

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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Patient Story

By Wednesday Ketron

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.

At the time, I was a thirty-eight year-old, healthy woman, 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 would be unable 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, determined, 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.



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 Greg was correct.

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 NICU.

I'd lived a fairy-tale life. I'd always dreamed of having three children. When GBS struck, I was a full-time mom with an eleven year-old

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Fall Update

“Old Friends Meeting For the First Time...”

Before we get excited about the joys of fall—beautiful colors of the changing leaves, pumpkins, ripe apples and crisp air—we'd like to share the details of our spring *Walk&Roll* season.

A huge success, with more than 600 patients, caregivers, families, friends, *GBS/CIDP Foundation International* liaisons, points-of-contacts, regional directors, board members, and staff in attendance, together, they raised over \$250,000.

With each walk we are closer to helping to achieve our vision that every person who has been affected by GBS, CIDP, MMN or variants, has convenient access to early and accurate diagnosis, affordable treatments and dependable support services.

These events would not be possible without the enormous support of our Volunteer Chairs and their teams. We cannot thank them enough for their dedication.

Pardon the pun, but, we are on a roll in 2016!

Spring meetings in Dallas, TX, Trinidad and Tobago, Knoxville, TN, Newburgh and Long Island, NY, Los Angeles, CA, and Basking Ridge, NJ raised almost \$60,000! Please consider joining us in...

Boston, MA ~ October 1

Indianapolis, IN ~ October 8

Washington, DC ~ October 8

Houston, TX ~ October 22

Del Ray, FL ~ October 29

Fort Myers, FL ~ November 19

You still have time to organize a *Walk&Roll* of your own! Please contact Jessica McManus, Jessica.mcmanus@gbs-cidp.org or call 610-667-0131 if YOU would like to host an event in 2016 or 2017.

Calling all teenagers...

Being a teenager is hard enough, believe us, we've all been there. Being a teenage who also deals with GBS, CIDP or variants, makes that special time of life even more difficult.

We are here to help. Our "Just for Teens" outreach has been designed especially for patients in their teens and for young adults.

If you are a teen looking for support, contact us today.

info@gbs-cidp.org



Disclaimer Information Questions presented in *The Communicator* are intended for general educational purposes only and should not be construed as advising on diagnosis or treatment of Guillain-Barré syndrome or any other medical condition.

Privacy Policy In response to many queries: Intrusive practices are not used by GBS/CIDP Foundation International. The organization does NOT sell its mailing list nor does it make available telephone numbers! The liaisons are listed in the chapter directory with their permission. We are proud that none of our members has ever been solicited or sent materials other than those concerning GBS, CIDP, and related syndromes such as MMN. We respect your privacy.

Dear Friends,

As concern about the Zika virus and its link to Guillain-Barré syndrome mounts, *GBS/CIDP Foundation International* has been contacted by the White House and some of the most prominent news media nationwide—all searching for answers that few of us have.

What that tells us is that our reputation, as “THE” go-to organization for Guillain-Barré syndrome, CIDP and variants exceeds expectation. What a pleasure it is to know that we’ve earned the respect of patients, caregivers, families, and the medical community to become a trusted source for research, information, love and care.

In this issue of *The Communicator*, you will find an update about Zika, and several patient stories that will inspire you regardless of where you are on your journey.

As the holiday season approaches, I encourage you to stay positive and, difficult as it may seem, to be thankful for the opportunity to walk this journey. Please know that we are here to support you in whatever way possible... you are not alone!

My best,
Lisa Butler
Executive Director



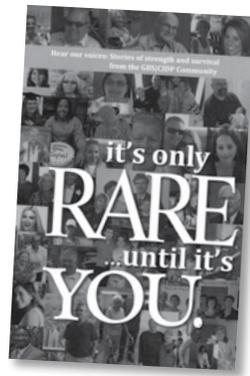
As the holiday season approaches, I encourage you to stay positive and, difficult as it may seem, to be thankful for the opportunity to walk this journey.

Looking for some interesting reading?

You will find a list of the most informative books on Guillain-Barré syndrome, CIDP, and variants in our website “library,” including an exclusive book recently published by the *Foundation*, *It's Only Rare, until it's You*.

It's Only Rare, until it's You, is a fascinating collection of real patient survivor stories guaranteed to lift you up in your journey as you discover how others survived the trauma and lived to tell about it.

