. 19, 2002 Thursday I think I have it right this day. My roommate, Ruth, just left. I felt attached to her somehow and I will remember her, "Oh, well." I felt disappointed today that Mark called me as he was getting ready and was already late for work. I felt the same when he didn't call last night before 8PM as I had asked. I called him at 8:05PM and he was deep into writing his Christmas letter for church. I feel guilty that I am being so selfish because I know he is doing soooo much, and doing his best to manage work—both works, and home. He is spread thin, and he is chaotic even normally, so this is a super-chaotic time. I am off the Heparin shots. I guess I am moving around enough. I think Tuesday was my first no-Heparin day. My progress is so good that I wonder if I'll be here much longer. I am steady to stand. I feel afraid of

going home in that I'll have so much to do or I'll have great expectations on myself.

Dec. 20, 2002 This date seems too close to Christmas. I have been a bit down today. I couldn't do pool because my heart rate was 133 beats/min. So, I was down there and was called back. They want to take me off *Nortriptylene* and put me on *Paxil*.

Dec. 21, 2002 Mary and Joseph weren't home for Christmas. Where did that hype come from? Jesus came when the time was right for God. People were still hustling and bustling around but Jesus came.

I slept okay. My new roommate was not having a good night. She watched TV a lot and I didn't hear it. The light from the TV screen seemed bright and annoying while I was trying to fall asleep. My brother, Steve, is going to be foreman as the guys install grab bars in the bathroom and a railing going up the stairs at home. My date to go home is still December 31.

Dec. 22, 2002 Winter. My Mom's birthday. No therapies today. I did crunches and I walked to the dining hall with my brother and sister-in-law, Dick and Pat. (And back.) It is hard to mind my own business. I have told my roommate Carlene to lie down and to not do this or that. She is a Christian—wounded.

Dec. 24, 2002 Christmas eve. I don't know how the last day got by without writing. Actually, I thought it was a couple of

days away. I can see that one day passed when I was busy. I did the usual therapies and family meetings, family therapy. Jeremie and Deryk, my sons, were my companions. So, last night in bed it took a while to relax and unwind. My discharge is set for Dec. 31.

Dec. 25, Christmas 2002 *New England Rehabilitation Hospital.* We ate dinner at the dining room. The tables had red paper table clothes with "reserved #13 Hurd" on ours. Patients were brought down and set at the table—I saw IV poles and wheelchairs and nurses with stethoscopes and 02 meters and other stuff to let you know you were in the hospital. The baby grand piano was open and a stooped, blind, woman played beautifully. She played Christmas music, a medley of Jewish music, and Happy Birthday according to traditions, Bach, Beethoven, Mozart, and Chopin. I couldn't….

Dec. 26, 2002 I don't know what I was thinking to write yesterday. Anyway, here's a step in minding my own business. I'm moving to Room 110B. I want to sleep, and I'm acting crazy trying to accommodate Carlene's coughing, and TV, and what not. I feel very tired and have a fear about the future.

Dec. 27, 2002 Dr. Sarkarati had me walk a bit without a cane or anything. I felt good. I just had PT with Kathy who I haven't worked with before. She worked me hard and I'm sweaty now. I did squats from my knees. I did walking and also hands and knees stuff. So I'm pretty beat.

My eyes are bothering me and I've had *Tylenol* by 2PM because of a headache over my left eye and also general headaches. I took *Ambien* last night to help me sleep. Being in a new room is always an adjustment. I hope tonight will be better.

Dec. 28, 2002 Saturday. I feel a bit blue today because the day is going slowly with little therapy or visits. I think the family is going to Pam's house today for the Christmas celebration. Mark is going with Jeremie and Deryk, but said he feels bad not to have any gifts to share. I've managed my tongue.

I felt pretty blue Christmas Eve night and also Christmas later afternoon. I'm winding down and even feeling a low appetite. I didn't sleep well last night either.

Dec. 31, 2002 Twilight. I am going home today. I felt yesterday like I was now well enough to go home and also still weak enough to see that I am not well. I still have headaches, especially in the evening. The end of 2002 is coming. The end of a long hospital stay. I have taken 10mg of *Paxil*. The psychiatrist here is recommending I take 20mg. I guess transitioning from *Northriptylene* to *Paxil* seems strange.

Home in bed, upstairs. Things looked small—doorways and rooms… but welcoming. I'm happy to be here and can look around with great appreciation. TV seems out of control and music from Eminem and Jam'n stuff seems more present than I remember.

Jan. 1, 2003 9:30PM I'm weary and wound up. It's a challenge to not let my mind get carried away in thinking I can do this and that. My body needs time still. My mind goes full speed. My body is only in first gear with an only partially engaged clutch. Deryk went up to Judy's. We met her half-way.

Deryk wanted to go. I'm so thankful he's enjoying this experience. It was soooo much stimulation. I'm asking the kids to turn down stuff and the ride in the car was nice, but that's how I got so wound up I think. The Christmas lights were nice to see. I am doing the stairs okay I think. I feel my quads.

Jan. 2, 2003 Deryk had a snow day today. Jeremie had school. Today I met with a nurse and a PT visiting here at home. I feel more tingling and even my hearing seems hypersensitive. It's 8:30PM and I'm getting to bed. I'm tired and a bit overwhelmed, not weepy, but a little stuck looking way out. A brief talk with MJ reminded me it's a step-at-a-time—a day at a time.

Jan. 3, 2003 Feeling tired and overwhelmed. I'm going to bed 8PM

Jan. 4, 2003 9PM I'm wanting to stay up a little later so night won't seem so long. It's tough to sleep.

Jan. 5, 2003 Sunday I still feel foreign to me. I feel so far off normal, but I am needing to be in each day and each step of this process. It looks so ominous and hard to carry on, but

one step and one day I can do–with help. I opted to not go to Judy's today and we did the half-way meeting to transfer Deryk.

My eyes are difficult to deal with and my tingly hands are painful and my back is sore from tingly stuff (between my shoulders.) My hair is drabby and I am a little blue and worried that this whole thing is still going on—like am I really getting better?

Jan. 6, 2003 8PM My temp read 100.2, 100.6, 100.0. I took *Tylenol l*ater than usual. I think it is not new really. I felt this way at the hospital and they would take my temperature with two different thermometers and would read a temp and one wouldn't. I would take *Tylenol* anyway. So I am a little discouraged that the temperature is still there, but not terribly surprised. I have felt a pain in my side and know that today I didn't do any specific relaxing work. I think I need to do that. I also need (I think) some things to make it easier—i.e., a pillow for down stairs and I'm not sure what else, maybe slippers or heat. I think I will get a journal down stairs and try to write during the day. At night I can write less.

Jan. 7, 2003 Tuesday. I talked about anxiety/relaxing with the OT, Marilyn, today. I'm going to the doctor tomorrow—*MGH Neurologists*. Lord, please guide us, and them, and help them be wise in treating me, Amen. I do worry still that I might be getting worse or something. I had diarrhea last night and a temp. Today at 6PM my temp was 99.3 so it is still present, I think.

Jan. 8, 2003 We left for *MGH* at 8:15AM and got there at 9:15AM. Then we waited for an hour. Mark asked what was up? The doctor had forgotten he had an appointment with me. So, he arrived 2 hours late. And, the attending physician, Dr. Venna, wasn't there either. So it felt a bit disappointing though he examined me and saw good progress. No major deficits in sight. So, I did leg exercises today and walked a lot at *MGH*. We arrived home at 2-ish after a little blood work and a soda. I am going to give *Paxil* one more try and see if the diarrhea stops. I am wishing I went to *Mt. Auburn Hospital* to see Dr. Wang for the Neurology follow-up. Perhaps I'll ask Dr. Pugh. Guidance from You God, Creator and Light is needed.

Jan. 9, 2003 I wore clothes today I haven't worn since before the hospital. That was deliberate and needed some effort to accomplish. I worked hard in PT but rested with OT. I'm planning to do PT tomorrow, too. Help me God to not overdo. I want to be well. I still worry I'm not—that there's more to the puzzle. Dr. Harris still seems to think vasculitis is possible. I don't get it.

Jan. 9, 2003 Writing in a different journal Red pen is for angry—really angry. I am not feeling angry… I don't have another pen in reach... I have been looking. So, I'm using red… It's an exception to a rule that I made. So. I have lots of exceptions I'm dealing with. I can walk except I'm using a walker. I can see except it's not clear. I can hold a pen but it's not comfortable. I'm recovering from Guillain-Barré

syndrome, the Miller Fisher variant… the prognosis is good and my recovery could be complete, but it takes time.

One neurologist said, *"time,"* with his eyebrows up and his hands extended apart. That seems like pretty clear emphasis that it could be a long time. Day-by-day, the progress feels hardly measurable to me—but as other people see me and comment that I sound better, or look better, I am encouraged. I am dependent on those words of encouragement. Being home after… Oct 26, 27, 28, 29, 30, 31, Nov. 1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 14, 15, 16, 17, 18, 19, 20, 21, 22, 23, 24, 25, 26, 27, 28, 29, 30, Dec. 1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 14, 15, 16, 17, 18, 19, 20, 21, 22, 23, 24, 25, 26, 27, 28, 29, 30, 31. Sixty-seven days is great and a bit overwhelming….

Jan. 10, 2003 I helped take down Christmas ornaments and clean up after the tree. I also set the table for Mark and me. The boys are in New Hampshire with the Boy Scouts. I used the walker basket to carry plates and stuff. I'm tired in my back. Doc Pugh thinks I should try some *Prednisone* to see if it helps with the fever and the possibility of lupus.

Jan. 11, 2003 Sunday 9-ishPM. I took it easy today. Went back to sleep after breakfast. Mark was at church and did the confirmation class until 4PM, so, I fended my own way today. The boys got back from their scout weekend at about PM and then Pam came with Nicole and Daniel at about 2-ish and Judy came at about 3-ish. Then the sister troops left and Deryk, too, about 4-30ish. I forgot, or delayed, the morning

Neurontin. So, tomorrow I'll try to do that. I took *Tylenol* at 6-ish because my back felt so tender.

Jan. 12, 2003 Tuesday I was sore today—back muscles, arms, legs. I rested mostly and did some speech exercises with Alize and grad student. I'm weary and want to be horizontal.

Jan. 21, 2003 Tuesday Morning. This is my first official day at home without Mark, or supervision. I will probably get a visit from the OT, or PT, or nurse, but I haven't heard yet. I feel ready and a little racey—like what can I do? …I am pleased with my progress! I'm writing that thought down because I easily forget.

Here's a picture I drew to remind me of Dr. Sarkarati, and my left leg getting off the bed.

"My whole body was like jelly. I could not hold my head up. I was unable to move."—EC

Marc's Story

I had been feeling run down for a couple of days. For some reason, my right leg just gave out twice walking down the hallway but I didn't fall. I didn't think much of it at the time—wrote it off as being super tired. Then on August 8th, 1999, at around 3 in the morning, I awoke in a huge panic. All I could think of was getting myself to the ER.

I jumped in my car and drove about 5 miles to the hospital. Sitting in the waiting area I could feel my body draining itself of energy. After about 2 hours, I was called in to see a doctor. It took every bit of energy I had to walk down the hall to see him. All I remember was the doctor yelling, *"Get me a spinal tap kit! Stat!"* There must have been more to the exam leading up to that but I just couldn't recall. I passed out.

About 5 days later I was coherent enough to understand what had happened. I was given a normal course of IVIG, with plasmapheresis deemed too dangerous to administer. I had been trached and vented, as well. I became aware that I was paralyzed from the eye lids down. It took 2 weeks before I could close my eyes. I was kept in ICU for 17 days before I was stable enough to be transferred.

I was transferred to a respiratory hospital where I stayed for 4-1/2 months. During that time, my weight was reduced from 175lbs to 128lbs. I had a feeding tube inserted. There were a

few days when my heart went into racing mode to the tune of around 180bpm. The docs were considering a pacemaker but the heart meds put things back on track. My pain level was outrageous. Even a thin sheet on top of me caused me intense pain. The pain lasted around 2 months before it subsided to a tolerable level. Any amount of pressure caused an increase in pain. Foot drop boots were intolerable.

I spent the next 5 months in a respiratory rest home. I still couldn't move my entire body. It took me another 3 months to finally rid myself of the vent. I was soon able to move my head side-to-side and after being pulled up to a sitting position I was able to hold myself up in that position.

Then I was moved to an acute-care hospital where I stayed for the next 28 days—which I call "finishing school."

That was the end of the line as far as hospitals were concerned. I had been fitted with AFO's but my heels were 2 inches off the ground on one side and 1-1/2 inches on the other. This prompted the docs to cancel any attempts to walk because my heels had to be at 90 degrees.

I had an idea that my orthotics person thought was very innovating. I had him build up the inside of the AFO's to cover the gaps on each side, thus giving me a 90 degree walking platform. At first, once pulled up to a standing position, I could take steps like Frankenstein. I could walk if I didn't bend at the knees. Just not very far. But, far enough to let me stand and change positions, like getting on a bed or couch. I had to accomplish all this without the use of my arms. They still didn't work and my hands couldn't form a grip either.

To make a very long story short, I went home in a wheel chair that I could only control with my head. I used a mouth stick to type on my computer.

While my wife was at work, my aunt and uncle would come over to feed me lunch. This lasted about a year until I could lift one arm enough to feed myself. I was in the head array wheel chair for another 2 years before I could use a hand controlled chair with a goal-post handle to push with my arm. I suffered severe axonal damage.

With a lot of determination, I can now walk around the house, feed myself, and type with one finger. The clinical condition

I'm presently in is called "incomplete quadriplegic." I still can't form a grip with my hands, or turn my palms upward. If I fall I can't get up. When I'm sitting in a 90 degree position or lower, I can't lift myself out of a chair.

The real saving grace in all this goes to my wife, Julie, who fought for me, cared for me, and who literally saved my life maneuvering the healthcare system. I can never thank her enough. Between insurance, nursing care, therapists, pneumonia, MRSA and all GBS has to offer, she stood strong. She made things right when wrongs were being done.

Again, this is a very short and condensed version of a very long story, and to all those with GBS out there, stay strong and if one way isn't working, try another.

it's only RARE...until it's YOU.

Maria's Story

It was October, 2013 when I was in the emergency room. No one knew what I was suffering from. At first they thought it was a stroke. A few days later, a hospital neurologist recognized the symptoms. My family said the doctor had just returned from a seminar on Guillain- Barré syndrome.

I was in ICU for 30 days, paralyzed from head-to-toe, and trached. During my stay in ICU, most of the nurses did their job well, however, the support staff—especially the evening and weekend staff—were mistreating me. Not taking care of the vents when they would turn me or other things happening in the room while they thought I was not aware. I was placed in very uncomfortable and downright painful positions. I was told that, when dealing with GBS you can't feel anything… and I guess you can't in the sense of the word, but deep down inside, you feel everything. It felt like every bone was cracking. I had to mentally place myself in my "happy place" if I had any chance of surviving this. Hours felt like days and days felt like a weeks.

After ICU, I stayed in a long-term facility for 4 months. Because of what happened at the first hospital, I was frightened the same thing would happen again. I did not have as many issues, but even at the second facility, I did have some. I was able to recognize who did their job because they loved it and

who did it just for the paycheck. And, even after all this time, I did not have a lot of information about GBS. I kept getting different opinions as to what the syndrome entailed or how long it would last, if it was hereditary, or if it would come back. I began range-of-motion exercises and the process of being weened off a ventilator. It was a very painful and long process.

