

# The Communicator

GBS CIDP FOUNDATION INTERNATIONAL

PROVIDING STRENGTH THROUGH SUPPORT



*Working for a future when no one with Guillain-Barré syndrome (GBS), chronic inflammatory demyelinating polyneuropathy (CIDP), and related syndromes such as MMN suffers alone and that everyone has access to the right diagnosis and the right treatment, right away.*

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## Despite a debilitating disease, Ironwoman Lynn Rogers goes for her 11th Chicago Marathon

*Excerpt courtesy of espnW.com  
By Anna Katherine Clemmons | Oct 6, 2018  
Special to espnW.com*

**Her first clue** was when her fingers turned numb.

When Dr. Lynn Rogers set out on an early-morning run in late July 2017, a week before departing for Canada to attempt her second Ironman triathlon, the then-40-year-old noticed that she couldn't feel her fingertips.

The following day, the tingling returned — but in her feet. Her tongue was next. Rogers went to the emergency room, where doctors performed a battery of tests but couldn't find anything wrong.

Rogers had been a fit, healthy, endurance athlete for over a decade. As director of the Neuralplasticity Lab at the Shirley Ryan AbilityLab (formerly the Rehabilitation Institute of Chicago), Rogers studied the brain and how it controlled movement. She was also a faculty member at Northwestern's medical school, balancing her love of scientific research with her passion for running and biking, waking up at 5 a.m. four to six days a week for training runs or rides.

During her first Ironman, in Madison, Wisconsin, in 2014, Rogers broke her foot as she ran out of the water post-swim. As soon as she mounted her bike, her foot began to swell. But she kept pedaling, trying to push with the quasi-functional part of her foot. After a brief stop in the medical tent post-ride, she ran onward, hobbling through the entire marathon. She finished the race — and spent the next four months in a foot cast.

These new symptoms, however, were a mystery. At work the next day, Rogers' coworkers at the rehabilitation clinic ran her through several assessments. Rogers, fully sober, couldn't pass a basic sobriety test. She headed back to the ER and endured another series of tests, including a spinal tap. Still, doctors could find nothing wrong. Six days out from the Ironman, Rogers boarded a plane for Whistler, British Columbia, determined to compete. She'd spent the past nine months training, and she had numerous friends and family members flying to Canada to cheer her on.

But as soon as she deplaned, Rogers could barely walk. She reluctantly realized she couldn't race; instead, she cheered her friends from the sideline. By the end of the race, she couldn't stand without support.

Aided by friends, Rogers made her way to the ER in Whistler, where doctors coordinated with physicians in Vancouver and Chicago. "They determined that if I could still breathe, I needed to get on a plane immediately," Rogers said. "That was the craziness we were in — wondering if I would keep breathing long enough to get home." Rogers made it through the flight, and upon



Dr. Lynn Rogers

continued ►

*We take this opportunity to thank CSL Behring for their support in making this newsletter possible through an unrestricted educational grant.*



*Our experiences are the thread  
that weaves us all together.*

## Dear Friends,

In this season of thankfulness, I am so grateful to you, the patient community. We had the honor of welcoming 575 members to our biennial symposium in San Diego just a few weeks ago. If you were with us, I hope you were able to share your journey and personal story. We ALL have a story, the choice is ours to share them but it is in the sharing when the emotional healing and recovery can begin. Our experiences are the thread that weaves us all together.

After attending the symposium our keynote speaker, Michael Coleman expressed the following:

"I am so honored to be a part of this family. My wife and I are still talking about that life-changing weekend on a daily basis...The physicians, industry partners, liaisons for all regions, EVERYONE was beyond expectations. I haven't been able to get this quote from Margaret Mead out of my head, *never doubt that a small group of thoughtful, committed citizens can change the world; indeed it's the only thing that ever has.*

It has been a long 2½ years of recovery but I have never been more motivated for both my own recovery and to be a resource for anyone affected by GBS or CIDP...I am always going to be All-In when it comes to this organization and my new family. We will never miss another symposium. We are so thrilled to have finally found our people!"

We consider ALL of you "our people". If you were not at the symposium, do not fear, 2019 brings even more opportunity to share. Not only will we be adding to our library of online resources, but we are planning over 65 chapter meetings, four one-day regional conferences and 17 Walk & Roll's all over the country! Where will we see you?

Your spirit, your courage and strength inspire us every day to provide the highest level of support, the most helpful education, fund the most promising research and represent your voice on Capitol Hill!

I wish you peace, love, health and happiness this holiday season,  
Gratefully,

*Lisa*

Lisa Butler, *Executive Director*



Please update your contact information to make sure we have your current email address. Your information will not be shared with anyone outside the Foundation.

Contact us online at [gbs-cidp.org](http://gbs-cidp.org) or by emailing [info@gbs-cidp.org](mailto:info@gbs-cidp.org).

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landing, she and her boyfriend, Tony, took a cab straight to Northwestern Memorial Hospital. Only this time, she wouldn't leave so quickly.

As Rogers exited the cab at Memorial Hospital, she had to walk half a block to the entrance. "That sticks out for me, because that was the last time I would walk," Rogers says. "Tony had to help me, and he got me into a wheelchair. And then, that was it."

Rogers was paralyzed from the chest down. More tests and another spinal tap finally revealed a diagnosis: Guillain-Barre syndrome. After three weeks in the acute ward, Rogers was moved to the Shirley Ryan AbilityLab rehabilitation clinic — the same place where she worked as a research scientist. But two weeks into physical therapy, Rogers wasn't improving.

In fact, her condition had worsened, so she was transferred back to Memorial. There, doctors tried plasma exchange. She received seven treatments over 14 days and slowly regained mobility. Still, even tiny movements caused extreme pain. Rogers could barely move her ankles — simply bending and straightening was excruciating.

For months, Rogers followed a frustrating routine: plasma exchange, recovery, relapse, more plasma treatments, more physical therapy, another relapse. By November 2017, four months into her hospital stay, doctors shifted her diagnosis to CIDP, chronic inflammatory demyelinating polyneuropathy, a chronic form of Guillain-Barre syndrome.

"It was terrifying," Rogers says. "It was starting all over again every time."

Rogers' running community rallied around her. Her friends showed up at the hospital each day with food, magazines or simply to keep her company. Castellini says that she'd text Rogers a note of support almost daily. "We all understood that if you got an email, she was feeling crummy, because she didn't have the dexterity to even type on her phone," Castellini says. "But if you got a text, that was a really good day."

