



GBS|CIDP
Foundation International

The Communicator

Providing Strength Through Support

Working for a future when no one with Guillain-Barré syndrome (GBS), chronic Inflammatory demyelinating polyneuropathy (CIDP) or related syndromes and variants suffers alone and when everyone has access to the right diagnosis and the right treatment, right away.

In This Issue

Page

- 2** Meet **Dr. Ruth Huizinga**, the first recipient of the Benson Fellowship research grant!
- 9** **CA Congressman John Garamendi** makes Congressional Address
- 10** 2014 Volunteer Highlights!
- 12** Become a member of the newly formed **GBS|CIDP Foundation Pillar Society!**
- 13** **"Why I Give"** Featuring Foundation Board Member, Santo Garcia
- 14** Symposium Spectacular!

Patient Story

By Kristen Weaver

Pittsburgh Walk and Roll Chair, Point of Contact

The summer before I turned fourteen was one of literal ups and downs. My knees and elbows were scraped and bruised from several falls. The signs that something was wrong were increasing day-by-day. I was dropping things and having difficulty opening bottles. When the scariest moment came, falling off my bike and being unable to stand up, my mother immediately called my pediatrician.

Thankfully, my pediatrician recognized the seriousness of my symptoms and referred me to a pediatric neurologist. Days later, I was getting ready to see Dr. Rajiv Varma, but my condition had deteriorated dramatically. My mom had to help me get dressed because I was unable to lift my arms above my head, and earlier that day I had fallen down the stairs. After a lengthy evaluation and many questions, Dr. Varma diagnosed me with Guillain-Barré Syndrome. From there, I was taken by my parents to the emergency room at Children's Hospital.

I became weaker as my stress level escalated. I spent about six agonizing hours in the emergency room, being seen by every neurologist, student, resident, fellow, and nurse. For a fourteen-year-old girl the last thing I wanted was to be different. I finally had a spinal tap which confirmed my diagnosis and a couple of days later I had an EMG and nerve conduction test. During my five-day hospital stay I



received several rounds of IVIG and showed immediate improvement. My life, however, would never be the same.

I continued to have relapses every eight weeks, which changed my original diagnosis to CIDP. In time I became aware of the signs of a relapse such as difficulty gripping a pen, feeling sensitivity in my fingertips, and the prevailing foot drop, before they were observable to anyone else. I finally came to terms with my condition after meeting other people who could relate to me at my first symposium. I was determined to live a healthy life and become more in touch with the connection between my body and mind.

With the practicing of Iyengar Yoga, a healthy diet and the support of my loving husband and parents I have not had a relapse in close to five years. I am an Early Intervention Special Education Teacher and the Chair for the Pittsburgh Walk and Roll. Every day I awake with my condition and live the fullest life possible.

Holiday Greetings!

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The 2014 Benson Clinical Research Fellowship Award

By Ruth Huizinga

It is a real privilege and honor to be the first Benson Clinical Research Fellow! I would like to take the opportunity to thank you all for this great initiative. The fellowship really comes at a crucial point in my academic career and allows me to continue with my

research on inflammatory neuropathies by establishing a small research group.

So with great pleasure, I would like to introduce myself in this newsletter. My career started at the Vrije Universiteit in Amsterdam, the Netherlands, completing a Master of Science in Medical biology. I became interested in neuroimmunology during my first laboratory internship, when I investigated how leukocytes infiltrate the brain in patients with multiple sclerosis.

I continued working on multiple sclerosis during my PhD-research at a research institute in Rijswijk, the Netherlands, focusing on anti-neuronal autoimmunity. After obtaining my PhD, I started to work on the pathogenesis of the Guillain-Barré syndrome in the group of Dr. Bart Jacobs at the Erasmus MC in Rotterdam, the Netherlands. The Erasmus MC has a rich history on research into inflammatory neuropathies and hosts a multidisciplinary research team working on many aspects of GBS and CIDP.

My research aims at understanding how preceding infections, like *Campylobacter jejuni*, cause the development of anti-neuronal antibodies. The finding that *Campylobacter jejuni* induces a strong innate immune activation in some persons, but not others, forms the basis of the project proposal for the Benson Fellowship. In order to understand more basic mechanisms of disease, I have been working in the lab of Prof. Hugh Willison in Glasgow, UK for seven months.

My other activities include teaching medical students about immunology and I coordinate the Immunology-day for the so-called "Weekendschool" in Rotterdam. This organization aims to increase the future perspectives of children that live in deprived neighborhoods. We teach immunology and show them the possibilities for working at a university medical center.

On a more personal note, I live in The Hague with my husband, and in our spare time we like to go sailing. Also, I have a small garden in which I grow some vegetables and flowers.

Finally, I would like to thank everyone who attended the meeting at Coronado Springs Disney Resort for showing such a great interest in my research project. I am looking forward to meeting you (again) at future meetings and showing you the results of the research funded through the Benson Fellowship!

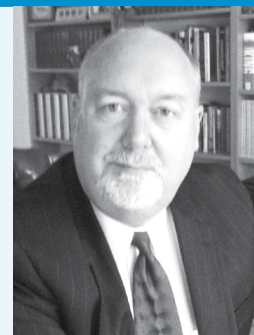
Disclaimer Information Questions presented in the GBS/CIDP Newsletter are intended for general educational purposes only, and should not be construed as advising on diagnosis or treatment of Guillain-Barré Syndrome or any other medical condition.