It's Only Rare until it's You is only available for purchase through the *Foundation*. Call 610-667-0131 to order your copy today! **An excellent holiday gift. \$15**



Did you know... Guillain-Barré is celebrating its **100th birthday** this year?

That’s correct. One hundred years ago, in 1916, Drs. George Guillain and Jean Alexander Barré identified the condition in France during World War I.

Some folks have commented that “Guillain-Barré syndrome seems like something no one would like to “celebrate.” *GBS/CIDP Foundation International* chooses to think otherwise recognizing the great strides that have been made in diagnosing and treating the life-altering effects of the condition. Without these discoveries, you would not have access to the support, research, education and advocacy available to you today.



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Since the outbreak of the Zika virus in South America last year...

...there has been an enormous amount of information about the neurological complications associated with Zika infection which has been disseminated to the public by media outlets, research publications, recommendations from the *Centers for Disease Control (CDC)* and *National Institutes of Health (NIH,)* web postings and press releases from various organizations, including the *GBS/CIDP Foundation International*.

We would like to place this information in proper context and clarify the current understanding of the relationship between Zika virus and GBS.

The Zika virus was first discovered in a Rhesus monkey in Uganda in 1947. The first human infection was reported in 1954 in Nigeria, and during the subsequent 60 years there have been only a handful of human cases reported; there was little attention paid to the virus because human infection was so rare and symptoms were mild and resolved without complications. During this time, the virus spread eastward to other countries in Africa and Southeast Asia, with the first major outbreak in 2007 in the Yap State of the Federated States of Micronesia (an island in the South Pacific.) There were approximately 900 cases reported, but only 19% had clinical symptoms of the infection (discussed below.) There were no neurological complications reported.

It is the potential catastrophic neurological complications that follow Zika infection that have made international headlines.

The next Zika outbreak occurred in French Polynesia in 2013, followed by smaller outbreaks in other South Pacific islands. It was during the French Polynesia outbreak that a relationship between Zika infection and GBS was first reported. In 2015, the Zika virus was detected in Brazil, and since then the virus has spread rapidly through South and Central America, Mexico, and many islands of the Caribbean, reaching epidemic proportions, most recently in Puerto Rico. The virus has spread north to the continental United States, and as of August, 2016, there have been 29 mosquito-transmitted infections, thus far limited to the state of Florida.

Zika virus is transmitted most commonly by the bite of the *Aedes Aegypti* mosquito. This mosquito is very common throughout South and Central America, the Caribbean, and the lower half of the continental United States, and explains the spread of the virus north from the southern hemisphere. Currently, 70 countries have reported Zika virus infection. This mosquito primarily feeds on humans, bites during

the day and night, may bite multiple people during a single meal, where the bite is often imperceptible. The mosquito reproduces in free standing water, and may lay eggs in



as little as a bottle cap of water. This, in part, explains the rapid rise in Zika infection in countries of South and Central America, where free standing water is common, combined with densely populated areas without access to screens and air conditioning (which reduce mosquito transmission.) Once an infected mosquito transmits the virus to a person, a subsequent bite of that person from another, non-infected mosquito, can infect that mosquito, which then spreads the virus with further mosquito bites to other people. This explains how people within the same family or neighborhood can become infected quickly. Lastly, there are many “travel-related” cases. These are individuals who have traveled to regions where the virus is common (so called endemic areas,) who became infected, returned to the United States, and then developed symptoms of the infection (where non-infected mosquitoes also may bite them and spread the virus.) As of this report, there have been 2,487 travel-related cases in the United States, and 8,968 in US territories (mostly in Puerto Rico.)

The virus also may be spread from a pregnant woman to the fetus and by sexual transmission, and there have been single reports of the virus spread through platelet transfusion. During the French Polynesia epidemic, 3% of donated blood screened positive for the virus, and all US blood banks are required to screen for the virus.

The symptoms of Zika virus infection can be similar to other viral infections like the flu. Symptoms are acute in onset but generally mild, and include fever, joint and muscle aches and pains, rash, malaise (an ill feeling,) headache, and conjunctivitis (pinkeye.) The symptoms resolve uneventfully, usually within a few days to a week. The diagnosis is established by blood testing that detects viral RNA or acute antibodies directed against the virus. There is no specific anti-viral treatment. Symptoms are usually managed with rest, increased fluid intake, and acetaminophen or other over the counter analgesics to treat fever and pain. Only 20% of infected individuals have symptoms of acute viral infection. The remainder do not know they have been infected, which has particular importance to women who are pregnant or actively planning to become pregnant, as they can unknowingly spread the virus to their unborn child.