In November, Rogers was admitted as an in-patient at the AbilityLab, requesting that she stay on the 23rd floor, the same floor as her own research lab. She had physical therapy several feet away from her desk and the

research team of scientists she supervised in studying patients like herself.

Rogers was also determined to run again. She had lost 25 pounds of muscle, and she relied on ankle braces, crutches or a wheelchair for mobility. But in November, she stepped onto an anti-gravity treadmill, wearing a harness to support half of her body weight. "It felt like an elephant running, because I was just smashing down on myself," Rogers says. Each day, she assumed a little more of her weight while trying to run on the treadmill.

On New Year's Eve, she attempted to run unassisted for the first time since her diagnosis. She alternated walking and running, traveling 3 miles in the span of an hour (her previous pace, pre-diagnosis, averaged at about an eight-minute mile). A CrossFit athlete, Rogers also focused on rebuilding her muscle mass, working with her physical therapists to find strength exercises she could complete with limited mobility.

So Rogers signed up for the 2018 Chicago Marathon on Oct. 7. Rogers worked with her CrossFit trainers on strength workouts adapted to her diagnosis. Rest was also critical; initially post-diagnosis, Rogers needed two-plus hours in the morning for her medications to kick in before putting on her ankle-foot orthoses and forearm crutches and attempting any sort of movement.

Slowly, as she has improved, she has relied on less pain medication and fewer devices for assistance. But she still needs eight to 10 hours of sleep to function.

"Because she was so physically fit, it really helped with the endurance aspect of the rehabilitation," says Dr. Elliot Roth, the co-medical director of the Brain Innovation Center at AbilityLab and one of Rogers' main doctors. "She also had the psychological makeup to understand the value and importance of exercise. She never said, 'Leave me alone, I want to stay in bed all day,' as some patients do. She wanted to get up and do more and be active."

Rogers walks with a cane and knows that each day brings unforeseen challenges. Perhaps most frustrating, CIDP has no known cure — and few treatment options. The plasma exchange has a shelf life; already, Rogers says her veins are worn down and won't be able to endure the treatments indefinitely. She can



try chemotherapy drugs, which have proven effective in some CIDP patients, but she has been told to prepare to be wheelchair-bound again.

Another major motivation for her to run the 2018 Chicago Marathon, which will be her 11th Chicago Marathon, has been fundraising for both the AbilityLab and the GBS/CIDP Foundation. Through Oct. 1, she has raised about \$6,000 total (just under \$4,000 for the AbilityLab and \$2,000 for the GBS/CIDP Foundation) in the hopes that she can help in finding a cure.

Still, no one knows how her marathon day will unfold, including Rogers. She might wake up with partial paralysis or with extreme exhaustion. Despite those potential setbacks, she is determined to compete. She has many supporters who will be with her along the race course — and thousands more afflicted by CIDP and Guillain-Barre whom she hasn't met, but whom she is inspiring from afar.

"They are all with me — all the faces I don't know of the people who don't think they can, who haven't had the good luck in recovery that I've had," Rogers says. "They haven't gotten this far, yet. But maybe they'll see that they could — and that it's possible."

**POSTSCRIPT:** Fourteen months after CIDP temporarily paralyzed her, brain researcher Lynn Rogers ran the 2018 Chicago Marathon—completing her 17th marathon in a time faster than her slowest, a 5:10—with a 4:18 time.





*Our volunteers gather together at the Symposium closing celebration!*

## Highlights from a 30th Celebration to Remember

**Cheers to 30 Years!** It was the best of all worlds this past November at the 2018 Symposium in San Diego where GBS|CIDP patient support, education, research and advocacy took center stage! Thank you to our presenters, sponsors, volunteers and every member of this amazing community for the moments & memories that will last a life time. A special thank you to our international circle of friends from around the globe including France, Canada, Australia, Japan, German, Italy, Mexico, Nepal, the Netherlands, England, Trinidad & Tobago. We are delighted to have met you and look forward to supporting you and expanding our programs for you worldwide.



### A Walk & Roll like NEVER BEFORE...

Our San Diego Welcome Walk kicked off the Symposium with a burst of energy, warmth and friendship – not to mention a glorious view of Mission bay at sunset! Over 300 participants gathered for a one mile walk to the Symposium opening reception. Sponsors of the event cheered patients from the sidelines and the spirit of hope and comradery grew stronger with each step.

### A Note to our KEYNOTES

Thank you to our Keynote Speakers, Dr. Richard Lewis and TV actor and GBS survivor, Michael Coleman for their powerful and supportive messages, setting the tone with an inspiring note for the days ahead! As jokingly expressed by Michael Coleman, “I love being in the GBS|CIDP club, but it was a heck of an initiation!”



## A BIG THANK YOU TO ALL OUR PRESENTERS

Jeff Allen, MD  
Linda Brubaker, MD  
Lisa Butler  
Diana Castro, MD  
Dane Christianson  
Amy E. Clarke, RN IgCN  
Michael Coleman  
David Cornblath, MD  
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Julie Rowan, MD  
David Saperstein, MD  
Joel Steinberg, MD  
Jeffrey Wertheimer, Ph.D  
Frank Williams  
Ted Yednock, MD



## A Special Moment of GRATITUDE to our Volunteers

VOLUNTEERISM AT ITS FINEST... Benson volunteer awards were given to four of our passionate volunteers by none other than Founder Estelle Benson herself. These dedicated volunteers best represent the mission pillars of the organization. Included in the roster were Board of Directors member and Regional Director Jim Yadlon, for his unwavering commitment to SUPPORT, GMAB member Dr. Richard Lewis for his determination to EDUCATE patients worldwide, GMAB member Dr. Kazim A. Sheikh for his innovative spirit and dedication to RESEARCH, and Liaison, Hill Day Advocate and Walk & Roll Chair, Tonya Charleston, for her passion and persistence in the area of patient ADVOCACY.

## ZEN Den, More Please...

Attendees are still talking about our new feature, the Symposium Zen Den! If you were unable to stop by for a visit or not able to attend the Symposium, not to worry – we hear you! You can expect more resources for calming the body, and the mind, in upcoming weeks with the help of our amazing “Zen Den” team.