I was then sent to a rehabilitation center for the next 2 months. The staff there was aggressive in a good way simply helping to get me out of bed. Every day I tried to push forward and every day was difficult. My trache and my Foley were removed and the first day I took a step on my own, it brought me to tears. It's amazing how we take little things for granted, like scratching your nose, using the bathroom on your own, feeding yourself, and so much more.

The reason I developed GBS was never really made clear. Previous to GBS, I underwent surgery and had a pneumonia shot. Two weeks later I was back in the hospital with GBS. During my battle with GBS, my trials included a repaired fistula; having a cyst on an ovary removed; a colostomy bag placed and removed; and an ileostomy bag placed and removed.

I thank God that I am finally back in one piece.

As I continue dealing with GBS, I experience what I believe are residuals, but no one can assure me of such. I just deal with the issues as they come and pray they are just a passing thing. My doctors and I are still learning. I am on social media and read a lot about others experiences with GBS but everyone's experience is so different that I don't want to compare mine to theirs. Some have had relapses or other issues that have presented after the onset of GBS. I'd prefer not to think about the possibility of a relapse rather, choose to live every day thinking of a brighter tomorrow.

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"I've been called a miracle—but in my mind, I am just a survivor of a relentless illness."—GR

Mary's Story

In 1978, my husband, Dave, and I were living in Germany and we had three young children, Paul, 3 years old, and our twins Jeremy and Matthew, who were only 10 months old.

At that time, I was struck with Guillain-Barré syndrome (GBS,) a rare disease that drastically changed our lives. Because GBS was traveling throughout my body, my legs couldn't move, I couldn't run, and I couldn't walk. My arms couldn't move. I couldn't hold my children and I couldn't feed myself. My hands couldn't move. I couldn't hold my husband's hand and I couldn't brush my teeth. My mouth couldn't move. I couldn't chew food. I couldn't laugh. I couldn't smile. I couldn't talk. I couldn't, I couldn't, I couldn't.

This terrible thing had totally paralyzed my body. I could, though, lay in bed, minute-after- minute, hour-after-hour, day-after-day, think and pray. I was being fed every few hours through a feeding tube in my nose. I did enjoy listening to my visitors chatter. I could communicate non-verbally by opening and closing my eyes twice to mean yes, once to mean no.

Because my lungs were not functioning properly, I was placed on a respirator (ventilator). I depended on that machine for every single breath. In some primitive way, that machine and I communicated with one another as it kept me alive every second, every minute, every hour, of every day.

My solo journey led me into a deep, dark cave where I was totally dependent on others for my survival. As I was descending into the deep abyss, this rare disease, Guillain-Barré syndrome totally paralyzed every part of my body.

In the depths of my fear, in the depths of my endless deep black pit, there was always a tiny light. Whether it was the middle of the day, or the middle of the night, that tiny light was always there in my horrible abyss of fear. Unable to speak aloud, my screaming could only be heard from within. *"Why me, Lord? Why did you let me become paralyzed? Why won't you let me be at home with our children?"*

As I inwardly thrashed about with my thoughts and feelings, God held me in His loving arms. As I inwardly cursed and screamed trying to fight the horrific nightmare, God comforted and consoled me. The Light, God's love, was always with me. In my silent world, God heard me. God loved me. God stayed with me. In the darkest hours of my nightmare,

His Light gave me hope.

How did I become healthy again? Like any other virus, GBS finally left my body. I then had the challenge of going through the baby stages of having to learn how to roll over, crawl, stand on my own, and finally, walk again. I actually had a contest with our one-year old twins to see who would learn to walk first. I won the contest!

"…I noticed that… something was 'very wrong.'" —AC

Melanie Taylor's Story

My story begins in January, 1986. My husband and I planned on our new year starting with a party to celebrate our 25th anniversary. 1986 was to be a busy, but wonderful, year with a lot of celebrating.

Our oldest daughter was soon to be married and she was the first of our children to graduate from college… a big deal as I only went through 12th grade and my husband did not graduate high school. He went into the Navy and received his GED while enlisted. Our son, Gordon had finished Vo-TECH and was working and living with us. Our, second son, Jeff was in college and swam the mile in nationals for his team in Washington. Our youngest, Pam, was graduating from high school, with honors and a letter in sports. I was also planning on competing at national *Sweet Adeline's* in Minnesota. Our Governor had invited us to sing at the Governor's Mansion and have brunch.

Then, all the plans stopped. I already had my bags packed to go the competition. It was Monday, March 24th. I woke up at 4AM and my legs were hurting. I couldn't sleep. This was the beginning of *"My Real Life Nightmare."!!!!* By Thursday, I had been to the doctor two times… having a hard time standing up. I went there for blood tests.

On Sunday, my doctor was out of town. The doctor on-call

recognized signs of Guillain-Barré syndrome (GBS,) and sent me to a larger hospital 85 miles away. We called my husband at work and he followed us to the new hospital as I was transferred by ambulance. The drivers told me we could waste no time because there was a possibility I could end up trached on the way. They stayed ahead of my husband, going more than 85 miles per hour. He was wondering what was happening.

By the next day I was on life support. Before they trached me, they said, *"if you have anything you want to say, say it now, you will not be able to later."* My last words to my husband were, *"If I don't make it, don't take too long to follow."*

You know the nightmare where you can't run, or move, and it's hard to breath, and you are being buried alive, and you can't tell anyone? That is how I felt. A real life nightmare. Could it get any worse?

The family was called right away and a priest gave me last sacraments. Not much hope.

Watching me give up hope, my husband promised that if I kept fighting, he'd buy me that apple-red car I'd always wanted, and he'd take me dancing every week. We had not danced much after we married… and he actually met me on the dance floor.

The doctors said they had an experimental treatment that had a 50% success rate. In 1986, not much was known about GBS. I was now completely paralyzed, unable to breath on

my own, and getting sicker with a bladder infection and pneumonia, so my family agreed to the treatment.

Seven plasmapheresis treatments and then I had a reaction. Hives. And, I can't scratch! Treatments are halted, but later that day, results. I could cough!

Finally, after a month of life support, I was able to breath on my own and was able to be moved to rehab, yeah!

Several months in rehab, and the world moves on. I missed a lot, but I was able to attend my daughter's wedding and the youngest's graduation. They were planned for the same weekend and it was the first I was allowed to leave the hospital for a few days.

Three months later, I was released and sent home. We have great friends and so many people came to my families aide while I was in the hospital. Yes, I was now home, but still unable to walk more than a few steps without a walker. I began walking each day, adding a few more steps each day. After a full year, I was doing pretty good, however, fatigue was a constant battle.

Almost a year to the day, my husband and I went to our first dance, and almost every weekend after that. We soon joined the *Minnesota Polka Club of America* and traveled all over, attending dance festivals and meeting people from all over the country. We wore a GBS pin on our costumes and shared all we knew about GBS with as many people as possible.

Now, I am a GBS liaison and have met Estelle Benson in person. What a wonderful woman and friend!

In 1986, we were voted king and queen of the polka club which has chapters all over the United States. The very next year, Estelle invited us to dance at the *GBS|CIDP Foundation International* Symposium in Dallas, Texas. What an honor it was to be with hundreds of people who have experienced GBS in one way or another. After our dance, we were treated to a standing ovation.

Our "real life nightmare" had turned into a wonderful dream for us. That was 30 years ago. I still get tired and my feet feel different, but I don't care. And, oh yes, I did get my apple-red car. Another blessing since I won it in a drawing!

it's only RARE...until it's YOU.

Patricia Blomkwist-Markens Story

Who could have imagined that I would meet the most amazing people because of Guillain-Barré (GBS?) That I would actually acquire a whole new family because of it? That I would be looking back to twenty-five years (and counting) of helping others, with such fulfillment and satisfaction? At least not me, when in September of 1990, on a Monday morning, I woke up with severe back pain.

Like anyone who experiences the first symptoms of GBS, I thought up an excuse for it: "been standing too long at the party yesterday." But the pain persisted and caused one sleepless night after another. Then, that strange feeling in my mouth joined in, as if I had had a *Novocain* shot at the dentist, I wasn't able to feel my teeth and struggled to bite into an apple. My legs became weaker, although at the time I wasn't really conscious of that. Looking back, I realized that the muscle weakness in my legs was the reason that my horse hardly responded to me giving leg pressure while riding her.

On Friday of that week - a day that is etched in my memory– my general practitioner arranged for me to be admitted to the hospital through the emergency room. The same evening a lumbar puncture was done but the results did not come in until a few days later. And with the results came the diagnosis: Guillain-Barré syndrome. My first question to the neurologist was*: "Will I die from this?"* He quickly reassured me, but that

reassurance was short-lived*: "In this day and age - no, but fifty years ago you would, because back then there were no decent ventilation devices available!"* So much for his bedside manner.

Despite treatment with IVIG I still continued to deteriorate, so I was moved to the ICU. In the bed opposite mine was a woman on a ventilator and all I did was stare at her, fearing that this was in my future too. A few days later, mechanical ventilation became inevitable. A tracheostomy was placed after about two weeks. Eventually, I remained on the vent for thirty-five days. In the meantime I went through the usual complications: pneumonia, inflammation of a venal access point, thrombosis. One of the scariest things was the frightening hallucinations, in which I witnessed and was part of all sorts of terrible things. In contrast to dreams, all events in hallucinations seem completely real, even after waking up. I remember all those 'adventures' vividly to this day.

Meanwhile, my parents had contacted *GBS|CIDP Foundation International* and spoke on the phone with Estelle Benson frequently. She managed to take away their fears and worries somewhat by assuring them that *"your daughter will get better!"*

While I was still in the ICU, a recovered GBS patient (whom my parents had managed to find) came to visit me: a young woman who had had GBS five years earlier. I had a million questions but asked only one, the question that every GBS patient asks, *"How long did it take you to recover?"* The image of this young woman, who WALKED into the ICU, stayed in my

mind and from that moment on, I drew all my hope from that picture. If she could do it, then so could I! Moreover, I was wondering if there was a patient organization for GBS in the Netherlands and I vowed to try and find out, and if there was none, to initiate a support group.

And, as they say, the rest is history. Soon after my recovery, I started the Dutch GBS|CIDP group. In the fall of 1991, I attended the 2nd International Symposium of *GBS|CIDP Foundation International*. I felt like Alice In Wonderland! Three days with several hundreds of people and it was all about GBS! There, Estelle Benson asked if I wanted to become a liaison for the *Foundation* in The Netherlands. In the subsequent years, I became regional director, member of the board of directors and vice president for international affairs.

Thanks to GBS, I have met the most amazing people, many of whom I now count among my best friends, and I became part of this huge, warm and loving "family." Supporting patients and their loved ones over the past twenty-five years has been hugely rewarding. Thanks to GBS my life has been enriched. I am extremely proud, honored, and thankful that I can give something back through the Dutch support group and *GBS|CIDP Foundation International* and I feel privileged to work with this wonderful group of dedicated and talented people who share the same goals and dreams.

it's only RARE...until it's YOU.

"Every scar has a story. Don't be afraid to tell it."

Peggy's Story

From early adolescence, I knew that my destiny in life was to be an independent woman. As a child of the Fifties, that meant, for me, not being dependent on a man for my livelihood or my definition of self.

My first summer job was at 14 years old, and I left home for college at age 17. After graduation, at 22, I travelled to Europe on my own. At age 25, I left my family home for my first apartment and began a career in social services that spanned nearly 40 years. At age 39, I purchased a condo that became my permanent home.

On July 1, 2008, at age 64, I retired from my job to enjoy the fruits of my labors and indeed I did. I read, took long walks, visited with friends, traveled and seriously pursued my interest in photography. I did what I wanted, when I wanted and how I wanted. I was in charge of my life. I answered to no one. I had earned it and I was enjoying every moment. I had decided that when I "grew up" I wanted to be a life-long learner and a life-long explorer. I had become just that.

Along with independence, I also enjoyed good health. Throughout my adult life, I had never been in the hospital, never been in an ambulance, never been to the ER, never broken a bone, never had more than routine medical tests, rarely took more than an aspirin and almost never had so

much as a cold. I ate well, exercised, did not smoke or drink alcohol, got enough sleep and kept stress to a minimum. I did all the "right" things and prided myself on having the protection of a competent and efficient immune system.

All that changed in the summer of 2010. On July 2, 2010, I had dinner with some very dear childhood friends. It was a wonderful evening although I was experiencing some back pain, different from any back pain I had ever felt before. The following night, my heart was beating faster than usual and my stomach wasn't feeling quite right. I didn't feel like staying home on July 4th, so I accepted an invitation to a barbeque. I found a comfortable chair and I ate carefully. When I returned home, I was tired and took a nap. When I awoke, I did not feel rested and my heart continued to beat too fast. So, I drove myself to the Emergency Room where they tested my heart, kept me overnight for observation and sent me home with a

healthy heart and a clean bill of health. That was my first trip to the ER and the beginning of a life-changing adventure into the world of healthcare—and an eventual diagnosis of CIDP. Suddenly and without warning, my competent and efficient immune system went into overdrive and I was very sick. My body had betrayed me.

During the next eight months, I had many medical tests. I also had surgery to repair a broken leg (the result of a fall from increasing muscle weakness), surgical removal of an abscess due to medication, and I cycled between hospitals and rehabilitation centers, both acute and sub-acute. Transportation was always by ambulance because by this time I could not walk. I worked hard in therapy but progress was slow or not at all. And there were setbacks as medications were adjusted. There was little I could do for myself. Basically, I required total care. The loss of modesty and dignity were bad enough, but the loss of control was the worst. Practically overnight, I had gone from total independence to nearly total dependence. It was humiliating. It was awful.

My family had wanted me to go home with home care, but I didn't feel ready. It frightened me not to have doctors, nurses and aides awake and available at night. I needed to be rolled in the bed at night, required diaper changes for bowel accidents and sometimes had problems with the catheter. Two people had to move me in and out of bed using a Hoyer lift. I could not imagine how this could be accomplished at

home, and I did not want my beautiful and newly decorated condo to look like a hospital filled with medical equipment. Going to therapy was the best part of the day. The therapists were upbeat and I enjoyed the energy and camaraderie of the other patients. As luck would have it, I began to feel healthier at around the time that Medicare was running out. Although I had long-term care insurance, I still had to pay privately for a while which was very costly. I also noticed that as a private pay, I received less attentive care and less therapy. It was time to go home.

Coordinating such a move was way too confusing for me so I hired a private care manager. This turned out to be a very smart move as there were many behind the scenes tasks to accomplish as well as working with the in-house social service staff. After extensive planning, I came home in an ambulance seated in a motorized wheelchair. The apartment was filled with people and equipment, and furniture had either been moved or placed in storage to accommodate wheelchair accessibility and to make room for a live-in home health aide. My care manager, Doreen, accompanied me home from the care center and we were met by her boss, Stacey. Annette, the home care nurse manager, was also there. They were all tall women and filled the living space with their physical presence. Their voices seemed loud to me and it sounded like they were all talking at once. As I looked past them and through them, I saw in the corner of the dining room a small Indian woman from Guyana named Eunice, who was to become my

aide and companion. Our eyes met and we began to size each other up. I saw my reflection in her eyes–nervous, unsure, apprehensive, confused and overwhelmed. I saw a stranger from another culture and so did she.