It is the potential catastrophic neurological complications that follow Zika infection that have made international headlines. It is now well-established that the virus has

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Since the outbreak of the Zika virus in South America last year...

a particular attraction to nerve cells in the brain of the developing fetus and to peripheral nerves in adults; it is therefore considered a “neurotropic” virus. There are severe neurological complications that can occur to the developing fetus following exposure to the virus.

As of August, 2016, an increased incidence of GBS or laboratory confirmation of GBS following Zika infection has been reported in 16 countries. There have been only 7 cases of GBS in the continental US, and 26 cases in US territories.

What does this mean for you? First, although the risk of developing GBS after Zika infection is higher than the background rate in the general population, the risk is still very low: approximately 1 in 4000 (at least in the French Polynesian population,) and perhaps even lower if the rate is closer to what has been reported in Brazil and Columbia. Second, GBS has not been linked to asymptomatic Zika virus infection, which represents 80% of all infections. Third, in contrast to densely populated regions in South and Central America, public health experts believe the risk of Zika infection reaching epidemic proportions in the continental United States is low, as it is more likely that there will be small, isolated outbreaks, and thus the chance of developing GBS is even further reduced. Fourth, there have been no reports of Zika-related GBS in patients who have had GBS in the past (or CIDP and other immune neuropathies,) or Zika infection worsening residual neuropathic symptoms in patients who have had GBS. Finally, there currently are no

published data regarding treatment response or prognosis in patients with Zika-related GBS, but there is no reason to believe that response to therapy and recovery should be substantially different from non-Zika related cases.

There are several measures that reduce the risk of Zika infection by mosquito transmission. The *CDC* has recommended routine application of mosquito repellent (containing *DEET* or other effective agents,) wearing long-sleeve shirts and pants, removing items around the home that may hold water and serve as a breeding ground for mosquitoes, using screens on windows and doors, and air conditioning when available. Pregnant women, or those planning to become pregnant, should follow recommendations from the *CDC* website to further reduce their risk of exposure.

Vaccine development against the Zika virus is underway and looks promising, but due to lack of funding from Congress, this critical research may be delayed or even halted. In addition, despite specific recommendations from the *World Health Organization*, there are no formal surveillance and monitoring systems in place to ascertain the nature and frequency of Zika-related GBS in the United States. We strongly suggest that you contact your congressmen to encourage him or her to urgently allocate appropriate funding for these activities.

For additional information, please contact Lisa Butler, Executive Director, 610-667-0131, lisa.butler@gsb-cidp.org

Courtesy of: Kenneth Gorson, MD, Professor of Neurology, *Tufts University School of Medicine*, Boston, MA, USA. Chairman, Medical Advisory Board, *GBS/CIDP Foundation International*
Bart C. Jacobs, MD, Department of Neurology and Immunology, *Erasmus Medical Center, University Medical Center*, Rotterdam, Netherlands. Vice-Chairman, Global Medical Advisory Board, *GBS/CIDP Foundation International*

With every dollar we are able to allocate to research, we are one step closer!

This year, we are pleased to announce the Estelle Benson Volunteer Award for Research has been awarded to Bart C. Jacobs, MD.

We are privileged to be the recipient of Bart Jacobs’ brilliance. His endless curiosity about “*what is GBS, CIDP and variants,*” has led to amazing research projects. Bart’s focus is on the epidemiology, pathogenesis and treatment of immune-mediated neuropathies, especially Guillain-Barré syndrome.

Bart has spearheaded the *International GBS Outcome Study (IGOS)*, which has more than 1,000 patients enrolled, worldwide. He is an associate-professor of Neurology and Immunology at *Erasmus University Medical Center*, Netherlands.

We are honored to have Bart so committed to our *GBS/CIDP Foundation International* family.

It is only through the generosity of our sponsors that we are able to present this award, and awards to other individuals dedicated to our mission pillars of support, education, research, and advocacy.

Thank you, and please recognize that...

This is your gift in action!



GBS|CIDP Board Member, Matthew LaRocco, instrumental in the Department of Defense Peer-Review Medical Research Program adding Guillain-Barré syndrome to the list of Eligible Conditions



Voted on to the *GBS|CIDP Foundation International* Board of Directors as advocate liaison in June, 2016, Matthew LaRocco, played a big role advocating for the *DOD* to make this decision.