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*“Please accept my belated congratulations on a great symposium. The venue was superb and, even after all of these years, I learned some new information!”*

–SUSAN GABAY-LAUGHNAN

*“Michael Coleman’s key note address warmed and inspired me. How wonderful to be so open to share your experiences with us. You are not alone.”*

–RANDY

*“It was a wonderful symposium and a fabulous experience and I cannot express in words how much I appreciated the scholarship I was given. I learned a lot and was able to meet many wonderful people who share my struggles. I am no longer alone in my battle so I am very grateful. Thank you!”*

–BOB HOLT





## DEDICATED Team of Medical Professionals

Where would we be without the passion and dedication of our GBS|CIDP of medical professionals? Over 65 patients were able to meet for 15 one-to-one discussion with some of the top neurologists in the world! And if more questions arose after their meeting, there was ample opportunity to ask during our 4 “ask the experts” breakout sessions. How committed they all are to our community! All volunteered their time, not a single one taking an honorarium. Thank you!



Additionally, a well-deserved & HUGE shout out to our sensational roster of presenters for sharing expertise on everything from dealing with fatigue, insurance and advocacy, coping with residuals, and much, much more. A special thank you to newcomers on the presenting team including, Jeff Wertheimer, Charla Illiano, Maria Fronczkowi, Amy Clarke, Julie Rowan, Linda Bruebaker, Ted Yednock, Sterling Panton and Frank Williams, for their outstanding presentations and workshops including: emotional health, PT/OT, best practices for IVig, integrative healthcare, guidance on sexual health issues for women, promising new therapies for GBS, and transformational topics and tips for coping with physical and mental stress.



## INDUSTRY Meets Patients One-On-One

Our Industry sponsors including CSL Behring, Grifols, Kedrion, Shire, PPTA, NuFactor, Soleo Health, RMS Medical Products, Accredo, NeuroCareLive/PlatformQ, Brivio, Kroger and Diplomat Pharmacy, seamlessly joined the conference-wide conversation, along with a buzzing crowd of patients and caregivers in a friendly atmosphere of story sharing and product education. To that end we are so grateful for the support and “patient-first culture” set by our industry partners and are excited to have them as a part of the GBS|CIDP community!

## GBS|CIDP Foundation Benson Fellow Awardees

The audience was delighted to meet our most recent GBS|CIDP Benson Fellow Dr. Ruth Huizinga, from Erasmus University Medical Center in Amsterdam and Dr. Janev Fehmi of the Nuffield Department of Clinical Neuroscience (NDCN) in Oxford, England, both traveling thousands of miles to present their research study updates. Ruth and Janev presented on their topics of interest including identification of genetic causal variants of GBS, and characterising the pathogenic mechanisms of nodal auto-antibodies in the inflammatory neuropathies.



## PATIENTS WIN Big!...

Thank You to all who purchased raffle tickets for Symposium raffles! Congratulations to all of our winners and a special congratulations to our big ticket item winners including a custom GBS fire pit created by artist Sean Young and won by member Kathryn Rierson. And a BIG heartfelt hug to the ladies who worked tirelessly crafting the GBS t-shirt quilt! Last but not least, a thank you from the bottom of our hearts to our kind and generous regional directors who donated the quilt back to the GBS|CIDP Foundation staff!







## Old FRIENDS Meeting for the FIRST Time...

Friendships blossomed throughout the three day event, and we were all delighted to see how many folks were exchanging contact information, and eager to talk with their GBS|CIDP regional directors, as well as other attendees from their region who shared a similar condition. New attendees were welcomed and supported by an enthusiastic troop of committed volunteers, staff and physicians. But, as with most GBS|CIDP Foundation Symposia, the atmosphere reached far beyond that of an extensive reunion of commonality – it did, no doubt, grow to a festival of kindness and kinship for patients & caregivers in need.



“

*“We are at the Symposium for the first time. It has only just kicked off but it has already been such an amazing experience for our family. Thanks to all who make these meetings possible so we can connect with others and learn!”*

—CHARLENE COWELL



## A SURPRISE ANNOUNCEMENT FOR 2020

After a fun and festive closing celebration, a special video was played announcing our location for the 2020 GBS|CIDP Foundation International Symposium! Drum roll... we are pleased to announce it will be October 1-3, 2020, in Alexandria, VA! The event will be preceded by a Patient Advocacy Day on Capitol Hill! More information will be shared in the spring, 2019 Communicator and online at [gbs-cidp.org](http://gbs-cidp.org). We hope you can join us!

### DEAR GBS|CIDP FOUNDATION,

Have been meaning to express my thanks again for the wonderful friendship and support received at the symposium. What a fantastic event. Congratulations to you on the organisation. It by far exceeded any expectations and the full impact is still settling on me. My wife Josephine had been cautioning me not to expect too much but now concedes the willingness and openness in sharing and caring was overwhelming. The access and frankness of the Global Medical Advisory Board members blew me away. Perhaps we are accustomed to Drs in Australia protecting their own little patch but these experts showed exactly why they are the leaders they are.

Best of all the Symposium covered all aspects of a patient's life and that of careers also. Well perhaps even better are the new friends and support group that I now have spread across the world.

Wish I had the words to properly express my gratitude but hope this in some ways goes to achieving that.

– VAUGHAN LIDDELOW,  
AUSTRALIA



## A Cherished Member of the GBS|CIDP Foundation's "Original 8" Returns

Judy Jacobs is one of "the original 8" – a passionate circle of 8 people lead by the most passionate of all, the founder of GBS|CIDP Foundation International, Estelle Benson, and a group whom Dr. Arthur Asbury from the University of Pennsylvania, deemed as "the missing piece." This summer at the GBS|CIDP headquarters in Conshohocken, PA, Estelle and Judy reunited for the first time in several years, sharing a rare glimpse of those very early days, when the future of the foundation rose and fell on their aptitude for hope and their capacity to care for those in need.

In 1972 very little was known about GBS. "My lips and fingers started to feel numb. My husband happened to have a doctor appointment that day so I went along. My condition worsened throughout the day and I ended up in Pennsylvania Hospital. They really didn't know what was wrong, but fortunately for me my son was a doctor, and was, against all odds, able to actually diagnose me over the phone. I had Guillain-Barre Syndrome," said Judy this past summer as she visited us just prior to her 101st birthday.