After Doreen and Stacey left, Annette and Eunice brought me into my bedroom to help me get settled. Gone was my queen sized bed with its bronze metal headboard, the cream-colored matelassé coverlet and custom-made decorative pillows to match the cream, green and lavender striped bed skirt. All that remained were the custom shades and lavender valences. How out of place they seemed. I had loved decorating that room and was so pleased that I had created such an attractive and peaceful space. Now it was jammed with equipment. In place of my beautiful bed was a twin-sized hospital bed with an overhead bar and a Hoyer lift. I did not want the overhead bar or the Hoyer lift and subsequently had them removed. Fortunately, I had gained enough strength before leaving the care center to transfer from the bed to the chair using a slide board so I never used the lift. But I still needed to be pulled to a sitting position. Later, a commode was added to the mix. My TV and recliner had been moved to the bedroom from the den/office in order to make room for Eunice's bed. I looked around the room and burst into tears, crying, *"This is not my room, this is not my house."* Annette tried to comfort me by reassuring me in a gentle voice that, *"Everything will be all right."* I was inconsolable. It hurt too much.

The only rooms that remained the same were the living room and the kitchen. I was unable to sit on the living room furniture as it was too soft for me to get up and down; I could not access my enclosed terrace as it had a step to climb over which I could not do and the galley kitchen was too small for the wheelchair. I was confined to the bedroom and the dining room that now served as an office with my laptop and papers taking up most of the table. The table had been repositioned to accommodate the wheelchair and four of the six chairs were now in storage along with a hand painted chest of drawers. This was not the home I had left. It was the home I returned to and it would take some time to feel like it was my home again.

After Annette left, Eunice set about cleaning the bathroom until it sparkled. I had never seen my bathroom so clean. Then we sat at the table to talk. The first order of business was what to have for dinner. In her soft voice, Eunice quietly and worriedly confessed to me that, "I don't know how to cook American food." I thought that was very sweet and I reassured her that, "We'll do it together." This was Eunice's first live-in job and it was her first thought and greatest fear when she first saw me. It was also the first time that I had lived with anyone in forty years. It would be a big adjustment for both of us.

Eunice and I quickly developed a routine and a very special relationship. I got depressed every Friday evening when I

knew she was going home, and I got happy again when I heard the door open on Monday mornings and was lifted by her beautiful voice singing religious hymns or funny Caribbean folk songs. She made me laugh, and she very gently pushed me to get better. She exercised with me every day and paid close attention to what the therapists taught me so that she could know what I was trying to accomplish. And she photographed me doing the exercises so that we could remember what I was supposed to be doing. At night we watched TV together in my bedroom, and I came to enjoy watching her enjoy my recliner. I also came to like sharing my bedroom and my life with her. My room was my room again, only different. It was made up of new memories. I often wondered what I had done wrong to be given such a dreadful disease. Eunice helped me understand that I must have done something right to be given the best aide anyone could ever ask for.

Sharing my kitchen took longer. Eunice and I both like to cook and we are both very organized. But we organize differently and use the space differently. My way makes sense to me and her way makes sense to her. We also call things by different names. At first, it became the cause of a lot of frustration and then it became the source of some funny jokes and a private language. Cooking American food also became a challenge for Eunice. We started with the basics – soft cooked eggs and "light and fluffy" scrambled eggs. Eunice was used to hard-cooked eggs and hard-scrambled eggs. She worked at it until she got it just right. We then moved on to canned tomato

rice soup. The first effort was a very thick soup as she didn't know that she was supposed to add water. Eunice is a "little of this, a little of that" kind of cook. It took a while for her to become a "follow the recipe" and "read the instructions" kind of cook. And then there was her dash of pepper vs. my dash of pepper. I screamed, "No" and startled her the first time she showed me a handful of black pepper and called it a dash! Now we work together like a well-oiled machine and have developed a repertoire of many tasty delights, some American and some Caribbean. Our recipes are highly regarded and shared with many friends, hers and mine.

Weekends did not go so well. I was assigned a different aide almost every weekend. Between the hospital, the care centers and home care, I have been attended by so many strangers that I have no accurate count. I do recall one incident at home in which I had developed what was essentially a diaper rash. The home care agency got so nervous that the coordinator assigned 'round-the-clock shifts. For one week, I had nine strangers pass through my home who were essentially paid to babysit me. From that experience, I learned the ways of home care and I never let that happen again. I also learned to fire those aides who were inattentive, had bad attitudes, were lazy and who stole from me or tried to scam the agency.

Most of the aides were from Africa or the Caribbean. This meant starting over every weekend not only with new and different personalities, but with cultural and language

differences as well. And since I no longer put things away, I could not describe to the aide where a particular item was located. I tried to impress upon the different aides the importance of returning items to the location where they found them, but that didn't really work. And I had to describe what an ice cream scoop looked like or the difference between a teaspoon and a tablespoon. And then there was the time I asked for cinnamon and got cream of tartar or I asked for cheerios and got bran flakes. This was frustrating to me and to the aides and required more patience on my part than I really wanted to exercise. Eventually, I adjusted. I had no choice.

It took some time, but after a while I developed a team of regulars. In addition to Eunice and Doreen, I added physicians, including one who makes house calls. Dwayne is a nurse who comes to the house to administer IVIG infusions every three weeks and Allan is a physical therapist who comes to the house once a week and meets me at the YMCA pool once a week for aquatic therapy. I almost added a weekend aide to the mix but after eight months I let her go and decided to try weekends alone. I had already tried evenings alone and it was working well.

It is now four years since I became ill with CIDP and just over three years that I have been living with it at home. It is a brutal disease and it is a brutal recovery. Physical therapy has played a major role in my progress. From having no

feeling in my legs and feet, from being unable to move my legs or roll over on my own, I am now able feel the floor under my feet so that I can walk with a walker and/or arm crutches. I am able to roll myself over in bed, I am able to get up and down off the floor using the bed rails. I am able to go up and down a few steps. I have gone from diapers to *Pull-Ups* to incontinence panties to regular panties with a thin panty liner. I have accomplished all this with PT—including specialized physical therapy for bladder retraining. The slide board is in the closet and the commode is in the basement storage unit as I am able to use the walker to walk to the bathroom. Now that I am stronger and more independent in the bathroom and kitchen, I am able to stay alone at night and on weekends. Eunice sets things up for me so that I can heat dinners in the microwave using a paper plate and I can stand long enough to rinse out a cereal bowl and some silverware. I still have to rearrange some things in the kitchen every Saturday morning as Eunice puts them away differently than I do. Now it makes me chuckle. A small price to pay for my new found independence!

Through all of this, I have continued on with my life. I no longer drive or travel and pain is an on-going issue, but I still do enjoy many of the activities that were always important and pleasurable to me. Most relationships with family and friends survived; some did not. And then there are new ones, like Suzette, a nurse who came into my life in the very early stages of my illness and who became my guardian angel

and friend. Fortunately, I live near the center of a town that has much to offer and I can get around on my own with a motorized wheelchair. I can meet friends for lunch or dinner, go shopping, go to the movies or just hang out taking pictures. I make to-do lists, work on projects, set goals and feel good when I accomplish them. I also manage my home and pay bills using on-line resources. And *Facebook* and e-mail make keeping in touch easier.

Never did I ask, *"Why me?"* because the answer is simple, *"Why not me?"* I've accepted my condition, but sometimes I still feel like this is an out of body experience, that I am watching this happen to someone else, especially since I don't look like me from the side effects of medication. So I created a new persona. I always liked jewelry, but I was no longer able to wear my good rings and necklaces due to the swelling in my fingers and neck. In my travels around town, I found two stores that sell inexpensive, attractive stretch rings and bracelets as well as adjustable necklaces. I also found colorful fascinators and sparkly headbands. Now I wear a lot of big fake bling and tops filled with sequins. Eunice has become my fashion coordinator. Every morning, she helps me select my outfit and coordinate my jewelry. I also paint my nails bright colors and Eunice paints designs on top of the color. I have become known for this look and people stop me to inquire where I got my jewelry and hats and who does my nails. It's a totally different look for me. It's fun!

I still have a long way to go and where it will end up I don't know. I worry about what I will do when long-term care insurance runs out, when Eunice is not able to be with me anymore or if and when I will no longer be able to remain in my home. I am already 70 years old and have many limitations. I try not to dwell on such thoughts as I have learned that life has a way of working out, that people and things come to you when you need them and that somehow I will find a way to make the right things happen for me. I always have and I am not going to let a disability change that.

Penny Shaw's Story

In 2001, when I was 58, I developed odd symptoms in my legs. Pain and weakness, falling on the sidewalk, and unable to get up without assistance.

I first went to my physician who had no idea what the problem might be. Nervous and living alone in an apartment, I carried my portable phone with me. Another evening, I fell and couldn't get up. I called 911 and the EMTs from my neighborhood fire station came and transported me to the ER at *Harvard-teaching Community Hospital* in Massachusetts.

The physician asked me to get up from the examine table and walk. I told him the problem was not walking, but falling. He found nothing wrong with me and sent me home.

A few days later, at home, I fell again. I called 911, got the same EMTs, went to the same ER, was told nothing was wrong and was sent home again. The third time I fell at home, and having the same EMTs for all three calls, they assured me they would insist I be admitted. I was admitted but to the Geri-psych unit , as they believed I was making my symptoms up for attention! This scenario is well known in the disability community. If a physician cannot determine a medical cause for reported symptoms, the default position is too often psychiatric.

I was given a bed and later asked to get up, as the psychiatrist wanted to interview me. When I told him I couldn't get up, he told me I was lying. After the interview, I asked to see a "regular" doctor. She came, had blood work done and later told me the results indicated kidney failure. She transferred me to ICU, all the while I kept saying to everyone *"It's my legs,"* but, to no avail. Retrospectively, I know my creatinine level was wrong. Not indicating, in my case, kidney failure, but a false-positive for a rare muscle disorder. After three days in ICU with no kidney failure, the team decided to listen to me. They did a muscle biopsy and told me I had Polymyositis. I was in a med-surg unit for a few days, commenting each evening to my attending, *"This is odd. My feet are paralyzed."* Next evening, *"My ankles are paralyzed."* Next day, *"My lower legs are paralyzed."* Then I had complete respiratory failure and was in the ICU on mechanical ventilation for four months, not expected to live.

A friend told me the medical team was frantic, not knowing what was wrong with me. After the ICU, I was discharged to a respiratory rehab hospital as I was medically unstable, where I stayed for a year. I was then discharged to a nursing home, on a trach and feeding tube, where I had been living for 13 years. In 2006, I was de-cannulated after 5 years intubated—to the surprise of many.

In 2010, I had a consultation with the Rheumatology Department at a Boston teaching hospital where I was made a research patient. After 9 years, I had my correct diagnosis, Guillain-Barré syndrome (GBS.) The team concluded I had GBS based on three factors: "Upward progression of paralysis"; the fact that Polymyositis is not a paralyzing disorder; and finally by looking at the original muscle biopsy slides, where the inflammation of the muscle tissue was insufficient for a diagnosis of Polymyositis.

Never being properly diagnosed, I never had the opportunity for GBS to be treated in its acute phase.

Today, I am in my 14th year as a nursing home resident due to quadriparesis, and my inability to not only walk, wash, dress myself, but cook and clean. I can use my hands in spite of the contractions of my fingers which overlap, and I can brush my teeth, feed myself, turn a page in a book, read, write and use a computer. My mind is intact.

In 2011, I purchased a power chair which permits me to go

outside when I want, after 9-1/2 years remaining inside. I'm an accidental nursing home, and disability, advocate.

Also in 2011, I read an article in the *Boston Globe* about the possibility that a nursing home bed-hold program might be eliminated. This would have put me at risk, after a hospitalization, of losing my "home" and having to live in another facility, if my current bed were filled while I was away. I wrote a letter in support of retaining the program to our House Ways and Means committee. The letter was circulated and I was asked to become a state and national nursing home advocate.

I am now an active nursing home, disability, and elder, advocate, a nationally published writer, speaker and consultant. You can find some of my work by *Googling* "Penelope Ann Shaw, PhD." I am leading an interesting, useful, and fun life as a survivor of acute GBS and recovery. I enjoy my personal life immensely, mostly my lifelong friends who have supported me in every way during my medical journey.

it's only RARE...until it's YOU.

Peter Oostra's Story: How GBS found me - TWICE!

June 12, 1997, down with a severe case of the flu for four days and not getting better. My wife took me to the doctor. He examined me and confirmed: *"Yes, you have the flu. Here's a prescription."*

I took the medication. However, during the night I began to feel very strange. To my alarm, by morning I was unable to move my legs.

My wife thought it could be from the medication. We waited several hours then contacted the doctor again. He listened to my symptoms and assured us it was not the medicine. However, since by this time I was also unable to move my arms, he advised me to go to the Emergency Room right away. Instead of calling an ambulance, we called our sons. They had to carry me from my bed to their truck to get me to the hospital.

The doctors there were not sure what was happening and called a neurologist. By now, it was late in the evening and the paralysis was still progressing. It had now reached my mouth and eyes. I was terrified!

After a series of tests, the neurologist declared, *"You have Guillain-Barré syndrome (GBS,) and Miller Fisher." "I have what?",* I said. *"It may get worse,"* he warned. *"If your breathing is affected, you may have to be placed on a ventilator."*

Peter and Johanna Oostra on their 60th wedding anniversary

Admitted to the hospital, hooked up to a plasmapheresis machine that "washed" my blood it and returned it back to my body. The procedure took five hours and was repeated for five days.

My breathing was checked frequently by blowing into a little machine. In order to avoid the ventilator, I did my very best to produce as much air as I could.

It was an overwhelming and scary feeling to be paralyzed that quickly. I felt I was being attacked by an invisible monster called GBS! My wife did some research and learned it would take quite a while for my condition to improve.

After plasmapharesis, the paralysis had slowed down and, thankfully, I never had to go on the ventilator! But I still could not move. A physical therapist patiently helped me learn to use my muscles again. It was slow going, and very painful.

First, we worked on my feet, then I had to learn to sit up again.

On the seventh day, I was tied to a 'standing-up bed' with a belt and actually was upright for 20 minutes. A very strange sensation, but I managed! I was determined to walk again.

I also had a lot of time to think. Here I was, 67 years old, retired for 6 years. My wife and I had been involved with volunteer work. We travelled all over the country to colleges or churches, wherever there was carpentry and other work to be done. We thoroughly enjoyed this ministry and were having the time of your lives. But now … this! However, there was no time to feel sorry for ourselves and we determined that, with the Lord's help, we *must* go on.

On the eighth day, after practicing in the "standing-up bed" and receiving plenty of physical therapy, I was moved to a rehab. More intense therapy followed. I still had trouble holding a spoon, or brushing my teeth. I could not shave myself. It took two long weeks, before I was able to stand and take some steps.

In the meantime, the muscles in my chest, between my shoulder blades, had become very painful. The neurologist considered additional treatments, but after a conference, it was decided not to proceed. Perhaps that was a mistake, because that pain has never left me. Over the years, we tried all kinds of pain medications and other approaches, but

nothing worked. Today, I try hard to keep moving, but the pain is always present.

The day arrived when I was discharged. It had been almost four weeks. There was still more therapy ahead. First at home, later at a treatment center where I continued to improve.

Finally, I was able to do many things again, for which I am most grateful.

Then… January, 2013. Another intense bout with the flu, including severe night sweats—and then, yes, another GBS attack! Same story as 16 years before, except this time I went to the hospital by ambulance. I was there for ten days, and this time, treatments were done with IVIG.

Two weeks of rehabilitation followed. At 82 and yet, again, with lots of prayer by family and friends, I pulled through a second time! Today, I am able to work around the house again, do some yard work and even play tennis. I still drive and enjoy my kids, grandkids and great grandkids. It's been an amazing journey. In October, 2015, I turned 85. I am very grateful I've been able to come this far after GBS visited me twice.