We are grateful for his work to influence the US Senate to name Guillain-Barré syndrome as an eligible condition on the *Department of Defense* peer-review medical research panel. The addition allows researchers access to the more than three billion dollars set aside for the program.

The *Peer Reviewed Medical Research Program*, established in 1999, has supported research across the full range of science and medicine, with an underlying goal of enhancing the health and well-being of military service members, veterans, retirees, and their family members.

Matthew, who reached out to us in 2011 after a severe bout with Guillain-Barré syndrome, immediately rallied to become a liaison and also Chair of our Advocacy Committee! In his brief time with us, the *Foundation* has already benefited from Matt's 20-year career in government and public affairs, representing Fortune 500 and international companies on complex issues before the US Congress, executive branch and other key decision makers on behalf of his clients.

Matthew is founder of the public affairs firm Washington, DC-based, *Columbia Strategic Counsel*.

Thank you, Matt!

November is National Family Caregivers Month

Take Care to Give Care!

The first rule of taking care of others: *take care of yourself first!* Caregiving can be a rewarding experience, but it is also physically and emotionally demanding. The stress of dealing with caregiving responsibilities leads to a higher risk of health issues among the nation's 90 million family caregivers. So as a family caregiver, remember to pay attention to your own physical and mental wellness, and get proper rest and nutrition. Only by taking care of yourself can you be strong enough to take care of your loved one. You really do need to *"take care to give care!"*

- **Caregiving can be a stressful job.** Most family caregivers say they feel stressed providing care for a loved one. With all of their caregiving responsibilities—from managing medications to arranging doctor appointments to planning meals—caregivers too often put themselves last.
- **The stress of caregiving impacts your own health.** One out of five caregivers admit they have sacrificed their own physical health while caring for a loved one. Due to stress, family caregivers have a disproportionate number of health and emotional problems. They are twice as likely to suffer depression and are at increased risk for many other chronic conditions.
- **Proper nutrition helps promote good health.** Ensuring that you are getting proper nutrition is key to helping maintain your strength, energy, and stamina, as well as strengthening your immune system. Maintaining a healthy diet is one of the most powerful things you can do to take care of yourself and keep a positive attitude overall.
- **Ensuring good nutrition for your loved one helps make care easier.** As many as half of all older adults are at risk for malnutrition. Good nutrition can help maintain muscle health, support recovery, and reduce risk for re-hospitalization—which may help make your care of a loved one easier.
- **Remember: "Rest. Recharge. Respite."** People think of respite as a luxury, but considering caregivers' higher risk for health issues from chronic stress, those risks can be a lot costlier than some time away to recharge. The chance to take a breather—the opportunity to re-energize—is vital in order for you to be as good a caregiver tomorrow as you were today.

During **National Family Caregivers Month**, we remind family caregivers that to be strong enough to care for your loved one, you must **Take Care to Give Care!**

For more information, visit caregiveraction.org

The Importance of Being Earnest

Earnest: a considerable or impressive degree or amount—*Merriam-Webster*

GBS|CIDP Foundation International announced it has earned a flawless score of 100 from *Charity Navigator* for Financial Health, and Accountability and Transparency.

Charities with these distinctions execute their missions in a fiscally responsible way while adhering to good governance and other best practices that minimize the chance of unethical activities. These two 100 ratings translate to a perfect record which is earned by less than 1% of the thousands of charities evaluated by *Charity Navigator*.

Since the award was given, the *Foundation* has received several significant gifts. In talking with these most generous supporters, we learned that the *Charity Navigator* designation was an important factor in their decision as to which of the thousands of charities available to them to support. Camille Yee, *Foundation* CFO for more than 24 years, stated, *“this designation is an encouragement to me as I strive to be the best steward of Foundation funds as possible. The mission to support patients is our foremost responsibility. Without sound fiscal management the GBS|CIDP Foundation International would be unable to do so.”*



Camille Yee, CFO

Here's are a few examples:

Anne Laver, Aiken, SC, wrote: *“Here is a photo of the group at Wellington, celebrating Big Red's win. A great celebration for an outstanding nonprofit. It was Boyd, along with these folks, who chose GBS|CIDP Foundation International as the recipient of the \$10,000.”* Regards, Anne

Pat Reese, wife of Dale Reese Foundation founder, Dale Reese, Blue Ball, PA, called to say, *“I choose ten charities a year to disperse funds in honor of my husband, Dale. When searching which local charities to support, I choose only those with outstanding ratings on Charity Navigator. Congratulations, on your well-deserved award.”*

Ronald and Christine Sobchick, Fullerton, CA, recently donated \$10,000. The Sobchick's daughter, Laura, was diagnosed 36 years ago with GBS. They wrote, *“GBS|CIDP Foundation International has done amazing research. We would like to continue this mission. Laura recently married and we have given this gift in honor of her.”*

Ron and Christine, we are honored to share in this joyous occasion with you and your family. Thank you for your gift.