"I spent 9 months in the hospital. They had no treatment at that time, no IVlg." Now, more than 50 years later, Judy is the oldest known surviving GBS patient. "I remember the physical and occupational therapy was very creative. I made a cutting board! And I remember reading about Estelle and Bob and their Foundation in the newspaper. I thought it was some sort of support group so I contacted them. I quickly realized, it was much, much more." A young man visited Judy in the hospital. "He was in high school and he had GBS." Judy was struck by how difficult it must be to watch her and others suffer with no real way of knowing what the future may bring. She was moved by how meaningful this visit became to her.

Although Judy's health was improving day by day, she was not progressing swiftly enough to attend her own daughter's wedding. "So they decided to bring the wedding to me! They got married in the chapel at the hospital." Although Judy had the correct diagnosis and the love and support of family, her empathy for those in the same condition "lying in a bed feeling like no one cares," grew and grew. She wanted to help. In fact, she needed to.

"I joined Estelle and Bob and their mission. My first task was to be in charge of the tribute card program, right there at Estelle's kitchen table." But it didn't end there. Judy would become one of the most influential voices in the community as well as being the first official "GBS hospital patient visitor", and a member of the GBS|CIDP board of directors. "It is a deep spiritual journey to have your life derailed. In some ways what started as handicap for me, has brought me many friends and great pleasure too."

These days in addition to paying delightful visits to old friends, Judy enjoys her 12 great grandchildren and, as a lifelong music enthusiastic, attends live concerts at the Mann Music Center, whenever possible. Happy 101st Birthday Judy!



# So you've been diagnosed with Guillain-Barré syndrome (GBS); now what?

By Joel Steinberg, MD, PhD

Founding Member, GBS/CIDP Foundation

Member, GBS/CIDP Foundation Global Medical Advisory Board

**In the beginning:** If you're like most patients you've never heard of GBS before you were told of that diagnosis. Even pronouncing Guillain-Barré syndrome can be a challenge. But what to expect? You're about to have many new experiences, while thinking in the back of your mind, 'I don't really need this; I don't want this'. Well, we certainly don't choose our illnesses. But if we develop GBS, we're stuck with it, at least for a while. So let's get acquainted with this illness and the new experiences and words it brings into our life.

By far most patients newly diagnosed with GBS are hospitalized. Ouch. Some of us just find the possibility of that experience maddening. You have a lot of company. No one wants to be a patient; no one wants to be in a hospital. But it's a matter of your health. So let's make the best of a lousy situation.

**SCARED?** Why not? Most new GBS patients are scared, for many reasons, fear of the unknown, not being in charge of your own life, etc. We have choices. Be angry, be frustrated; then let common sense take over and be accepting. It will be a time to go with the flow. And, if you're used to having things your own way in life, watch out. To paraphrase Bette Davis (circa her 1950 movie), it's going to be a bumpy ride. Just remember, all of those professionals taking care of you have only one goal, do their best for you.

**UPON ADMISSION** to the hospital most new patients are placed in a nursing unit where your heart beat and breathing can be closely monitored. That's because GBS carries a risk of complications such as difficulty breathing and fast or slow heartbeat. So expect wires and other gadgets to be attached to your body. You may be in an intensive care unit, where the patient to nurse ratio is typically one nurse for only 2-3 patients. Thus, you'll get lots of attention. Be thankful.

Several professionals will be seeing you. Physicians will typically include an internist, who oversees treatment of the internal

organs (muscle, heart, etc.); neurologist; a pulmonologist or pulmonary medicine (lung) specialist; and perhaps a physiatrist (as in 'fiz-eye'-ah-tryst) (rehab doctor), cardiologist (heart), intensivist (also usually a pulmonary doctor), etc. One of these will serve as your attending physician, or, if you will, the head doctor, who orchestrates the care by others.

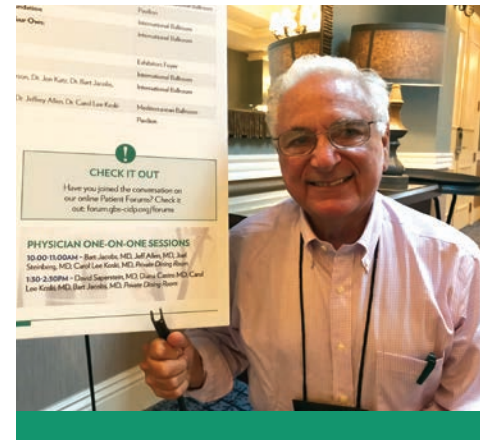
In addition to physicians, several other professionals will be providing care: nurses, respiratory therapists (RT), physical therapists (PT), occupational therapists (OT), social worker, etc. Having so many people involved in your care can be dizzying. Hopefully most wear an identifying tag and introduce themselves so you'll know who's who.

**MEDICALESE:** You will find that most medical professionals will be talking a foreign language, called, if you will, medicalese (that is a real word, per the Merriam-Webster dictionary). Just ignore those multisyllabic words. If you are really curious about what's going on, just ask. Most professionals will be able to translate what they're doing and planning into simple language.

## LET THE TREATMENTS BEGIN:

If you're sick enough, for example, can't walk independently, you'll likely receive one of two treatments that usually help you improve faster. These are high dose intravenous immune globulin (IVIG) and plasma exchange (PE), a.k.a., plasmapheresis. These are administered via a clear flexible plastic tube, a catheter, with a needle at the end, inserted into a vein, usually an arm vein. Inserting the needle may hurt just a twinge, but once it is in, there's usually no more pain. Your doctors will explain the how and why of these treatments.

**YOUR NEW LIFE AS A PATIENT:** Before you were sick you were likely living a normal life, with family, work, etc. responsibilities. That has now all been disrupted. Your loved one will now be understandably fretting about your welfare, and busy trying to adjust their life to your illness. If you were the breadwinner, they



will likely be making plans to deal with that disruption. If you were parenting, that activity too will have to be taken over by others. Now is your time to be the patient, while family and friends figure out how to make do in your absence. You as the patient will of course be carrying the biggest emotional burden of your illness. But those about you, family, etc. will also be busy, figuring out how to make do with your uncertain but hopeful future.