Ray Lopez's Story:

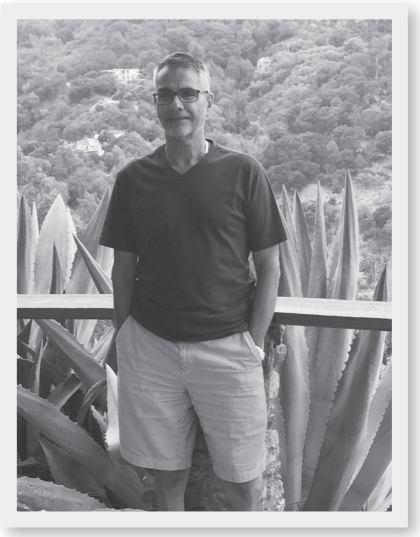
My journey with Guillain-Barré syndrome (GBS,) began on June 15, 1988, following a holiday vacation in Venezuela.

At age 35, I had recently purchased my first home on Staten Island, NY, was in great health and enjoying my job as Assistant Director of Food Service at a New York health care facility.

The day following my return from vacation, I felt extremely fatigued, weak, and began experiencing severe intestinal problems which I initially attributed to my vacation. The intestinal problems persisted for several days, to the point when I drove myself to the emergency room. Following an evaluation and testing, I was released, advised to drink plenty of fluids and get bed rest.

As the days passed, my intestinal problems persisted, and my overall health continue to deteriorate to the point I could not walk, stand, grip anything, or balance myself to move. At my parents urging, I was transported to *Lutheran Medical Center* in Brooklyn. Following further evaluation, including a spinal tap, tests revealed a high protein level and confirmed Guillain-Barré syndrome (GBS.)

By that time, total paralysis from the neck down began to attack my respiratory system which heightened the severity of my deteriorating condition. To prevent respiratory failure,



I was trached prior to transport. The procedure itself, under the intense ER lighting and only under local anesthetic, fully awake, was a nightmare that remains with me to this day.

In 1988, plasmapheresis therapy was not readily available. That reality required me to be transported from *Lutheran Medical Center* to *Columbia Presbyterian Medical Center* in New York City.

When I reflect back on my 10 months of total paralysis, my recovery, and where I am in my life today, I remember back when I initially began to regain my motor skills in my lower extremities—the importance of a positive attitude, my drive, and my ambition. Each of these represented the strength that helped me regain control of my life.

Today, as I continue to live with GBS and its challenges, I am

thankful for my family and friends, my 23-year career as Food Service Manager for the *New York City Board of Education,* and my 20-year relationship with my partner, Ken.

My positions as liaison for *GBS|CIDP Foundation International*, and as a volunteer for the Neurology Department at *Staten Island University Hospital*, represent my opportunity to share my journey, my experiences and outcomes to, hopefully, represent a positive, motivating message, to everyone I come in contact with.

it's only RARE...until it's YOU.

"I couldn't communicate. My husband bought me a board with magnetic letters on it and I was able to point to letters… but it took ages to do it. Doctors, nurses, and relatives are not very good guessers."—YK

Robert Prestwich's Story:

It was Sunday evening of Memorial Day weekend 1974. On the way home with my wife and two small sons in the car, my signature didn't look right when we stopped at the gas station. My first sign.

I was a 28-year old sophomore in veterinary school at *UC Davis* two weeks before finals. One of which, coincidentally, was for a neurology class. By Tuesday morning, I had tentatively diagnosed myself with Guillain-Barré syndrome (GBS.) A trip to the family doctor, along with my suspicions, lead to a neurologist and the local hospital. At that point, no longer able to stand by myself, I braced myself on a pillar outside the hospital while my wife parked the car. Next step… a wheelchair. Testing was done and GBS was confirmed.

In 1974, before the swine flu epidemic, little was known about GBS and it was not yet established as an autoimmune disease. There was no known treatment and no *GBS|CIDP Foundation International*. The literature stated steroids were not effective. I was placed on *Valium* as a muscle relaxant. A respirator was placed next to my bed and I was given a buzzer to press if I quit breathing, although at that point pressing a button was impossible. A panic attack occurred when, in the middle of the night, I realized I was alone and helpless. Concentrating on my breathing subsequently made it impossible to breathe normally… it was terrifying.

After one month in acute care without a need for the respirator, I was transferred to *Sacramento Medical Center* for rehab. Physical therapy was the order of the day, 7 days a week, up to 8 hours a day. By the end of three months, disease progression had bottomed out leaving me totally paralyzed from the neck down. I could speak and move my head. Signs of muscle return had not yet begun. I was discharged from the hospital to home care with physical therapy three days a week. By Christmas Day, I was able to get myself from the bedroom, a short 25-steps to the living room, after 40 minutes of effort with a walker. For the next year I progressed from wheelchair to walker to crutches and eventually to a cane. I was then able to re-start my veterinary studies. After two more physically and intellectually demanding years, I finally graduated from veterinary school.

Here I am 42 years later. I necessarily had to learn many compensatory ways of dealing with my disabilities post-GBS. I have major muscle weakness in my hips and legs and many permanently atrophied muscles throughout my body. In spite of this, I have had a very successful and satisfying career, having owned two veterinary hospitals, and, been a partner in another hospital and an emergency clinic. Motivation helped drive a need to meet the physical demands of my profession.

Outside of veterinary medicine, I was capable of 25-years of racing competitive motocross. Working out at the gym, and doing home improvement projects, has continued to keep me moving. Since motocross, I began extended backpacking

trips on the Pacific Crest and Tahoe Rim trails. I am a slow, but dedicated, hiker.

Today, my problems consist mostly of muscle fatigue and balance issues. The use of a cane is an increasing necessity, especially when forced to stand in one place for any length of time. GBS, for me, has been a long-term struggle of endurance and motivation, I expect for the rest of my life.

Life, as I know it, has been rewarding.

Dr. Robert Prestwich

"Another night with nightmares, night-terrors. I was bound. I couldn't move a finger. I was trapped in an enormous spider web. I screamed out. I woke up. Was it true?" —SK

Russ Walter's Story:

Guillain-Barré syndrome (GBS,) hit us like a bolt out of the blue!

In March 2005, Paul, my future husband and I, had just returned from a hiking and rappelling vacation in Australia where I had been experiencing heart fibrillations. My cardiologist at the *University of California San Francisco* decided to implant a defibrillator. Complications ensued and two more surgeries later, I was finally home and in recovery.

A couple of days after Paul went back to New York, my hands and feet started to feel numb and tingly. I thought I was tired and went to bed. The following morning, I could barely crawl across the room and was brought into Emergency. Fortunately, they were experienced with GBS at *UC* and knew what tests to perform—they diagnosed GBS in short order. I rapidly went into complete paralysis and respiratory shutdown. I spent six weeks in Neurological Intensive Care in a methadone-induced coma receiving plasmapheresis and IVIG. The methadone, which alleviated the severe pain, swept me into a vortex of nightmares and hallucinations, many of which I remember as if they happened yesterday. (In one of them I'm a German-speaking American soldier in WWII with an artillery squad stationed behind German lines shooting down enemy aircraft. In another, I imagine the Intensive Care Unit

must be some kind of expensive hotel and I wonder how much it's costing Paul for us to stay there!)

Paul was traversing the continent every weekend, yet I barely knew he was there! My blood pressure, heart rate and blood sugar were fluctuating wildly. My eyes were filled with moisturizing gel because I was unable to blink. I was fully intubated and on a respirator, thinking I was talking to others when I was completely paralyzed and unable to speak at all. I remember thinking I must have gone mad, and wishing it would all end mercifully.

After GBS had run its course, the paralysis in my upper body began to abate. I was transferred to Acute Rehab at *St. Mary's Hospital,* still paralyzed from the waist down and weighing in at 112 lbs.—40 lbs. gone in a flash! Still in withdrawal from the methadone, a challenge in its own right, I could barely distinguish dreams from reality, and told the nurses I thought I was already walking. They put the bed guards up in a snap! The physical therapists began to work with me, and sometimes had to dole out some tough love to make me do what I had to do. I won't pretend that I was the easiest patient in the ward! By the time I went home, I could shuffle around with a walker.

Paul resigned from his job at *Sony* and moved here to take care of me. Thanks to his great Italian cooking, I regained my weight and packed on a little extra! Through outpatient physical therapy, I learned to get around on my own with

a walker and then a cane. A full eight-months from onset, I returned to my job at *Banc of America Securities*. The management there was incredibly caring and supportive.

One day, the physical therapist took my cane, stepped about ten feet away, and told me to walk to him. I told him that without the cane I was too scared and couldn't. He said, *"Yes, you can. Do it!"* And I did it—finally back on my own two feet!

I consider myself so lucky. I had Paul's support, care and love, to make the fight worth fighting. I had great medical care and the best physical therapy possible. Ten years on, I have residual foot pain, can't ride a bike, and have to navigate the world very carefully—small prices to lead a full life again.

"These moments served as signs of hope, emblems of progress, and above all, reminders the positive is oftentimes there, waiting to be found."—KD

Ruthie Mae Wehmeier's Story: Doctors Need to Listen to Patients

I am a 73-year-old working widow.

In February, 2015, I contracted a urinary infection for which I took antibiotics for 7 days. A week later, it was back. I went on another regime of antibiotic for 7 days. Then, constipation set in.

The month of March began with another UT infection. Then my back started hurting nothing, seem to ease the pain unable to sleep set or walk without pain in back. I took over-the-counter pain meds. My son tried rubbing my back but he said my muscles would move from one spot to another. Add to a backache, my hands and feet had the feeling that they were asleep.

March 28th, I called the doctor for pain meds. *Tramadol* was prescribed for pain. I took one pill and napped. I had to use the bathroom. When I arose to go, a pain hit me in the stomach landing me on floor. Not sure what was happening, I crawled to my bed, dialed 911 and said I was in severe pain. The operator asked if I could get to the door and open it. I did that by holding onto walls. I called my neighbors to tell them what was happening.

Another case of doctors not listening to patient. At the ER,

I told them about the stomach pain, back pain, and the feelings in my hands and feet. The doctor said that I was there for "stomach pain," not back pain. ER took x-rays of my stomach and said they were admitting me, but not sure why. The doctor came to me and said I had a bleeding ulcer. The next day, I was told I had a hematoma. I still had the backache and tingling feeling in hands and feet no one wanted to hear about. The doctors said my back hurt from lying in bed. I was weak, unable to walk on my own. I continued to hear it was because *"you are weak from lying in bed."* On April 4th, I had surgery. A main aneurism in my stomach. April 5th, I had a second artery burst, and surgery again. I was still unable to walk on my own. The hospital did an x-ray of my stomach, and an EKG, before discharging me.

I went to a rehab the evening of April 14. The hospital sent

me there with a diagnosis that read, *"unable to walk due to being in bed so long, and weakness."* I could walk—about 12 steps—with help, and my back still hurt. My hands and feet were still feeling asleep. I told the rehab nurse that my back hurt and that I wanted to have a nerve doctor examine me. Again, I was told, "*you are just weak from being in bed."*

This was the beginning of my reverting into an infant. I asked doctors and nurses to get me a neurologist, or a brain doctor, because I knew something is wrong. All of them gave me same answer, *"you are weak from being in bed."* No one would listen to me. The rehab began, scheduled twice a day. Therapists were walking with me, holding me up. I could walk about 20 steps with help. Unable to get from my bed to my wheelchair, I could not get to the toilet without falling, so diapers were started. In would sometime choke when I swallowed my own saliva… choke to the point it would scare the nurse, and me.

Again, I ask to see a neurologist. I felt as if something was wrong with my brain or with my nerves. Again, as they said, "*you are weak, you need to get up and move."* They would put me in a wheelchair and leave me to wheel myself. I could not sit up well, and therefore, I would slip.

Therapists tried to help me sit up on a mat, and then lay down. I was unable to lift my legs to lie on the mat. I could not feel my feet, so I was unable to lift my legs. A therapist would pick up my legs and put an arm around my neck to lay me on the mat. He would want me to roll over to my stomach.

My reply was HOW? I had no idea how to get my body to roll over. I would rock back and forth like a baby. With help, they would get me over than it was "raise" your head. Like a baby, I would bounce my head around. The therapist said to use my arms to push myself up, but I had no strength. They strapped me in a device to keep me locked, standing up in order to strengthen my legs. Instead, I just got weaker.

Then I began choking on water and could not swallow pills. I choked very easily on food. Sometimes, a speech therapist sat with me while I ate. Or, one or two of my very good friends would sit with me to help me eat. It was hard to hold a spoon. I had no grip to hold onto anything. I was unable to lift my legs into bed, unable to roll over in bed, unable to sit up alone. I could not write, or sign my name. Another friend, would bring my bills and write the checks. I tried to sign my name and could not read my signature.

I am still telling everyone that my back hurts and to please get me help. I told nurses, nurse's aides, and the house doctor. I guess they all thought I was just weak. Nevertheless, I was getting weaker and getting more like that of an infant child.

My children could tell I was getting worse each day when they talked with me by phone. They began calling the house doctor to tell him to get me to a specialist for fear of something being wrong. They received same message, *"She is weak. She needs to get out of bed more and work on getting stronger."* Both of my children called my primary physician and told him they

thought I was dying. My son took me to see him on April 14, and he ordered a lab workup that day.

The doctor said there was more than just weakness wrong with me. My son told him that I was getting worse and I need a specialist. The doctor gives my son the names of two physicians to contact for appointments. One, a neurologist, the other a urologist.

I was now back in rehab, and on a urinary catheter. Both of my kids then contacted my primary stating they felt the hospital was allowing them to stand there and watch me die right in front of them. I was then transferred to another rehab, where I spent the night. The next day, I saw a special neurologist who had me admitted to the hospital from his office. I had an MRI that night, and on April 24th, a spinal tap. I was started me on a drip of IVIG for 5 days, to reduce the symptoms of Guillain-Barré syndrome (GBS.) I still had back pain, tingling in my feet and hands, and the feeling that I had a belt around my chest that was too tight.

After 5 days, I was sent to the third floor rehab. I had pillows to help hold me in a sitting position and to lie on my side. I could not sit on the side of bed without someone being in the room. I was bathed in bed. When food came, the nurses would look in on me and I was asked if I minded leaving the door open so they could hear and see me.

Nurses gave me meds by putting the pill on my tongue. I

could not feel if a pill was in my mouth. Water, I sipped by straw. Food, cut in small pieces. Hands were so cold I had to wear socks on them. I could not stand alone.

In May, I was walking about 60 steps at a time, until May 28th, when pain put me back in a wheelchair. I had another spinal tap showing Guillian-Barré was active again, and I was put back on IVIG for another 5 days. Again, I was walking and standing.

I left the hospital on June 16th, assigned to rehab. I still needed help taking pills, bathing, getting in and out of bed, dressing myself, getting in and out of a wheelchair, and still wearing diapers because I could not tell if I had gas or a coming bowel movement. I was unable to roll over on my side and stay there.

I wrote this because, if the doctors had listened to me, specifically about the pain in my back and the feeling in my hands and feet, and if they had done their research, Guillian-Barré syndrome would have surfaced sooner. If this had happened, I feel that I would not have turned into an infant.

I came home on August 15th, and with help from friends I am walking with braces and a walker. I can cook, bath and take care of myself.

When I look at an infant, I now appreciate how hard it is for that tiny person to hold his or her head up, roll over, or crawl. This ordeal I has taught me patience, and that the

small things in life really do matter. Things like sitting in the sun, walking through the neighborhood, volunteering to help people, having my freedom to come and go on my own, getting down on the floor and bouncing back up, working in my yard. Just a few of life's simple pleasures that mean a lot to me.

it's only RARE...until it's YOU.