Big Red's Win



CHARITY NAVIGATOR
Your Guide To Intelligent Giving

For more information about our score on *Charity Navigator*, visit charitynavigator.org/index.cfm?bay=search.summary&orgid=10284

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Patient Story

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 would spend the next thirty-three days in the hospital—days I will remember 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; then 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 time 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 most thankful for my devoted husband, Greg—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 and feel blessed to have been given the opportunity.

Patient Update

On the cover of our Spring, *The Communicator*, we introduced you to 26 year-old Sean Young. Sean was diagnosed with GBS in late October, 2015. We wanted to share with you, a letter sent to *GBS/CIDP Foundation International* Medical Advisory Board Member, Dr. Richard A. Lewis, Los Angeles, CA, from Sean's grandmother, Michelle Silva:

Dr. Lewis,

Several months ago you were kind enough to consult with Sean's neurologist, Dr. Blondell Gage, in Modesto, California, about Sean's case. He had a very severe bout of GBS and ultimately remained in intensive care for nine months with complete paralysis from the neck down—and on a ventilator.

Because you were so gracious and kind to reach out to our family, and Sean's doctors, I felt it was only courteous that we provide you an update on Sean.

In mid-June (2016,) Sean began to experience buzzing sensations throughout his upper body. It was frightening for him, but Dr. Gage felt it could be a signal that his nervous system was reawakening. By late-June, Sean was experiencing small amounts of movement in his shoulders, arms and fingers. By early-July, he was using a Passy Muir valve to speak through his trach, and gaining increased movement, every day, in his upper body. By mid-July, Sean was transferred from Kaiser's ICU, in Modesto, to Santa Clara Medical Center's acute rehab.

Miraculously, I can tell you that today, Sean is completely off the vent and feeding tube and eating like a horse! He is using his arms and hands quite well and gaining strength daily. He has graduated from his power chair to a manual, rigid, wheelchair—and, most importantly—he is home!

In August, Sean began outpatient therapy to strengthen both his upper and lower body and was released from Santa Clara Medical Center. His progress has been stunning to say the least! Doctors and therapists are completely in awe of his rapid progress. His new nickname is "Rocketman"!!!

Sean, and our entire family, want to thank you so very sincerely for your willingness to reach out to us and help. It is difficult to express the comfort that your wise counsel gave all of us.

I remember when you were asked if Sean would recover from this after so many months of paralysis. You responded, "that it was very possible that he would." It gave us such great hope. That HOPE saw Sean—and all of us—through some very dark days!

We wish you all the best in your esteemed career of helping people with neurological disorders and diseases, and we promise to update you on Sean's continued journey of recovery."

*With sincerest gratitude,
Michelle Silva*

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CHANGE SERVICE REQUESTED

INTRODUCING

2017 One-Day Regional Conferences

These, one-day, regional, chapter meeting/mini-symposium will bring local physicians, patients, families and caregivers together in three convenient locations:

FORT LAUDERDALE, FL
Saturday, March 4, 2017

BALTIMORE, MD
Saturday, May 6, 2017

CHICAGO, IL
Saturday, September 23, 2017

Please visit gbs-cidp.org to see photos from our 14th biennial Symposium 2016 in San Antonio, TX

SAVE THE DATE!

Join us in San Diego for our 15th biennial Symposium, November 1-3, 2018

Directory

Check the enclosed chapter directory and contact the chapter nearest you. In addition, our "Subgroups" are listed below.

Diagnosed with MMN?

Contact: Dominick Spatafora
dominck@dvsconsultants.com

Miller Fisher Variant Group

Please call the National Office for contact with others.

Children with GBS

Lisa Butler, 610-667-0131
GBS/CIDP Foundation International
Email: 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

Looking for a 20-Something Contact?

Contact: Kyle Van Mouwerik
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 the office to find out how to join!

National Office: 610-667-0131

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 the *Foundation* office to sign up!

Be sure to inform the International Office 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