**THAT BREATHING MACHINE:** About a third of new GBS patients will develop sufficient difficulty breathing so that they have to put on a machine, a ventilator, that temporarily does the breathing for them. To accomplish this, a flexible plastic breathing tube (endotracheal tube) is first inserted through the mouth and down the airway or trachea. Before the tube is inserted medication is given to ease any discomfort. And if the patient is too agitated while on the machine relaxation medication will be given. The goal is to make you comfortable. Being on a breathing machine does carry risks, but is by far much safer than alternative of not being able to breath. While on the machine and if not sedated you will usually be able to hear, see, think and interact with visitors. But with a tube down your airway you will not be able to talk. Blinking may become your only means to communicate. Every effort will be made to get you off the breathing machine as soon as possible through a process called weaning.

Besides treatments to try to shorten the course of your weakness (IVIG or PE), other care will likely be given. If you can't move much, treatments will likely be given to reduce the risk of developing blood clots in leg veins, called deep venous thrombosis. Some type of heparin product, often called a blood thinner, will usually be given as an injection

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under your skin, i.e., subcutaneous. And cuffs may be placed around your legs to squeeze them intermittently, to help prevent blood stagnation. If doctors deem you a significant risk to develop stress ulcers medication will be given to reduce the risk of their development. Famotidine, popularly known by its brand name, Pepcid®, and pantoprazole (Protonix®) are in common use for this purpose.

**LIVING WILL:** A word here about living wills. This can be a really sensitive issue. Why bring it up? For those patients on a respirator, a breathing machine, the future and chances of recovery may seem bleak. This is especially so if you need to be on a ventilator for more than a week or so. Be aware that most patients do have a fairly good recovery. Even if you and your loved ones are fearful, the outlook is good. See for example the internet Vimeo video, 'Kit's Journey' for the story of a tough GBS case with a good outcome. Fortunate living wills are usually written with the caveat that they are only to be invoked if the patient has a terminal illness, without expectation of a meaningful recovery. Wording varies. The outlook for most GBS patients is quite good, even if the future seems bleak while on a ventilator. So invoking a living will for a GBS patient is rarely indicated.

#### **TINGLING, INSECTS AND SUCH:**

Let's address abnormal sensations. Hmm. Just what is this all about? Normal people of course feel, in many ways. We try a new pair of shoes. It may at first feel tight. We touch something too hot. That burn hurts. GBS is notorious for causing a host of feelings, some strange. Even though the outstanding symptom in GBS is weakness the first symptom in some patients is actually pain, of the back and/or thighs. Besides pain, patients often early in their illness, or as they start to recover, may experience various abnormal sensations, what we docs call paresthesias. These can range from numbness to tingling, of the feet, fingers, to pain, to whole body vibrations, to formications, a sense of small insects or worms crawling under the skin. Sometimes these paresthesias are brief; sometimes they are brought on by over exertion and become the patient's signal to rest. Occasionally naive physicians wonder if the patient is using these complaints to seek attention. They are quite real, and can be challenging to treat. If mild, just wait till they resolve. If they are problematic,

there are many treatment options, from a heating pad, to acetaminophen (Tylenol®) to a lidocaine (Lidoderm®) patch, etc. Two popular medications amongst GBS-treating doctors to treat neuropathic pain, pain due to nerve damage, are pregabalin (Lyrica®) and gabapentin (Neurontin®). In high doses these can cloud the mind, making you feel loopy. So the usual recommendation for dosing is 'start low, increase slow'. Your neurologist or family physician can offer guidance on treatment.

Enumerable events will take place during your hospitalization. You may be in the hospital for as little as a week, but often longer, and occasionally much longer. It all depends on how rapidly your strength improves. One major step while in the hospital is planning where you go upon discharge. Typically a discharge planner, social worker, case manager or similar person will review your medical status when your doctors indicate that you are stabilizing. They will review your ability to participate in activities of daily living (ADL) (walking, using your hands, dressing, etc.) and determine what type of post discharge setting may be best. Choices typically may include an in-patient acute rehabilitation hospital, sub-acute rehab, or something else. Patients ready for discharge are usually still too weak to go home.

**THE TRANSITION TO REHAB:** In a rehab setting, often a weeks-long process, a physiatrist will often orchestrate your care. The PT and OT treatments that were likely started in the acute care hospital now come into full operation. You will be kept busy, but with precautions. You don't want to wear out. So you may be exercised until you just start to experience fatigue, then be firmly directed to rest. Pushing yourself during this early recovery period from GBS will only exhaust you, thus requiring a prolonged time period of rest before you have the strength to resume therapy. So it is best to pace activities, and rest before wearing out. In the rehab setting any treatments that were begun during your acute hospital care (e.g., antibiotics for pneumonia, blood thinners, etc.) may be continued as your doctors deem appropriate. During this rehab experience most patients start to see the light at the end of the tunnel. Most slowly regain strength and the ability to use your hands, then stand, then walk. It can be a slow process, over many weeks, even longer. Not all patients gain full return. This is a time to be patient,

and hopeful. During rehab, as strength slowly returns, therapists will be adjusting your exercise program accordingly. For example, they will be looking out for substitution. If some muscles to perform a movement are noted to be weaker than others, customized exercises may be used to help strengthen those weaker ones.

**ALAS, TO HOME:** You may be well enough to be discharged from a full time overnight rehab facility while still weak. Various arrangements can be made to continue your rehab after discharge. For example, a 'day hospital' provides therapy at your rehab site. After breakfast at home you are picked up in your wheelchair and delivered by ambulance to the rehab site for therapy. At the end of the day you get a ride home, to have dinner with the family and sleep in your own bed. This happens daily.

As you approach sufficient improvement, discussions can be held with your employer about returning to work. Newly improving GBS patients usually don't have the stamina to work full time. Not infrequently, a return to employment may start with working a short a time, perhaps an hour a day. Then, week by week, as your endurance improves, the work period can be increased. Sometimes vocational readjustments are warranted. Conferring with your social service person and local, state and private employment agencies can be helpful.

Use our local support groups, or start one: This article covers some highlights of the GBS experience. Talking with fellow GBS patients and families can be worthwhile, to realize others have gone through a similar experience and managed to cope. Local support group chapters of the GBS/CIDP Foundation provide an excellent way to accomplish this. You and your loved ones are encouraged to reach out to the Foundation to locate a group near you or start one.

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#### **ABOUT THE AUTHOR**

Dr. Steinberg joined the Foundation as a founding member as he was recovering from GBS. He authored the Foundation's booklet, Overview for the Layperson, its ER poster and various articles. He currently is a hospital internist, in the Cooper University Hospital's Division of Hospital Medicine in New Jersey.