"Therapy, therapy, therapy…
and you will be fine."—GK

Sandra Restino's Story

It was August, 1969, at the age of 21, when I first came down with bronchial pneumonia. Although I was on medication, I noticed strange symptoms as the days went on. I couldn't raise my arms to comb my hair, my legs became weak, and my fingers started to curl. I never felt numbness, but I couldn't understand why I wasn't able to stand up without assistance.

By the following week my mother took me back to the doctor and he could see immediately how weak my limbs were. After a thorough examination he said I had Guillian-Barré syndrome (GBS.) My mother began crying upon hearing the news, but the doctor reassured us I would recover but that it could take up to 6 months. He also said, if it affected my diaphragm, I would have to be in an iron lung to help me breath. There were no respirators in 1969.

Several days later I was admitted to the hospital for tests, which included a spinal tap. At that time, I was hospitalized for 3 weeks. The spinal tap results came back negative, which was a relief. I began making progress with physical therapy and B12 injections. No other medication was given. Once I was discharged, I had physical therapy 5 days a week plus at-home therapy, too, along with vitamin B12 injections.

I almost lost my job for being out of work for 4 months. When I did return, I had to be driven because I did not have the

strength in my fingers to do a simple task like turn the key in the ignition. The muscle between my thumb and index finger remain week till this day, but it's better than it was then. That's the only weakness I have, which allows me to say, I made a full recovery.

After being aware of GBS, I remember reading about it in a medical dictionary a year later and not much information was available. All it stated was that there was no medication for it.

Now when I hear someone coming down with any type of paralysis like my two uncles who passed away with ALS, for example, I appreciate more, now than ever, that I can function and lead a normal life.

My heart goes out to anyone struggling with this disease. Thank you for allowing me to share my story with you.

it's only RARE...until it's YOU.

Sharon Dodd's Story

I have been lucky enough to have survived two different types of cancer–so far. When I was younger, I thought I was invincible. I would work long hours, and in general, I did not take care of myself.

Lesson 1: You can't take care of others, if you don't take care of yourself. While doing a self-breast exam, I discovered a lump in my right breast.

Lesson 2: *Women:* Do self-breast exams once a month. Pick a day that is easy to remember, like your birthday date. If you feel something unusual, have it checked. Don't assume it is a cyst. *Men:* Strongly encourage the women in your life to do self-breast exams.

My biopsy showed that it was breast cancer. I choose to have a single mastectomy. I had what is known as, *"triple negative breast cancer."* I had dose-dense chemotherapy with *Adriamycin* and *Cytoxan*, intravenously, every 2 weeks for six cycles, followed by 12 weeks of IV *Taxol*.

Lesson 3: Do what is right for you. Many women would have chosen a lumpectomy and radiation. I chose a mastectomy. Chemotherapy took a toll on me. I had to quit work. It took about a year after treatment to resume my energy.

Then, along came Chronic Lymphocytic Leukemia (CLL.)

Lesson 4: If your doctor won't talk to you, or explain things to your satisfaction, find another doctor. My oncologist did not seem to want to discuss my CLL options in a way that met my expectations. So, I went to *MD Anderson* for a consultation.

I had two gene deletions, –p17 and loss of the –TP53 tumor suppressor gene. It is known that patients with –p17 gene deletion or –p53 gene mutation have poor outcomes with conventional chemotherapy and immunotherapy. Recommended treatment was chemotherapy and immunotherapy, followed by an allogenic bone marrow (stem cell) transplant.

Or, be dead in 2 years!

The bone marrow transplant was the most difficult I've ever done in my life. There were so many nights I was unsure I'd be awake in the morning. Fortunately, they woke me up numerous times every night to draw blood, and to give me transfusions and antibiotics.

Three weeks after my transplant, I was about to go home, when acute graft vs. host disease raised its ugly head. I was swollen like a toad and had a rash all over, nausea and severe diarrhea. Routine treatments, such as steroids, did not work. I was then treated with rabbit ATG—given intravenously for three days. Fortunately, that worked.

Three or so months later, I began falling down. I couldn't lift my arms to put the recycle bag in the recycle container. I seemed to have no control over my muscles. My balance was definitely off. Sometimes, with no warning, I would just fall down. It was very frustrating. Then, I developed significant pain in the palms of my hands and the soles of my feet. My feet would be so cold; it didn't matter how many pairs of socks I put on, my feet felt like ice. It took several months, but I finally was able to see a neurologist, Dr. Eduardo De Sousa at *the University of Oklahoma Medical Center*. He diagnosed Chronic Inflammatory Demyelinating Polyneuropathy (CIDP.)

The theory is that my body created antibodies to the rabbit ATG that I was given for only 3 days. My body continues to make those antibodies, which attack the myelin. The CIDP may also be due to the graft vs. host disease itself. Dr. De Sousa also feels that the *Taxol* that I was given for breast cancer may have been a contributing factor.

We tried IVIG treatments, but they did not work very well. We then tried plasmapheresis and it worked. I continue to have plasmapheresis, which takes two to three hours, on Monday, Wednesday, Friday, and again on Monday, every three weeks.

Chronic graft vs. host disease returns at times, with elevated liver enzymes, fatigue, nausea, diarrhea, and sometimes a rash.

I have regained strength in my upper arms and thighs, and my balance is much better. However, I do have difficulties focusing and with my memory. Dr. De Sousa surmised that it might be due to the dose of *Gabapentin* that I take, so we have been gradually decreasing my dosage. Unfortunately, that has led to odd sensations, such as feelings like ice water running on my big toe and the next toe of my right foot, to the point that I have to stop and look at my foot to be certain that I have shoes on and there is no water. Very strange. I have also noticed some weakness in my thighs and upper arms. I guess everything is a bit off.

Lesson 5: If you think you are not strong enough to go through a trial, you CAN do it.

Lesson 6: Be nice to your friends. You will find that some "friends" are uncomfortable with the idea of cancer, but your true friends will stand by you.

Lesson 7: You are not your body. You may have had a mastectomy, an amputation, gained or lost a lot of weight due to medications, but you are more than your body.

Sharon Mather's Story

In 2005, It started with back pain so severe, I took medical leave from my job as a microbiologist for three weeks. My doctor put me on *Vicodin,* which did not help. My pulse and blood pressure were elevated. Blood tests showed my sodium level as below normal. One side of my face became paralyzed, they sent me to the Emergency Room because they thought I'd had a stroke. I was diagnosed with Bells Palsy, after being admitted to the hospital. The neurologist put me on *Prednisone* and *Acyclovir.* My back pain lessened. I had to wear a patch on one eye to counteract double-vision.

I decided I was well enough to go on a previously planned two-week vacation to Hawaii with my family. My back pain began to worsen. I ran out of *Vicodin* and had to see a physician while in Hawaii. My pain was so severe a bed sheet was painful. I slept all day, instead of going out sightseeing. I suffered alone. My family did not understand the pain I was in. They thought I had become addicted to *Vicodin.* All I could think about was the pain, and when it would be time for my next dose of *Vicodin.* There was never any relief from the pain.

I remember the first time my legs gave out and I almost fell down a flight of steps. Also when I could not lift my legs to get into the car. By the time we returned home from the worst vacation of my life, I needed a wheelchair to get around in

the airport. My body temperature fluctuated from very hot icy to cold. I felt like I could not catch my breath.

Once at home, I went to see a spine specialist who immediately sent me to see a neurologist. I was put on IVIG and told I could not return to work until further notice. The diagnosis varied from Guillain-Barré syndrome (GBS,) CIDP and/or Miller Fisher syndrome, assumed so because of my facial paralysis.

After six months, I was able to return to work. I recovered except for residual numbness in my feet and toes.

Two years later, in 2007, I relapsed. This time they put me in a hospital rehab unit for ten days. I was treated with IVIG, developed facial paralysis, double-vision, severe back and leg pain, as well as weakness in my arms and legs. My blood sodium level was low, and I also had an elevated blood pressure and pulse. I used a walker and elevated toilet seats, but feel very fortunate not to have been placed on a ventilator, with either episode. This time I was able to return to work after three

months and a full recovery, except for the residual numbness in my feet and toes.

In 2009, I suffered another auto-immune disease called Idiopathic Thrombocytopenia Purpura (ITP.) My platelets were at a critically low level, which remains a chronic condition today. Auto-immune diseases run in my family. My youngest daughter has rheumatoid arthritis, which also occurred in previous generations.

I read an excellent article in the *GBS|CIDP Foundation International* ***Communicator***, about the severe nerve pain associated with GBS|CIDP, and how it is often not treated appropriately. I have to agree. I will remember the pain for a long time, and hope to never suffer like that again.

it's only RARE...until it's YOU.

"Life is precious and our time on this earth should be valued."—SD

Sibylle's Story

My story began while I was vacationing in Thailand. I arrived in Bangkok in June, 1984. I had just finished a large part of my graduate work and had even passed part of my exam to become a high school teacher in Germany, my country of origin. I was 26 years old and on my first trip all alone to see the world and prove my independence. Peter, an old college friend of mine, lived there, so I was going to visit him.

I had a few months left before I had to dive, anew, into serious study, so I decided to take advantage of a great opportunity to fly to Thailand for little money. Off I went on the biggest adventure of my life, not knowing that I would never return the same.

The sounds, sights, and smells of Bangkok were amazing. Everywhere you looked you saw street vendors and little pickup trucks called "tucktucks," with passengers hanging out on all sides. Merchants sold food and other items like jewelry, artisan baskets, and clothing. There was even a market floating on the river. Each vendor had his own boat set up with items to sell. The only way to actually buy them was with your own boat. It was nearly impossible to see the murky water of the river through all the colors. It was hard to be alone in a city so far away from home, but I felt exhilarated. I remember thinking that nothing could happen to me, because I was going to take good care of myself. What ever happened, I was

in control of my life.

To visit Peter, I had to travel south from Bangkok, to a little town close to the border with Malaysia. Southern Thailand was beautiful: purely tropical, lush and green. Tropical rains made the forest glitter like silver and the ocean was a blue mirror hemmed by wonderful white beaches.

I spent some time with my friend, eating exotic foods, sleeping under a mosquito net, and spending a lot time at the beach.

But my sense of adventure made me anxious to depart to see more of the country on my own. I flew to the island of Phuket. I checked into a beach hotel so cheap that it was nearly free. It was paradise. I sat on the beach, admiring the ocean, feeling free as a bird.

I met David, who became my future husband, at a beach bar where he was sitting, having a drink. We began talking and took a liking to one another. We got to know each other more and more, had dinner together in simple but delicious Thai restaurants, and ended up spending all of our days together, until he had to leave.

That's when I decided to visit another Thai island, Ko Samui. It was on the other side of the peninsula. It turned out to be a much quieter place, less tourists and less urban. You had to take a long boat ride to get there, which suited me very well. My goal was to get away from crowds.

I had two choices to find the tropical beauty which was Ko

Samui. One was a six-hour, overnight boat ride—the cheaper, and much less convenient, way. Or, you could go on a fast boat that took less than half the time. I managed to take that vessel.

I was in awe when I saw this unbelievable beautiful place. It was not built up at all. The hotels were even less expensive than Phuket. All bungalows were made of straw. It was a vacation location for the young and free. Since I was both of those things, it was perfect. I fit right in. It did not take me long to make friends having met a young couple from Canada.

It was soon then that the trouble started. I suddenly developed a bad cold. My throat started throbbing, I began to sneeze and cough. I was annoyed at that. How silly to have a cold in the tropics, on my wonderful vacation. I decided to ignore it. I just wanted it to quickly go away. But it didn't. It got worse instead. One night, I felt so lousy, and I had the weirdest nightmares. I was lost somewhere, being attacked by spiders. I could not move, I was trapped. Is this a dream or is it reality? I would soon find out.

The dream scared me. When I woke up the next morning I was drenched in a feverish sweat. I felt absolutely horrible.

Self-preservation went into action. I just had to fight off this terrible flu. My thought was to just go to the straw bungalow of my new Canadian friends. Together we could find a solution to this problem. I was desperate for them to tell me that I was

really fine. Yes, a good night's sleep and a visit to the island doctor for some cold remedies was all I needed. The doctor didn't have anything for me. He told me that it would pass in a few days. Good. That was the news I wanted to hear. I spent the remainder of the day resting.

Another night with nightmares and night-terrors. I was bound. I couldn't move a finger. I was trapped in an enormous spider web. I screamed out. I woke up. Was it true? Why did my feet feel so strange? They were numb with pins and needles. I shook them, I wiggled them. The sensation did not cease. I tried to get up. But I felt weak, I had trouble standing. With enormous effort I managed to go outside of my hut. The sand under my feet felt funny. The sensation was not right. It felt fuzzy and odd.

I dragged myself over to the Canadians. They were a bit shocked when I told them about these strange sensations. Was this really the flu? They suggested we go for a nice walk on the beach. Yes, I was certain that was going to make me feel better. Fresh air has always been a good remedy. So off we went. But my feet didn't improve. If anything, the sensation got worse. My feet did not feel the sand clearly any more. It was more of a fuzzy sensation. I did not make it to a very long stroll. I had to be half-carried back to the hut. This is when I lost it. What on earth was happening to me? I started to panic. What was I to do all alone on this remote island? I knew instinctively that I had to somehow get myself back onto

the mainland. How could I do that all alone, feeling as weak as I did? The Canadians were leaving that night, and even though I had basically just arrived I had to depart with them. I needed their support, physically and emotionally.

We set out that evening taking a 6-hour trip on the slow night boat. I have trouble believing that this voyage was real. We were cramped like sardines in the belly of the ship. Nearly all the passengers were Thai. They traveled with huge families with bags and bags of food, clothing and who knows what else. If I were not ailing, I would have loved this exotic adventure. But under present circumstance it was hard to bear. I had fever chills and my weakness was increasing by the minute. I was lying there in a daze. All the noise and commotion around me was muffled, removed by miles. I did not pay attention to anything. I was not sleeping. I was not awake. My fear was replaced by utter lethargy. After hours and hours of this we finally arrived on the mainland. What to do and where to go now? My Canadians boarded with me on a train going south. Their destination was Malaysia. The train had a stop in Songklah, the town where my British friend Peter lived. I had to get back there. I had to find help. So I said goodbye to the Canadians and they continued on as I dragged myself out of the train. I had hardly any strength left.

My condition was getting worse very fast. I cannot remember how I got myself into the cab to Peter's place of work. The only thing that is still in my mind is telling the cab driver that

I was not well. Then I recall not being able to make it up the flight of stairs that led to Peter's office. I remember being at the bottom of it, not knowing what to do. Then I vaguely remember somehow being dragged up. I remember Peter's horrified look when he saw the state I was in. I must have looked pretty bad.

Well then, my memory fails me again until I find myself lying on the couch of a Thai family that I had never seen before. Later I learned that Peter had brought me to these nice people, because his apartment was empty from morning to night while he worked. Victor, the husband of the family with whom I found myself, was British. He was Peter's friend. Victor was a lovely guy and his Thai wife was as sweet as could be to me—the stranger from the west.

It was weird being with total strangers, lying on a couch in the living room in faraway Thailand, getting weaker every day. In fact, my weakness slowly turned into paralysis. It crept up my feet to my legs, to my torso and chest, and ultimately through my shoulders down my arms into my hands. Within a short time—hours—to be exact, I could no longer get off that couch.

Peter, who checked in on me every day, Victor, and his wife, decided that my situation had become dire. They checked me into the small hospital of the little town of Songklah. It was a simple but clean place run by European missionaries. The paralysis had attacked my entire body. My eye muscles

failed, which led to double vision. I really could not make out anything anymore. I was disoriented, terrified as can be, lonely, and absolutely miserable. My thoughts were that I was going to just die there in Thailand. How could this have happened to me? This was not something other people acquired on a trip like diarrhea and stomach problems. This was very different, much more serious. I don't think that Peter, or my Thai hosts, had ever seen anything like this before. Neither had I.

Songklah Hospital was a funny little refuge. Everything was simple and bare. First I was examined and observed. A spinal tap was done, taking some fluid from my spine to examine it. Then I was brought to my room. The spinal tap revealed that I had an autoimmune disease that attacked my nervous system. At first it was thought to be MS, but then it was diagnosed as Guillain-Barré syndrome.

Days went by. My symptoms were getting worse daily. My eye muscles were now completely paralyzed. I saw everything double. I couldn't move my lids. My whole body started breaking down. The entire staff of this tiny hospital became seriously worried about me. One evening, when my condition was particularly awful, the doctors and nurses all stood around my bed, praying for me to be healed. It was an eerie feeling. I thought that I wasn't far away from being given the last rights.

When I began to develop breathing problems the decision was made to get me to Bangkok, to a big, modern and advanced

hospital, the *Samitiveh*. I was transported on a commercial flight, being motionless on a stretcher. I don't remember much of this, just my ride in an ambulance from the airport to the hospital. It was madness. I had to undergo test after test after test. The GBS diagnosis of was confirmed.

In both MS and GBS, the body's immune system goes haywire and attacks the nervous system. In both cases, this causes a dissolving of the myelin sheath, which with GBS, can cause total paralysis. Every single muscle in the body is affected. For that reason, it can lead to death by asphyxiation.

So that's what I had. Better than MS—I guess. It suddenly occurred to me that I might not make it back to Germany to finish my exam in time. I was still hoping for it though. I really did not want to throw away all my hard work and not earn my master's degree. I told the doctors that they had to get me well by the fall, but they gently tried to tell me that it wouldn't happen. I chose not to believe it, unaware of the enormous setback that would make any thought of returning to Germany any time soon impossible.

A few weeks into my illness—which had reached its plateau—a major event robbed me all consciousness: I suffered a stroke.

From that point on things became blurry and unclear. I had been paralyzed all over. Now a second paralysis had hit me: my left side was affected. Flaccidity became spasticity. Cramps as intense and painful as I had ever known existed hit me.

I heard my own voice, screaming. I was only half conscious for about 10 days, which was like a bad dream for me. I was trapped in a dream which did not allow me to wake up. I heard voices, I noticed people around me, they talked to me, they fussed over me, but I could not respond.

When I woke up from my nightmare, I was utterly disoriented. I could not see (not with my brain at least.) I uttered nonsense, I had totally lost control of my bodily functions. The list of what I couldn't do went on and on.

Besides the physical breakdown, one of the worst effects was that I could no longer write. I had to start forming my letters from scratch, like a first-grader. My brain had lost the connection. Here I was, a graduate student of literature and language, unable to write my name. I spent months relearning.

Weeks went by. I was given *Valium* to lessen the cramps and to help make me sleep. Nights were the worst part. There were no distractions. Pain and helplessness was overpowering. During those terrible nights, the reality of my situation slowly dawned on me. I was in a foreign country, far away from home, from family and friends. My life was hanging in midair. I had no idea what would ever become of me. The idea of having become a cripple was totally ominous. I was healthy and young. My adulthood had just started. What woman in her twenties would ever think of lying in a hospital with a stroke, of all things?

Physical therapy had begun at the hospital in Thailand. I had to relearn so many things! The damages from Guillain-Barré syndrome, and from the stroke, were unclear at that time. But, I do remember that motion slowly started returning on the right, whereas the left was a bag of useless limbs. My arm was stiff as a board, twisted in some weird knot, and my leg was not responding to any of my commands. I spent hours in PT. It was exhausting. No other physical workout had ever been that hard.

I was terrified the day I had to return home to Germany after spending four months in Thailand. I had no idea how I would ever go back to my former life. The person I was no longer existed. I was frightened that my friends would not understand. I was scared of allowing them to see me like that. In Thailand, nobody knew me before my GBS and a stroke, hence there was no danger of being compared to my former self.

I was coming home to emptiness, unable to complete my degree, or continue living in the apartment I had shared with a friend. Where should I go?

I ended up spending four months in a rehab center in Germany. I had to undergo physical, cognitive, and emotional rehab all day long. I remember the first time they took me out of the building to teach me how to walk outside on uneven ground. It was unreal.

So, I picked myself up out of the dark hole in which I had fallen. I met with my friend, David, again. We even went back to Thailand, the "scene of the crime." An inner cleansing, coming to terms.

This all was 28 years ago. I still have physical limitations as a result, but I have decided to not let those limitations stop me from living. David and I married in 1986. I finished my masters at *UCLA* in 1989, became a mother in 1991 and again in 1994.

My life now is divided between "before," and "after." Even though I am left with many physical problems, I am happy.

My health issues, today, all stem from orthopedic issues, which were caused by the neurological situation. I needed foot surgery, shoulder surgery, and a total knee replacement. I often have joint pain and nerve pain, but I have a great family, two wonderful daughters and a great husband who went through thick and thin with me. I live in a beautiful house in Connecticut. I left my former life behind, but I will never forget it.

My battle with this illness taught me some very useful things: I've learned a lot about my body. I exercise daily at the gym. I swim. I do yoga. I try to eat healthy.

Last, but not least, I realize life is precious, and our time on this earth should be valued.

Find the good that's in your world.

"Find the good that's in your world."—SD

Stephen Carroll's Story, GBS Letter for the *Foundation*

Hi Willlard,

Sorry to hear about your affliction. I know what a shock this must be to you. You, unfortunately, seem to have had an especially serious case.

When I contracted axonal Guillain-Barré syndrome (GBS,) in 2001, as you have, I was really depressed. I could not understand what was happening to me or why it was occurring. While in Intensive Care, the neurologist that my family physician contacted, came in the room to visit me. He concluded that I had GBS and said to me, *"congratulations, you have the best of the bad illnesses."* He was referring to MS, ALS, and other autoimmune diseases which are usually much worse. Actually, that made me feel better. I could be worse off. I was optimistic about my eventual recovery but wondered about it since I was then 71 years old. I did not know I had the axonal version of GBS until I was tested at *Johns Hopkins Hospital* several months after being afflicted. It's quite rare in this country. I was told then that I would recover, but the date was uncertain as there is wide variation of recovery times. In my case, I took about four and a half months.

I began physical therapy a month later, three times a week on an out-patient basis. About ten months later I was able to brush my teeth and comb my hair. However, I experience a lot

of residual damage. Fortunately, I finally found a wonderfully competent physical therapist having had several prior who were not so good in my opinion. I took a water aerobics class three times a week for six months and that really helped a lot. Since that time, I have lived a fairly normal life.

As a *GBS|CIDP Foundation International* Liasion for Maryland, I have met and talked to a lot of patients with GBS and CIDP in many variations of severity. I have concluded that all the successful recoveries were due in large part to willpower and by doing the necessary physical therapy. I found that being optimistic that things are likely to get better, is in fact, much better for your ultimate recovery. However, one recovered patient said to me in my first few weeks of GBS, *"don't expect a steady recovery—it's usually slow, with two steps forward and one step back."* Knowing that, I was not discouraged when a setback occurred. I did have minor relapses like everyone, and of course, every case is different.

The GBS community is wonderful and I have attended several international GBS|CIDP conferences. I have met many marvelous people, recovered patients, and caretakers—as well as medical professionals who are supportive and hopeful and have interesting stories to tell. Some say the illness changed their whole life even for the better.

Best wishes and my deepest sympathy. Keep fighting.

Stephen Carroll

Stuart Butler's Story

When I picked Stuart up from school on Wednesday, he had just fallen on the playground and had a large bruise on his leg. He limped a lot. By soccer practice on Thursday night, he was running in slow-motion and shuffling his feet. On Saturday, he was still limping and had actually collapsed on the ground a few times.

We took Stuart to see a physician-friend of ours. He looked at Stuart's leg and doubted there was a fracture but said, *"to keep an eye on it… and that children can't 'fake' a limp."*

When Stuart collapsed walking down the stairs at church on Sunday, exclaiming, *"Woah,"* it was time for an x-ray, but it showed nothing. Despite the results of the x-ray, Stuart collapsed repeatedly that day. We were becoming more than just a little concerned. Was something wrong, or was Stuart just being a goofy 5-1/2 year-old boy?

Monday came and we kept Stuart home from school because he had an intestinal virus. His stomach was calm by mid-day, but his gait was now more like an awkward stagger. Our concern changed to worry, because we knew something was not right!

On Monday, January 28th, I took Stuart to see our pediatrician, the last appointment of the day. Our doctor examined him and concluded by asking him to walk down a hallway, a

distance of about 40 feet. Stuart could not walk down the hallway without using the walls as support. Whatever is happening, it was progressing rapidly! Stuart had an ataxic gait. The doctor felt he should be hospitalized for a series of tests to confirm a specific diagnosis.

Stuart saw a neurologist on Tuesday afternoon. The doctor performed a brief examination and a strength test. We were amazed to observe, that along with the obvious problems with his legs, Stuart could not raise his arms above his head. We were equally shocked that Stuart had no responsive reflexes in his upper or lower body.

Stuart was immediately diagnosed with Guillain-Barré syndrome (GBS.) Unfortunately, we were well aware of GBS as Stuart's paternal grandfather suffered with GBS a short time after undergoing chemotherapy for Non-Hodgkins Lymphoma. We were assured that there are no genetic connections, and that this was a rare coincidence.

Within minutes, we were on our way to ICU for a spinal tap. The tap confirmed elevated protein levels in Stuart's spinal fluid. We then learned about the risks of respiratory failure and that GBS was now accelerating throughout Stuart's body.

A series of four immunoglobulin treatments (IVIG,) were to begin at 24-hour intervals. Grandparents flew in immediately as we began building a support team. Our friends began cooking meals. We accessed the Internet and discovered

the tremendous resources available to us through *GBS|CIDP Foundation International*. Our education was beginning. We prayed and prayed.

Stuart's GBS moved quickly. By Wednesday, not only could he not walk, but he could not use his arms to feed himself. By Thursday, however, the IVIG began to do its job. As quickly as the GBS moved up his body, it began to dissipate. While we watched this phenomenon, every breath was monitored.

When Stuart began vomiting, his ability to breath was in question. Although GBS never did affect his lungs, at that point we had another scare. A lab report revealed Stuart had typhoid fever. Although this diagnosis was later refuted... what next?

Eight days after entering the hospital, Stuart was released to return home to his family. His brothers Peter, 3, and Walker, 6-months, eagerly awaited his return! We had quite a load to bring home. Stuart's friends on our street created a poster-sized photo collage. His classmates each made him a book of pictures based on *"When you return we will…"* Stuart had pictures from his cousins, books, videos, and finally, his own *Game Boy!* He came home to room-size, hand-painted banners, balloons, baskets, and many, many prayers.

Stuart left the hospital in his shiny, new, wheelchair carrying his shiny, new, walker. Although seeing our little boy wheel himself around the halls seemed so wrong, we were hopefully

that, with these devices and intensive therapy, Stuart would be just fine.

For the first week, Stuart did improve each day. We saw some limited progress. We knew we had to be patient. This would be a long process that involved physical and occupational therapy five days a week. But, within ten days of returning home, we were scared again. Signs of progress seemed to be diminishing and Stuart seemed worse. What did this mean now?

We contacted the Child Support Group at *GBS|CIDP Foundation International*. We spoke with previous GBS patients and were then convinced Stuart needed help. We rushed back to our pediatrician who agreed, indeed, Stuart had grown weaker since his hospital discharge. Our neurologist was contacted immediately. EMG and nerve conduction tests were scheduled to follow. These tests were extremely painful for Stuart. Due to lack of nerve or muscular response, the tests lasted close to three hours. The immediate results indicated Stuart's GBS may be the axonal form of GBS, often associated with poor results.

Stuart's class play was scheduled for two days later. He had not attended school for one month, but was invited to visit for rehearsals and the performance. It was Grandparent's Day. As I carried Stuart on stage and sat him in his wheelchair, his smile was constant. He was so happy to be reunited with his friends! Yet, his smile would soon be replaced with tears.

Following the play, we drove to the neurologist's office to discuss the results of the EMG and nerve conduction tests.

On February 28th, the tests confirmed that Stuart's rare condition, Guillain-Barré syndrome, was now even more rare. Instead of damaging the myelin sheath that coats and protects the nerves, Stuart's actual nerve axons, or cores, showed damage. Immediate hospitalization was ordered.

GBS as a chronic condition was discussed, as well as the possibility of more damage or even permanent deficits.

We again contacted the *Foundation* to speak with a pediatric GBS specialist. We, and the doctor, collaborated on Stuart's status and treatment. Grandparents returned and prayers intensified. Stuart returned to the hospital for five more IVIG treatments. The morning after the first treatment, all of the doctors attended to assess Stuart's prognosis. Stuart was able to lift his leg from a prone position. We were thrilled. Stuart continued to improve and, once again, left the hospital in a wheelchair, carrying his walker.

A vigorous routine of physical and occupational therapy followed. Stuart's attitude was tremendous. He never asked us why this happened, but only asked about the timeframe for his very confident, and assumed, recovery. He wanted to be able to walk by Easter—when his grandmother and cousins would arrive. At that time, his goal looked highly doubtful, but we were all motivated by his enthusiasm. His condition

improved as he kneeled, sat supported and crawled. His preferred method of in-house transportation was pushing with his hands and feet on a "skooter-board," ordered from a physical therapy catalog. Stuart, and his three-year old brother, played catch around the house with our six-month baby in his walker!

The evening of his grandmother's and cousin's arrival, my husband, Tom, left for the airport to pick them up. I stood, standing in the kitchen doing dishes when I looked over to see Stuart stand up and begin to walk. My first thought was that I was experiencing a divine miracle! Stuart continued to walk around and around the room with pure glee.

When his dad returned from the airport, all three boys were at the front door waiting to greet him and our guests. He had actually reached his own goal! Our tears of joy, relief, thanks and love continued into the night as neighbors appeared in pajamas to watch Stuart walk.

Stuart still had a long way to go in therapy. We even had to add aqua-therapy. Although he missed almost six-months of school, the support was unending. When Stuart turned six, we exchanged the wheelchair for a shiny new bike. Stuart went on to swim on the swim team and attended day camp. He played fall soccer. Stuart was rarely frustrated. He worked hard, maintained a sense of humor, learned about people with worse conditions than his, began to understand empathy and believed in himself.

We are so proud. Our experience was life-changing, and we feel so thankful. Because of it, our love and faith have grown and we continue to celebrate each new day.

it's only RARE...until it's YOU.

"If you think you are not strong enough to go through a trial, you CAN do it."—SD

Taylor Crawford's Story

Most high school students are unwrapping Christmas gifts, feasting with their families, or watching football games in good spirit during their Christmas break. I was filling up on vending machine popcorn, and reluctantly being comforted by the continuous beeps from my sister's breathing machine. This pivotal moment in time—seeing my older sister's struggle—fueled my passion to become an occupational therapist and help others like her have a better quality of life.