## What tax strategies can be used for charitable contributions?

**Many people know** they can deduct donations to charity from their income taxes, but increasing your knowledge of tax planning strategies can maximize your giving impact. For example, did you know that year-end is a great time to make consider making charitable donations which may reduce your income tax liability?

Consider the different tax benefits of gifting cash or appreciated assets and which makes more sense for your family. Additionally, the Tax Cuts and Jobs Act of 2017 altered how many donors make their gifts. Consider “bunching” gifts thru Donor Advised Funds to receive immediate tax benefits and establish a pool of assets for annual gifting to all the organizations you like to support.

As always, all these ideas should be discussed with your tax advisor.



## GBS|CIDP partners with Platform Q for Live Educational Program

*Designed for Doctors, Patients & Hospital Employees*

**No matter what** your connection to the GBS|CIDP community may be, the Foundation is working hard to raise awareness and create educational programming that speaks directly to your needs.

In 2018 GBS|CIDP Foundation, in collaboration with Platform Q, produced 3 live online educational programs (NeuroCareLive) to help patients & caregivers, physicians, and medical employees in a hospital setting, to better understand the rare conditions of GBS, CIDP and variants of the condition. Members of the GBS|CIDP Global Medical Advisory Board, along with other specialized physicians, patients, and the Foundation's Executive Director, Lisa Butler, participated as program panelists and answered questions from viewers, in real time!

Learning objectives for patients & caregivers included recognizing the symptoms; understanding all the treatment options available and identifying sources of support for managing issues and complications associated with GBS & CIDP. Physician and Hospital programs focused their learning objectives on recognizing signs and symptoms that may suggest a patient is presenting with

an acute or chronic inflammatory neuropathy; formulating a differential diagnosis for acute-onset CIDP from GBS and/or other similar neurological conditions; recognizing electro diagnostic testing features that are characteristic of immune-mediated demyelinating neuropathies and identifying points of referral for patients with immune-mediated demyelinating neuropathies. CME credits are offered to physicians who complete the following programs:

- Case-Based Approach to the Differential Diagnosis, Treatment, and Long-Term Follow-up of CIDP, found at [www.neuroserieslive.com/CIDPCME](http://www.neuroserieslive.com/CIDPCME)
- Improving the Recognition of GBS and CIDP in the Hospital Setting, found at: [www.neuroserieslive.com/CIDPHospitalAwareness](http://www.neuroserieslive.com/CIDPHospitalAwareness)

A video of the live Patient & Caregiver Educational programming can be found at the Foundation's website at [gbs-cidp.org/neurocarelive-cidp](http://gbs-cidp.org/neurocarelive-cidp).



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## ONE DAY REGIONAL MEETINGS ARE BACK FOR 2019

A little spirit of a chapter meeting & a taste of a symposium – these one day conferences will offer support, education, research updates and opportunities for patient advocacy. Each meeting will bring together local physicians, patients, caregivers and loved ones for a day of sharing, learning and connecting. Registration is \$40, including all sessions, breaks & boxed lunch. (Does not include accommodations). For more information contact Kelly McCoy [kelly.mccoy@gbs-cidp.org](mailto:kelly.mccoy@gbs-cidp.org). Registration will open on January 1, 2019.

### 2019 MEETING SCHEDULE

**Princeton, NJ**  
March 9, 2019

**Colorado Springs, CO**  
April 6, 2019

**Indianapolis, IN**  
September 7, 2019

**Boston, MA**  
October 5, 2019



## Why Walk for GBS|CIDP?

**Have you heard?** Walk and Roll for GBS|CIDP is a great way to raise awareness, show your support, make friends and build a local network. This year, we've taken it one step further. We walked for scientific innovation, a quicker diagnosis and better treatments. We walked for RESEARCH!

### 2018 WALK & ROLL UPDATE

We started the year with a lofty fundraising goal of \$150,000. This would allow us to fund three (3) \$50,000 research grants to investigators who have dedicated their time and talents to studying these conditions.

And so, we are thrilled to announce we have **REACHED OUR GOAL** of \$150,000. Over 2,000 walkers from coast to coast joined us for this very worthy cause. **THANK YOU** to everyone who made each of these possible, especially our dedicated and passionate walk chairs.

In 2019, you will find us still walking, rolling and raising funds for Research. Each walk is one mile closer to overcoming the challenges of living with GBS|CIDP and its variants such as MMN. Invited you friends, family, neighbors, and community to join our mission.

Find a walk near you, or plan one of your own! Contact Walk & Roll manager, Jessica McManus at [jessica.mcmanus@gbs-cidp.org](mailto:jessica.mcmanus@gbs-cidp.org). You can also find more details at [www.gbs-cidpwalk.org](http://www.gbs-cidpwalk.org)

### SCHEDULE – 2019 *(partial listing)*

**Clovis, CA**  
March 9, 2019  
9:00am

**Charleston, SC**  
April 13, 2019  
9:00am

**Washington, DC**  
April 27, 2019  
9:00am

**Twin Cities**  
June 1, 2019  
9:00am

**Pittsburgh, PA**  
September 21, 2019  
9:00am





# Research in CIDP: Are we making progress?

By Jeffrey A. Allen, MD

Member, GBS/CIDP Foundation Global Medical Advisory Board

**CIDP as a named disease entity** is now about 4 decades old. The laboratory data that helps define the disease, nerve conduction studies and in some cases cerebral spinal fluid and nerve biopsy, is even older; and the initial description of what has now come to be known as CIDP was probably first published well over 100 years ago. CIDP evidence based treatments, corticosteroids, IVIG, and plasma exchange, have been known to be effective since the 1980's and 1990's. In 2018 progress of CIDP research can seem... stagnant.