My sister—my best friend—came home from college on December 19, 2013 not feeling like her normal self. We took her to *Urgent Care. "It is only the common flu,"* the doctor said, until three days later. She complained of part of her face feeling as if it had been shot with *Novocain* and two of her fingers were numb. We immediately took her to the hospital where she was admitted for observation. Her first night at the hospital was as normal as expected. Several of our friends came over and we sat up laughing and joking. Little did I know, this would be the last day I would hear her voice for months to come. Our hopes for her to be home by Christmas day were short lived. The next day, she woke up having trouble breathing, speaking, standing and seemed to have lost all physical strength and mobility.

It's Christmas time, how can this be happening. Everyone was so confused, the seriousness of everything neglected to

sink in. All we could hear were the sounds of her life-support machine—all of its beeps and blasts of air. My sister was diagnosed with Guillain-Barré syndrome and its Miller Fisher variant. She was now paralyzed from the neck down.

Guillain-Barré syndrome, and Miller Fisher are rare disorders where your body's immune system attacks the nerves and the myelin. For three weeks, I watched my sister lay lifeless in ICU RM2070 with tubes wrapped up over her bed, down her throat, and protruding out of her arms. The only seeming comfort in her room was the golden holiday garland I had taken from our Christmas tree at home and hung on the wall above her bed.

Two month's later, I finally heard my sister's voice again. That morning, I helped the techs get her dressed, slide her into her wheelchair, and wheel her down the hallway to her therapy session. She was finally able to swallow.

So, that day, we made what I knew was her favorite, strawberry-banana-blueberry smoothies. She struggled trying to cut the bananas; her nerves were still not fully functional. After a couple of tries and about fifteen dropped blueberries later, she picked one up and threw it into the blender. My eyes instantly began to water as tears, like bullets, streamed down my face. She gazed at me and mumbled, *"it's okay."* It didn't really sound like her, the voice was cracked and forced, over her tracheotomy. But it was her, and I knew she was going to be okay.

Everything that happened to her, and experiencing her struggle first hand through therapy sessions and countless visits to the ICU, has shaped my interest in occupational therapy. All of those events encouraged me to grow and now require me to become more mature, and independent. I want to feel the joy of helping people, young and old, to have a life again. Therefore, I believe embarking on a career in Occupational Therapy will allow my passion, devotion, and drive to help others to heal, come to fruition.

"Guillain-Barre' broke me open.
It can be a gift if you allow it."—RS

Terry Knight's Story

I was a healthy 56-year old mother of two, grandmother to three.

In September of 2010, I was given a flu shot. Shortly after, my toes started tingling and nine days later I was stumbling and could hardly walk.

My husband's doctor agreed to see me because my husband thought I had had a stroke. I was immediately admitted to *St. Mary's Hospital* in Huntington, WV.

During the next two months, I was diagnosed with Guillain-Barré syndrome.

My family stayed close by and took turns spending nights with me. I was on a ventilator and couldn't speak. My blood pressure either ran high or low. Sporadic. Same for my heart rate and body temperature.

Soon treated with IVIG, I had already experienced a lot of nerve damage. Blood was drawn, what seemed to be, continuously. I developed pneumonia and pancreatitis... constantly on breathing treatments. A urologist indicated I had a blood clot on one of my kidneys. Small clots routinely clogged my catheter. Suctioned a lot, I vomited a lot. I had three different PICC lines from which one, I gleaned a staph

infection. One of two tracheotomies closed up like it was supposed to. The other had to be closed surgically. I was treated for Thrush, had shots administered in my stomach to prevent blood clots, numerous bladder infections, and had be given insulin shots to combat the steroids.

After three relapses and a diagnosis of GBS, I had a seizure.

Next came months of living with a stomach tube, often loose-fitting and foul smelling. Then, severe headaches, double-vision, leg, back and hip cramps. X-rays, CT scans and multiple MRIs and developing a bad rash from lying on my back for 20 months.

One wonders how much one individual can take, but after all the above, I developed Osteoporosis and lost 40-pounds. My hair became so tangled, I chose to have it cut. My teeth had discolored because my brushing wasn't the best during this time. With no one attending to my nails, several became ingrown.

Did I mention the 13 different medications?

I had three swallowing evaluations involving intubation through the nose and throat. Difficult as it was to do, therapy helped me learn how to feed myself and walk again. The Osteoporosis ultimately caused some back fractures and the loss of 2-3" in height. After 20 months, I was able to finally return home. But, all was not over. 5 months later I had gall bladder surgery, then the second trache closed and yes, hernia surgery.

I have permanent nerve damage, but I am thankful to be walking, able to write, feed and clothe myself, and drive. My husband, children and grandkids walked with me through this horrific experience. Hardheaded Christian that I am, I made up mind to go through this and smile as much as possible.

I could have easily died more than the many times I was hospitalized had it not been God and the many prayers that had been offered up for me. I thank Him for His mercy.

it's only RARE...until it's YOU.

"It's been a hard life… but one I wouldn't trade with someone else."—DAH

Tom Steidinger's Story

Starting the new year—2016, my mind goes back to the time my life was changed forever.

I was 63 years old, the husband of my wife, Dianne, of 37 years, and father of 7 children and 16 grandchildren. I was a very active man, driving a truck for a well-known company along with my brother Donald.

Donald was on a dispatch route away from where I was driving when I received a cell phone call from him. *"How is the weather where you are and how is all going?,"* was part of the conversation. My answer was, *"that all is well except that for some reason I am seeing double on all the signs along the road."* He did not like that report and said he would call the dispatcher to send me back as soon as my load was delivered. I received a message on my mail account to go to Dayton, Ohio, pick up another load and deliver it to Detroit, Michigan, before returning home.

Dianne has often told me that I can never say no to a job for some reason. It was so with this request. I took the route and delivery as usual. When I was close to home, I called Dianne and told her to meet me at an intersection that would take us straight to the eye clinic. After taking the test I was informed that I was seeing double and to get to an ER ASAP.

Thinking it was something in the blood vessels on each side of my head, the ER doc took a test which came back negative.

I was told to just rest awhile and see how all was in a day or two. My pain was getting so severe at times that Dianne and I decided to travel to the *Mayo Clinic* in Rochester, Minnesota. We were told that it must have been a small stroke.

After a couple of weeks, my feet began to hurt with pain I have never felt so severe. Walking became very strange and unsteady with pain at all times. We were back at the *Mayo Clinic* after many tests by our neurologist.

Realizing we were there just weeks prior, we were now being told it was not a stroke per-say, but the beginning of the trouble I now have. After being tested at the clinic for 10 days, I was diagnosed with Chronic Inflammatory Demyelinating Polyneuropathy (CIDP.) By now, I was being placed in a basket, and onto tracks put into the bathroom and lowered into the shower, and on another track lowered onto the stool. This was the very best treatment a person could receive and knowledge from doctors we knew were the best in the country.

So began the biggest challenge in my life. After 3 months in a physical therapy hospital, and being told by one doctor that I will no doubt benefit from a psychiatric visit from time to time, the changes in my lifestyle, after being so active, may just overwhelm me.

Having seven IVIG plasmapheresis treatments, and many, many others, along with help of our family, I spent many sleepless nights in pain and anxiety often with some depression.

I was asked if I would volunteer at a local nursing home as a receptionist. Through that acceptance, I also became involved in operating a loom to make rag rugs. Having invested into smaller looms, Dianne and I are very busy making table runners, placemats, trivets, scarves along with many different jean and rag rugs at our *"LOOM ROOM."* Being in a wheelchair from CIDP, I have come to realize that when life becomes so confused, the road ahead so dark, with twists and bends along the way, and with pain and fatigue almost every day in one sort or other, it is only with the help of the all-knowing, all-seeing Father above, and being His hands and feet by doing volunteer work, and helping in the smallest ways, a wheelchair can become a car we can drive, a vehicle to carry us through even with all the weight of depression and the handicap of CIDP.

I am still the husband, a father, and a grandfather to 24 grandchildren…the children living all over America...and,

I have a Heavenly Father I trust and Who knows what is best for all.

Trent and Alex in Jackson, Mississippi; Rodney and Denise in Prescott, Arizona; Rick and Kim in Palmira, Missouri; Troy and Bobbie Jo in Normal, Illinois; Becky in Bloomington, Illinois; Beth and Corey, and Beverly and Bruce in Fairbury, Illinois; and Dianne and I here in our home in Fairbury, as well.

My advice to all in the GBS and CIDP family is, *"Should life give us lemons? Let us make lemonade from which others can benefit."*

I truly believe, with the help of each other sharing one another's experiences—the thoughts, the pain, and the depression we go through in our time on earth—there is a silver lining around the dark cloud we may have, or have had, over us at one time or another. The path may change, but we are still who we are and always will be. God Bless our GBS and CIDP family.

it's only RARE...until it's YOU.

Tonya's Story

If I were asked before April 21, 2009, *"What I saw myself doing in the next 6 years?"* I can assure you that fighting and embracing Guillian-Barré syndrome was not on the list.

At the time, I was working full-time, our girls had busy schedules, and my husband was busier than all of us. We loved traveling, crafting and competitive sports. When I slowed down to relax, you would find me in the perennial garden around our property from sun up to sun down!

Just like a southern summer storm that seems to blow in all of a sudden, life as I knew it just stopped! Initially, I felt run down. But it wasn't that good kind of exhaustion from a perfect workout. It was that lingering fatigue that keeps pulling you down and no matter what you try, your body continues to feel drained.

I finally made an appointment to see my primary care physician. I was told to cut back on my daily routine, go to bed earlier and cut out caffeine in the evenings. About 3-weeks later, I had tingling and numbness in various areas of my body along with severe pain that would interrupt my sleep. I went back to my doctor in Waldorf, MD, for a second time. Labs were ordered and I was told to continue reducing my activities, take a multivitamin and add more iron to my diet. He would like to see me again in about 4-weeks, but sooner if there were any other changes.

Within 30-days, of my initial doctor visit, I had lost 20 pounds, and gained tingling and numbness, all over my body. The pain was so bad, I could not sleep. It was definitely something serious. At my third physician visit, I was told it might be a thyroid disorder and that if I had an ultrasound, it would help in the diagnoses. I was given a prescription and told to hold on to it, until I spoke with the doctor the next day.

I called my insurance health nurse as I was leaving the doctor's office. She could not believe the ordeal I had experienced and sent a short list of endocrinologists and neurologists in the Alexandria, Virginia area.

An endocrinologist saw me immediately. He diagnosed me with Grave's Disease and began working to get my thyroid function under control. He also advised me that this was not the only issue and sent me to *Inova Mount Vernon Hospital* for an EMG. In the middle of my EMG, the procedure was stopped due to horrific pain and I was led across the lobby to the ER where I was diagnosed with GBS. From April, 2009 until somewhere around July, I received approximately 20 IVIG infusions. There was still something lingering underneath it all, however, that concerned the neurologist, so by the next 9-months I was seen by two additional neurologists and a rheumatologist.

At this point I still had pain, tingling, numbness, and fatigue. I was walking with assistance, but struggling to regain my independence. My doctors were giving up on me, but I

refused to give up on myself. I demanded another opinion. I had to advocate for myself. My independence had been taken from me and I wanted it back!

I arrived at *Johns Hopkins Hospital* on April 27, 2010. I was then diagnosed as having a complex neuromuscular disorder, positive neuronal AChR, chronic fatigue, pain, numbness, tingling, and no reflexes. On July 7, 2010, my thyroid was removed, and within 9-months, I began plasmapheresis every other day through April 22, 2011.

It's been 6 years now, and the tingling, numbness and pain are a part of my everyday life, but I refuse to slow down. Warm massages helps manage the residuals. I have re-engaged in life's activities with our busy science-and-tech 9th grader. She loves having me around more; I substitute teach, volunteer and garden when the mood strikes me. And I spread my smile everywhere! I love the mottos, *"Just Do It,"* and, *"It is what it is."*

I am now a *GBS|CIDP Foundation International* Liaison who advocates, educates, and supports those with GBS, CIDP, and other variants. I organize chapter meetings to help patients like me meet one another and learn more about their conditions. I am proud of how far I have come, and I feel gifted to be able to share my story and listen to others as they tell theirs.

There is so much to look forward to in life! I can't wait to see what is next!

"When you are scared to death, you saddle up and ride." (Actor, John Wayne) —GK

Tyler's Story

Friday, March, 2, 2013 was my last normal day. I had been for a run on my lunch break that day. Saturday, I noticed some weakness/soreness in my legs and didn't think much of it. On Sunday, my legs were noticeably much weaker. We took a trip to *Costco* that day. I had my wife, Erin, drive, had her get my son, Owen (6 months old at the time,) in and out of the car and carry him into *Costco*.

All of these things were normally my responsibility, so I remember her asking me what was wrong. All I could say was that my legs felt weak, and I didn't feel right. I remember, in *Costco,* I had to walk holding on to the buggy, and I kept feeling like my legs wanted to give way. This feeling lasted the rest of the day, causing me to stay parked on the couch at home. Later on, after we went to bed that night, I got up and fell in the bathroom. Erin had to get up and help me back to bed.

At this point I had more than a hunch that something was wrong. Erin asked if she should call 911 or take me to the ER, but I declined, saying, *"I will just go to the doctor in the morning."* When I woke up and tried to get out of bed, my legs completely collapsed, and I fell without making it one step from the bed. At this point I could barely move my legs. Erin helped me to the couch and arranged a doctor's appointment for 11AM.

We had to call two work buddies to come to the house, carry me to, and get me out of, the car and into a wheelchair at the doctor's office.

While we were at the doctor's office, I was correctly diagnosed with Guillain-Barré syndrome (GBS.) My doctor scheduled a spinal tap at the hospital in Wilmington, NC to confirm the diagnosis. My parents left for Wilmington immediately, going straight to the hospital. My mother-in-law also left home immediately, but she went to our house to help take care of Owen so Erin could return to the hospital. My sister, Rae, lives in California, so we stayed in touch with her over the phone.

My memory about the hospital stay in Wilmington is pretty foggy. When I first arrived, I had to use the bathroom but was unable and I was administered a catheter, which was not a pleasant experience.

That first night at dinner, Erin left to pick Owen up from daycare and get him into bed. That evening my pastor came to visit me, and he actually fed me my first hospital dinner. I was already too weak to feed myself. It was then that I learned that my pastor had actually had the same illness. This was the first time I had someone share their firsthand experience with Guillain-Barré syndrome with me. I knew I was in for a rough ride which actually turned out to be much worse than I expected.

My condition worsened at the hospital in Wilmington. Paralysis crept throughout my body and, by Friday, I was no longer

able to breathe on my own. All of this was happening while I was having my first round of treatments which were supposed to help me improve. However, I kept getting worse. The docs wanted to transfer me to a larger hospital, one with a larger neuro department and the ability to do a plasma exchange. On Friday, I was air lifted to *Moses Cone* in Greensboro. *Moses Cone* was a good fit for me because all of Erin's family lives in the Greensboro area. Erin and Owen stayed with Erin's parents while I was in the hospital in Greensboro. I have no recollection of being transferred there.

In Greensboro, I began plasma exchange immediately. GBS is thought to be caused by autoimmune factors like antibodies. The plasma exchange process removes antibodies and other potentially damaging factors from the blood stream. It involves connecting your blood circulation to a machine that exchanges plasma for a substitute solution. I don't really remember it making me feel good or bad, at that point, I only remember being very uncomfortable… and in pain.

By March 13, I had gone through two plasmapheresis treatments out of a schedule of five. By that point, I had pneumonia in both lungs and a partially collapsed left lung. That was also the day they put in a trach to make me more comfortable on the ventilator.

The first five or six weeks at *Moses Cone* are hard to recall, probably because my case was very severe. I do remember being transferred in and out of various departments and ICUs. Most memories are of pain and discomfort. Always

hot or cold. I had weird painful sensations in my back. I had an extreme case of dry mouth. I could not drink anything because I would aspirate the liquid into my lungs. They would let me have mouth swabs (moist sponges on a stick) and then they would suck the liquid back out of my mouth. I drove my family crazy asking for mouth swabs every ten seconds. My lungs and throat were also filled with phlegm. The nurses and respiratory therapists would continually have to aspirate.

While at *Moses Cone* I received heparin shots three times a day. Heparin is a blood thinner that helps to prevent blood clots. At one point, I had seven different IVs and PICC lines stuck in me at once. Erin snapped a photo of me that day. I did not look happy to say the least. Then again, who wouldn't be unhappy lying helplessly motionless in an ICU bed with needles being stuck into them?

Becoming paralyzed overnight is absolutely horrifying and at the same time, terrifying. In my case, I was in a nearly complete state of paralysis for weeks. I felt helpless lying in bed paralyzed. I could do nothing on my own. All I could do was lie there and pray. I mainly thought about Owen. I remember thinking that I did not want to miss any of Owens's milestones—my one true worry. In my head, I knew I was going to improve. My whole family told me, "*This is all just temporary.*" I knew my case was severe, so no one knew how long it was going to take. I just wanted to be there when Owen began to walk and talk.

Erin made videos of Owen to share with me. This was what cheered me up the most, as well as what motivated me the best. I remember telling Erin to make more videos, make more videos. The best time of the day was when Owen would come to see me in the hospital. Erin would show up on the unit, pushing him in his stroller, to visit me—my real motivator. Seeing Erin, and my family, was extremely comforting. I don't know if I would have been able to handle everything without them.

Another thing that was extremely helpful was all the financial support we received. Our friend, Dani, started a page on *Gofundme.com*. Many people donated a lot of money to me and my family via this website. My sister Rae also taught a dance class for donations out in California and raised money for me that way. This money helped pay for medical bills, our mortgage, and all of our regular bills while I was not working.

Although I was out of work for five months, losing my job was never a concern. Erin told me early on that she had spoken to my employers and they said my job would be waiting for me when I recovered.

Getting behind on the car and house payments was a concern until Erin informed me of what Dani had done on *Gofundme.com*. I remember we were talking about it one night, and Erin said we were going to be fine. She logged onto our bank account to show me just how much money was raised, and I was blown away. I also collected all my vacation time from

work along with some short-term disability. It really was a good feeling to not have to worry about money while I was in the hospital. It allowed me to focus on my recovery process.

For the longest time I was unable to speak or move. I could, however, mouth words and nod my head ever so slightly. Erin was the best at understanding me. She and my parents had the most patience trying to understand me. When they could not understand me, we used a letter board. Erin would point at letters, and I could signal when she was on the appropriate letter. Until my voice recovered, this was one of the ways we communicated.

On April, 2, 2013, my heart stopped beating! I had just recently been transferred to long-term acute care. My family, the acute-care team, and I were in the middle of a meeting. They were discussing my care plan when all of a sudden I fainted. When I came to, a nurse was on my chest giving me compressions; everyone was scrambling around trying to keep me alive. The doctors never really discovered why my heart stopped. They performed multiple tests, had heart specialists come in, and were never able to diagnose why it stopped. After this episode, I was transferred out of long-term acute care and into Cardiac ICU. I was now at my worst. Erin informed me that I had another severe case of pneumonia, I was recently unresponsive, and was now suffering from ICU psychosis. ICU psychosis is common with long hospital stays are mixed with heavy drugs. During my stay, I did have some vivid hallucinations.

Thankfully, after my second round of treatments, I really turned the corner. Recovery was slow and began with the ability to shrug my shoulders, then lift my hand, then my arm. The major step in my recovery process was regaining my ability to breathe on my own. I struggled with that process for quite a while as it took a few weeks for me to be weaned off the ventilator.

While I was in the hospital, I had a peg tube inserted directly into my stomach right above my belly button. I was not used to eating real food so I don't remember feeling really hungry. I do remember when I was finally cleared to begin eating and drinking again, I had ice chips, water, milk, applesauce, and crackers. I don't know if anything ever tasted better to me in my life than those four things did on that day. This was day two of breathing on my own and having a speaking valve on the end of my trach tube. I could talk, eat, drink, and breathe on my own for the first time in 47 days. Looking back on the whole experience, that day was a major stepping stone in my recovery process and probably one of the best days of my life.

When I finally made it to rehab, my body was so weak I could do nothing on my own. I had to completely retrain my body to do everything. Every little thing felt like a milestone: holding a cup, washing my hands, brushing my teeth, getting myself from a lying to sitting position by myself, holding my body in the sitting position by myself, and the last and most difficult, standing and walking.

Again, I was very motivated at that point to get better; I was pretty tired of being in the hospital. When they shared my expected release date, I was incredibly motivated to walk out of the hospital, and I accomplished my goal with the help of a walker and leg braces on June 5th.

At first, when I was at home, time there was surprisingly boring and kind of depressing. In the hospital, I was doing rehab sessions all day long. At home, my home-health therapists came by only once a day for about 45 minutes. Needless to say, I had a lot of time on my hands, and I still needed help doing a lot of things.

As you can tell from my narrative, I have improved. By the time I wrote this, I was back to work and playing a lot of poker. For me, life is now almost back to normal. I'm still waiting for some sensations and full range of motion to return in my feet and ankles. Lack of, keeps me from running and playing volleyball. Other than that, I can do whatever I want!

A final thought to those effected by GBS: Life will eventually return to normal. It was a long—and still is—an ongoing process for me, but here I am living a normal life.

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Weneday Ketron's Story

Carrie Underwood was standing in a pickup truck suspended by wires, moving over the crowd and over my head, singing beautifully. People all around me were singing along, smiling, and standing on their feet. I was enjoying the whole experience, her singing, the setting, but I was sitting down. I was weak and becoming frightened. Something seemed very wrong with me.

I was a thirty eight year-old, healthy, full-time mom, attending the concert with my twelve year old daughter, Kayla, and my husband, Greg. I had looked forward to accompanying Kayla to her first concert since giving her the tickets months earlier on her birthday. I knew that if I couldn't shake off the feeling of malaise in that venue, I wouldn't be able to do it anywhere.

Despite the excitement, I still felt something was very wrong physically, so I communicated that to Greg. We decided to leave a few minutes before the concert ended, trying to beat the mass exodus.

The stairs leading to the exit had never before looked so formidable. I held on tightly to the railing, determinedly, but clumsily swinging each leg up each step. It was very slow going. I glanced at the line that was forming behind me, worried that people would think I was drunk. All I saw was patience and concern on their faces. It was obvious to everyone else that something was physically wrong with me.

My legs were weak, I couldn't walk normally, my back ached, my extremities were numb and tingly, I was having difficulty going to the bathroom, my mouth tasted like a dirty copper penny, and I was very uncomfortable.

On October 23, 2010, the day after the concert, I checked into a hospital Emergency Room. During our fifteen-minute wait, Greg, who had no medical training, began searching my symptoms online from his phone. He told me he thought I had Guillain-Barré syndrome (GBS.) We had never before heard of it. The ER doctor ordered some tests and confirmed the diagnosis.

Later that day, my legs gave out and I collapsed onto the floor with a loud thump. I couldn't move my legs at all! Before any words were out of my mouth, and almost instantly, Greg was right there. He'd heard my fall. My mom had too, and she was screaming loudly for the nurse. Greg looked at me

compassionately and told me he was going to pick me up off the floor. Terrified and wide-eyed, I said, "*I can't move my legs! I can't help you! I can't support any of my weight! I don't know if you can pick me up.*" So far, Greg had been helping me walk, but I'd been helping, too. He promised he could pick me up. As he was lifting me, the nurse appeared. The two of them got me back into the bed. I couldn't move my legs or even wiggle my toes! The nurse said it was just a part of GBS, and my first taste of its real, serious, effects. I was stunned. They said this could happen, but I hadn't really expected it would. It was awful!

Next, my face became completely paralyzed without my even being aware of it. I overheard the nurse say something to Greg about me starting to rapidly decline. I was suddenly terrified. This perpetual optimist was feeling anything but optimistic. What else could go wrong? I started to cry as I was moved, still in the bed, to the neurological intensive care unit (NICU.)

I'd lived a fairy-tale life. I'd always dreamed of having three children. When I got sick, I was a full-time mom with an eleven year-old daughter; a one year-old daughter, who I'd stopped nursing only a few months earlier; a twenty four year-old stepson; and a loving husband. Getting sick had never been in my plans, and there was no back up plan for how to take care of my youngest, who had never been enrolled in day care.

I spent thirty-three days in the hospital. I will remember

those thirty-three days for the rest of my life. I was completely dependent on others to keep me alive. I had to relearn how to sit, stand, walk, talk, and even eat. Everything I had taken for granted in life took on a whole new meaning. I had never before been so filled with overwhelming fear, excruciating pain, and deep sadness; and later, immense joy and incredible gratitude.

Today, I am left with tingling toes, a changed face, and a deep appreciation for life's blessings. I can walk, run, and climb. I can use the bathroom by myself. My external smile is not symmetrical or full, but has progressed to the point that it is obvious when I am smiling or frowning. When I make a kissy face, I feel the muscles in my face strain, but I am able to give and receive kisses.

I treasure any extra time I get to spend with my family. I savor the sounds of my youngest daughter's giggles, treasure the bond I have with my oldest daughter, and rejoice over the friendship I have with my bonus son. I am in awe of my children's beauty both inside and out, and I am thankful for my devoted husband, my rock through it all.

I wrote and published a book about my experience called *"Geeyahn What? My Guillain-Barré Syndrome Survival Story."* It was my hope that the book might bless others, and I am told that it indeed has. I am an official liaison for *GBS|CIDP Foundation International*, and have the opportunity to visit newly diagnosed patients in the hospital. I almost always

physically jump up and down in front of a newly diagnosed person. That way, they can see that there is hope and that there is sunshine after the rain. When I was hospitalized and terrified, other survivors visited me; now, I am paying it forward. I feel blessed.

it's only RARE...until it's YOU.

"No matter how insignificant an improvement is, it's the start of progress which become exponential over time."—KH

Widy's Story

My name is Aledawi Figueroa, but everybody calls me Widy. I am from Isabela, Puerto Rico. I am happily married to my husband, Obeth Soto. We have two children, Alanis Valeria and Obeth Julián.

I studied business administration, majoring in industrial management and human resources. After finishing college, I continued studying education—my passion—concentrating in special education. I love personalized instruction so I founded *Smile Again Learning Center, Corp.,* in 2005. At *SALC* we offer tutoring, English and Spanish courses, test prep reviews, among other services.

I love spending time with my family, reading and helping others. I've always worked with youth groups in church and, together with my husband, we give motivational talks to groups and couples. My favorite quote is, *"what is darkness for you today can be light for others tomorrow,"* meaning that no matter how hard you're having it today, you can be sure that your experience will help someone tomorrow.

That is exactly what Guillain-Barré (GBS) confirmed in my life. In November 2013, my family and I were living a dream come true. I was finally pregnant with my second child—this time a boy. Alanis had asked for a brother ever since she was able to talk and her prayers had finally been heard. We were all excited because the pregnancy was going perfect. In

February, 2014, 18 weeks into my pregnancy, my hands and feet started feeling numb and tingly. I contacted my doctor and she said it could be from water retention due to the pregnancy. But, a couple of days later, symptoms started getting worse. My tongue started feeling tingly, as well as my hands and feet, and I could no longer walk on my own. That's when I fell to the ground while taking some pre-baby pictures with my family.

At this point my husband knew that it wasn't water retention and we called the doctor. She saw me the next day and called in a neurologist. That's when I was diagnosed with GBS. I was treated in the hospital with immunoglobulin and was transferred to a rehab center. I was not allowed pain relievers because of the pregnancy so I went through it all with the help of God, my family, my friends, prayers from many, many, people, and my set goal to be able to walk by the time my baby would be born in July, 2014.

After many therapies and exercises, most of them in a pool to relieve pressure on the baby, I was able to walk and hold my baby when he was born. It was a tough journey but I've always felt that it was a blessing from God.

I have faith that God has a purpose for everything and that everything happens for a reason. I have and continue to use this life changing experience to help many people, some with GBS and others who may just be facing a tough challenge in life. I hope to be able to help many, many, more.

Yael Kadock's Story

The backdrop was a beautiful golf course with spectacular views of volcanoes. My husband and I were watching our 8-year-old daughter play golf when I started feeling my hands and feet feel numb, and water on my hands felt like ice. It was 11 October, 2015.

On Monday, back in Guatemala City where we live, I couldn't get out of bed. My knees felt weak and I had trouble walking. That was when I told my husband to take me to the hospital, as the uneasiness was very different from anything I´d felt in the past. Up until that moment, I had been in very good health, played tennis twice a week, and tried to eat healthy.

Doctors ran several tests, but the diagnosis was unclear; on the third or fourth day at the hospital, mobility in my limbs noticeably decreased and discomfort was greater; an electromyogram confirmed Guillain-Barré syndrome (GBS.)

The following week is a blur to me, but I know I was transferred to ICU, had a tracheotomy (a respirator to breathe) and a gastrostomy (a feeding tube to the stomach) and was completely paralyzed. I also had complications—pneumonia, high blood pressure and a collapsed lung. I could only nod, couldn't speak, couldn't breathe on my own, couldn't move. I must say, however, that I don´t remember waking up and feeling scared.

The following weeks were difficult; I was alert and conscious of the discomfort, pain and very long days and nights. I was given two rounds of immunoglobulin as treatment. What was more frustrating to me was that I couldn't communicate. My husband got me a board with letter magnets and I was able to point at the letters… but it took ages to do it, and nurses, doctors and relatives were not very good guessers. With my husband, brother and sister, mother and best friend by my side (and the prayers from all the people who weren't,) and thoughts of my two adorable girls, I managed to keep positive about my condition.

After learning to breathe on my own again, the respirator was removed and I was finally able to speak to my daughters, but what could I say to them after a month and a half without seeing them, talking to them… and without breaking into tears? I never got to explain that I was leaving for the hospital and that everything was going to be okay. We never imagined

that I´d be there for months. I missed them so much. One night, my little golfer´s name was mentioned on TV, she had won the national championships! That was when I spoke to her on the phone to congratulate her. My mom tells me that my younger daughter, who was 5, held my photo and started crying, she couldn't talk to me then. I was ecstatic to be back.

The weeks that followed until my release were all about physical therapy, medicines, and finally food! I was healthy but had to rehabilitate, and I had to learn to do everything over again. They kept saying that things at home were going to be much easier. And they were.

I was released on 19 December, 2015. By the end of April, 2016, I had gained my dexterity, went from using a wheelchair to a walker, and to finally walk, jump and run!!!

I now play tennis twice a week and live a normal life. I never thought I´d be so positive about my experience and that it didn't hold me back. My family and I proved to be a great team, and we learned that if you put your mind to it, you can overcome any adversity.

I still have occasional numb hands, and pins and needles in my feet, especially at night. I turned 40 this year, and every day in the years to come, I am, and will always be, grateful to be alive and to be able to do anything I want.

it's only RARE...until it's YOU.

"A final thought for those affected by GBS: Life will eventually get back to normal. It was a long, and still is, ongoing process for me, but I am living a normal life." —TO