And yet, despite appearances, scientific achievements within the field are unquestionable. Physicians and scientists from around the world have passionately engaged all aspects of the disease from the most fundamental immunologic derangements to better defining the clinical spectrum of CIDP to exploration of new CIDP treatment options. Thus far in 2018 over 140 CIDP papers have been published in peer reviewed medical journals<sup>1</sup>. The publication growth by decade, reflective of intellectual curiosity, has been steadfast. In 1990 a total of 31 papers were published, followed by 84 in 2000, and 107 in 2010. Just in the last several years we have learned that about 10% of those with CIDP harbor one of two autoantibodies called neurofascin 155 or contactin 1. These antibodies target a specific portion of peripheral nerve and may have important treatment implications. We've learned the challenges that are encountered when diagnosing CIDP, and have a better understanding on how to avoid diagnostic pitfalls. From a treatment perspective we have very recently learned that subcutaneous immunoglobulin (SCIG) is safe and effective for CIDP maintenance therapy, but that unfortunately the immunomodulating medication fingolimod does not have a role in CIDP treatment. While certainly not comprehensive of all that has been learned over the last couple years, it is examples like this that offer insight into the progress being made and what direction the field is headed. That direction is one of a greater understanding of what makes one person's CIDP different than the next. What is the underlying immunologic problem, and what does that tell us about the diagnosis, prognosis, and treatment of any individual person.

Around the world there are currently a multitude of studies that are exploring ways to get more out of our current CIDP treatments. These studies include the ProCID and DRIP studies, largely being conducted in Europe, which will help us better understand how IVIg dose and administration frequency influence efficacy. In the Netherlands the ongoing IOC trial will help us understand how often remission occurs in CIDP. The GRIPPER study conducted in the US may shed insight on how CIDP symptoms fluctuate in between IVIg infusions. Each of these studies anticipates conclusion in 2018 or 2019. Collectively they will inform us on how to personalize IVIg treatment: how to get more out of the treatment for those that need it, and how to get patients off treatment if it is no longer needed. Looking farther out, the OPTIC trial conducted in the Netherlands and UK will explore the roll of combining IVIG treatment with corticosteroids. This trial is expected to conclude in 2023.

Equal to better understanding how to improve our current treatment protocols is identification of new treatment options. There are many many ways to suppress or manipulate the immune system. While some of these interventions may achieve the desired result of suppressing the inflammatory attack on nerves affected by CIDP, the risk of aggressive immunosuppression can be substantial and unnecessary. The goal is to maximize efficacy while at the same time minimize risk, with escalation of risk proportional to disease severity and prior treatment history. One line of treatment that has fostered some degree of enthusiasm is that of B cell depletion therapy with rituximab. A randomized controlled trial of rituximab in CIDP is currently underway in Italian centers. US physicians have expressed similar interest in exploring this treatment pathway, and a clinical trial of B cell depletion at US centers is currently in development. While the role of B cell depletion in the treatment of CIDP is presently unknown, the hope is that these trials will help us learn which groups of patients within the broader context of CIDP might benefit from rituximab or similar medications. The hope also is to understand how these interventions can be tailored to individual patients such that unnecessary risks can be avoided.

In 2019, patients with CIDP throughout the world can anticipate initiation of a CIDP study that will be known as INCbase. INCbase will not explore a specific treatment or intervention in CIDP, but rather is a registry designed to learn more about those affected by the disease. One of the challenges of finding treatments in CIDP is the realization that CIDP has many faces, and those faces may be mediated by different immunologic insults. The objective of INCbase is to better understand what defines the faces of CIDP. What symptoms constitute the clinical boundaries of CIDP? What testing is helpful in the diagnosis? Why do some treatments help some people, but not others? How does the pathophysiology of the disease differ from patient to patient? Participants in INCbase will simply be asked a series of standardized questions and have a standardized series of metrics collected, such as grip strength. In some cases blood may be collected

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as well. Participants will be followed on a periodic basis over a couple years. Ultimately this information will be critical in the development of treatment protocols that are specific to any individual patient, at any given stage of their disease.

## Around the world there are currently a multitude of studies that are exploring ways to get more out of our current CIDP treatments.

While many of us, patients and clinicians alike, yearn for an escalated pace of progress in the field of CIDP, the knowledge gathered even within just the last several years is undeniable. We are all in debt to those affected by CIDP that participate in the research that helps advance the field forward. Patients interested in research participation are encouraged to talk to their doctor about programs that might be locally available. Physicians at GBS/CIDP centers of excellence (<https://www.gbs-cidp.org/support/centers-of-excellence/>) can be particularly helpful in this regard. The field is trending toward personalization of therapy, whether that be by getting more out of our currently available interventions or by discovering which patients might be candidates for different treatment options that are both effective and safe. A better understanding of the clinical and laboratory boundaries that define CIDP and how individual patients under the CIDP umbrella differ will add immensely to treatment personalization. We all eagerly await the results of actively enrolling CIDP trials and look forward to initiation of new studies, such as INCbase, identification of new novel antibodies, and clinical trials of B cell depletion therapy. Collectively these studies have the capacity to change the landscape of CIDP management in ways unknown in the not too distant past. We are making progress.

1. Pubmed search of "chronic inflammatory demyelinating polyneuropathy OR CIDP" accessed on 10/5/2018.



## GBS|CIDP FOUNDATION AT NORD'S RARE DISEASES & ORPHAN PRODUCTS BREAKTHROUGH SUMMIT

On October 15 and 16 in Washington, D.C., GBS|CIDP Foundation's Executive Director, Lisa Butler, and the Director of Marketing & Communications, Maureen Neville attended the NORD Rare Summit, with nearly 800 other members of the rare disease community. The summit, the biggest Summit to date was themed "A New Era of Patient-Focused Innovation", was examined from a variety of perspectives throughout the conference. The importance of patient involvement in advocacy, research and progress in rare disease was clear over the course of the conference. GBS|CIDP Foundation exhibited along with other patient advocates, and participated in a panel discussion regarding patient registries. "We all have so much in common, no matter how rare the condition. Staying connected to other leaders of rare disease foundations and organizations is an ideal way to share resources, tips and learn from each other's triumphs, challenges, and yes even the great lessons of mistakes," says Neville.





# GBS|CIDP Foundation Signs 10 Letters to Congress

by Philip Goglas II, Legislative Director, Health and Medicine Counsel of Washington

In 2018 the GBS|CIDP Foundation International signed-on to ten letters to Congress, as representatives of the GBS|CIDP and variant patient community.



## 1. Non-Defense Discretionary spending (NDD) Spending Letter to Congress – NDD UNITED

This letter was to continue to urge Congress to reach a deal that “raises the caps” on nondefense discretionary programs and maintains parity. These programs include public health funding specifically the Department of Health and Human Services and the National Institutes of Health.

## 2. CDC Prevention Fund Sign on Letter – THE TRUST FOR AMERICA'S HEALTH

This letter expressed the disappointment with the \$750 million cut to the Prevention Fund included in the continuing resolution/temporary extenders package passed in December. The letter asks Congress to reject any additional cuts to the Prevention Fund and to replace the CDC funding that was lost.

## 3. Part B Drug Payment Adjustment Letters – PART B ACCESS FOR SENIORS AND PHYSICIANS (ASP) COALITION

These letters were sent to House and Senate Committee leaders asking for intervention this year with a technical correction that ensures the Merit-based Incentive Payment (MIPS) score adjustment is not applied to Part B drug payments. This letter was drafted because of the policy possibly making it more difficult for physicians and other healthcare providers, particularly those in small practices and in rural settings, to administer Part B medications in their communities, creating a dire patient access issue.

## 4. Signatures for PAUSE/HELP Act – AIR 340B

The bills include reforms that many interested parties feel will help improve the 340B program and improve patient access and care.

- A moratorium on new hospitals and child sites being added to the 340B program for 2 years
- Reporting requirements for 340B hospitals, similar to those required of non-hospital 340B grantees
- Additional authority for HRSA and GAO for oversight of 340B hospitals

The 340B program enables covered entities to stretch scarce federal resources as far as possible, reaching more eligible patients and providing more comprehensive services.

## 5. Medicaid Formulary Access – Support Letter – NORD

The coalition letter was addressed to Medicaid Directors across the country emphasizing the importance of preserving patient access to orphan therapies in Medicaid. With many states seeking to make changes to their Medicaid program through Section 1115 waivers, NORD's hope is to begin a dialogue with Medicaid Directors regarding

ways to interact with patient organizations and rare disease experts in order to improve patient access to innovative new medicines.

## 6. FY19 NDAA Letter on CDMRP – DEFENSE HEALTH RESEARCH CONSORTIUM (DHRC)

The Defense Health Research Committee engaged members of the House and Senate Armed Services Committees in anticipation of this year's National Defense Authorization Act once again including potentially bad language for the defense health research programs, or the Congressionally-Directed Medical Research Program (CDMRP) which includes the Peer-Reviewed Medical Research Program (PRMRP). The DHRC circulated a letter that will be sent to all Armed Service Committee members to refrain from including any language that would have a detrimental impact on research at the CDMRP and other medical research conducted by DOD.

## 7. NIH Letter Recommendation – THE AD HOC GROUP

The Ad Hoc Group circulated a letter which recommends \$38.4 billion for the National Institutes of Health (NIH) in FY 2019.

## 8. Impact of short-term limited duration health insurance plans STLDs – THE AMERICAN HEART ASSOCIATION, AMERICAN LUNG ASSOCIATION AND AMERICAN CANCER SOCIETY

The American Heart Association, American Lung Association and American Cancer Society lead a patient-based organization sign on letter to both Congress and the Administration expressing concerns about the impact of the federal rule proposed to expand the availability and duration of short-term limited duration health insurance plans (STLDs) which will lead to higher premiums and fewer choices for patients with chronic health conditions.

## 9. Pennsylvania Medicaid Work Requirements – BURRITO COALITION

The letter expressed deep concern with House Bill 2138 and any proposal that would create new barriers to accessing healthcare by requiring people enrolled in the state's Medicaid program to either prove they work a certain number of hours per week or meet exemptions. If passed, this policy would jeopardize access to care for Pennsylvanians.

## 10. Use of step therapy protocols for Part B drugs in Medicare Advantage (MA) – FEDERAL STEP THERAPY COALITION

The Federal Step Therapy Coalition sent a letter regarding the recent announcement that Medicare will permit the use of step therapy protocols for Part B drugs in Medicare Advantage (MA) plans beginning this coming year.

International Office  
375 East Elm Street  
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Conshohocken, PA 19428

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## ARE YOU A CARE GIVER FOR A PATIENT WITH GBS|CIDP OR A VARIANT OF THE CONDITION?

Stay tuned in 2019 as we rollout our new resource Guide for Care Givers. Interested in participating in a Care Giver Focus Group? Contact Director of Marketing and Communications, Maureen Neville – [Maureen.neville@gbs-cidp.org](mailto:Maureen.neville@gbs-cidp.org).

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**LOOK OUT FOR OUR SPRING ISSUE OF THE COMMUNICATOR WHEN WE REPORT ON:**  
**CIDP Patient, Trent Fielder Completes the Iron Man Challenge in New Orleans**

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### CONTACTS AND RESOURCES FOR ALL STAGES OF LIFE WITH GBS|CIDP & VARIANTS

#### DIAGNOSED WITH MMN?

Dominick Spatafora  
[dominck@dvsconsultants.com](mailto:dominck@dvsconsultants.com)

#### MILLER FISHER VARIANT GROUP

Please call us for contact with others.

#### CHILDREN WITH GBS

Lisa Butler, 610-667-0131  
GBS|CIDP Foundation International  
[lisa.butler@gbs-cidp.org](mailto:lisa.butler@gbs-cidp.org)  
Son, Stuart, had GBS at 5 1/2 years old

#### CHILDREN WITH CIDP

For children diagnosed with CIDP  
contact Holly Cannon whose  
daughter, Hailey, has CIDP.  
[holly.cannon@gbs-cidp.org](mailto:holly.cannon@gbs-cidp.org)

#### LOOKING FOR A 20-SOMETHING CONTACT?

Kyle Van Mouwerik  
[kyle.vanmouwerik@gbs-cidp.org](mailto:kyle.vanmouwerik@gbs-cidp.org)

#### TEENAGERS WITH GBS AND CIDP

For teens ages 12 to 18 with GBS or CIDP  
to connect with one another, share stories,  
and support each other. This group is  
also open to teenage children of patients.  
Contact us to find out how to join!

#### PREGNANT WOMEN WITH GBS

Robin Busch, 203-972-2744  
264 Oenoke Ridge  
New Canaan, CT 06840  
  
Robin has offered to share her  
experience with GBS which came  
about during her pregnancy.

#### ADVOCACY

If you are interested in advocacy  
activities on a federal, state, or local  
level, contact us to sign up!

#### INTERNATIONAL OFFICE

610-667-0131

Be sure to inform us if you have been  
diagnosed with one of the following.  
This will add your name to condition-  
specific communications.

- AMAN
- AMSAN
- Anti-MAG
- Campylobacter
- GBS X2
- Miller Fisher
- MMN