Privacy Policy In response to many queries: Intrusive practices are not used by the GBS/CIDP Foundation International. It 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 and variants. We respect your privacy.

Dear Friends,

As the holiday season approaches, we take time to reflect on the past year while preparing for the new year, to give thanks for our many blessings and to wish the Foundation community best wishes for a happy holiday and a healthy new year!

As we near the close of 2014, I want to take this opportunity to highlight a few of our many initiatives, all supporting our mission pillars of: support, education, research and advocacy.



- We re-launched the GBS|CIDP Foundation website. This new format allows more convenient and user-friendly access to all of our information, including more patient stories, medical information, current news, current events, videos and links to additional sites and information.
- This summer we produced five videos highlighting: adult GBS, pediatric GBS, CIDP, MMN and our Centers of Excellence! Visit the website to view all five!
- In May, we hosted our largest group ever on Capitol Hill. With this group, we conducted nineteen Congressional visits and hosted a congressional briefing, to help raise awareness and request support to improve research, access, and patient care.
- Many of you joined us for our largest ever symposium in Orlando (see pages 14-15 for highlights)!
- At the symposium we awarded the first Benson Fellowship grant to Dr. Ruth Huizinga (see page 2). This marks the Foundation's most significant commitment to funding research!
- This year, our dedicated Liaisons held over 50 chapter meetings providing support and education in local areas. This represents a 20% increase in meetings from 2013!
- Our presence on social media had increased by doubling our followers which increased our daily engagement to over 575.
- Our Walk & Roll program continues to gain momentum. We hosted three Walks in 2013, seven in 2014, and plan for over ten in 2015.

*These initiatives demonstrate
our continued commitment
to deliver you the best support,
education, research and
advocacy possible!*

These initiatives demonstrate our continued commitment to deliver you the best support, education, research and advocacy possible! None would be possible without your generous support which continues to drive all that we do. We gratefully recognize your donations, both of your time and resources. On behalf of our Board of Directors and our team in Narberth, we give you thanks and offer our best wishes to you and your families!

Happy Holidays!

Ken Singleton

Executive Director



CONTACT US
International Office
The Holly Building
104½ Forrest Avenue
Narberth, PA 19072

1.866.224.3301
1.610.667.0131
Fax: 1.610.667.7036
www.gbs-cidp.org
email: info@gbs-cidp.org

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Eculizumab Enters a Clinical Trial in Guillain-Barré Syndrome (GBS)

Kazim A. Sheikh, MD

Department of Neurology, University of Texas Medical School at Houston, Houston, Texas

Member of the GBS/CIDP Medical Advisory Board



Newer immunomodulatory and/or neuroprotective treatments limiting inflammation and associated nerve injury during the acute phase of GBS are extremely desirable. This is because despite two beneficial treatments, i.e., plasmapheresis and intravenous immunoglobulin (IVIg,) GBS remains a major public health burden. A significant proportion of patients require mechanical ventilation during acute phase of the disease and 20-30% are left with severe and permanent neurologic sequelae, including 10-15% who cannot walk unaided. Peripheral nerve experts believe that limiting inflammation during the acute phase of the disease can decrease the amount of nerve injury and neurologic sequelae.

It is exciting that a new treatment, i.e., eculizumab is entering a Phase II clinical trial for the treatment of GBS as over the last 20 years no new treatments have entered in the clinical arena of GBS. Eculizumab is a humanized monoclonal antibody that inhibits complement activation (C5 convertase activity). Eculizumab is already in clinical use and approved by the United States Food and Drug Administration (FDA) for the treatment of paroxysmal nocturnal haemoglobinuria.

This advance stems from experimental and translational studies over the last 10-15 years examining the pathogenic mechanisms involved in nerve injury during acute phase of GBS. The mechanisms underlying autoantibody-mediated pathogenic effects on peripheral nerves in GBS are particularly relevant for this development. Cumulatively, clinical and experimental studies strongly suggest that both the adaptive immune system (autoantibodies against glycans/gangliosides) and the innate immune system (complement system and Fc gamma receptors (FcγRs)), participate in the autoantibody-mediated inflammatory injury to nerve fibers. Therefore, therapeutic strategies, which are aimed to reduce the level of pathogenic anti-glycan autoantibodies, and to prevent the detrimental innate immune effectors including activation of the complement system and FcγR-mediated inflammation, offer promise to limit nerve injury in GBS.

The pathogenic role of complement system has been an active and fruitful area of research in GBS. The term complement system represents a series of serum proteins that, once activated by adaptive immune system,

produce inflammation by attracting macrophages (inflammatory cells), and enhance phagocytosis of antigens by opsonization (nerve cell injury). Complement can be activated by three possible pathways; the so-called classical pathway is especially relevant to nerve injury because it is activated by complexes of antibodies and antigens. Complement activation converges in a terminal trail that starts with activation of C5 and subsequent formation of the membrane attack complex (MAC, C5b-9).

Specific activation products of complement (C3a and C5a are known to be anaphylatoxins) attract phagocytic cells. The MAC, consisting of C5b, C6, C7, C8 and C9b forms a pore to the cell membrane, which results in osmotic lysis of the target cells.

In GBS, pathological data implicate the role of activated complement in mediating injury to nerve structures (myelin, Schwann cells, and axons). Increased levels of specific complement components/fragments (C3a, C5a and C5b-9) in serum and cerebrospinal fluid of GBS patients indicate a widespread activation of the complement cascade during the acute phase of GBS. Complement involvement in experimental nerve injury in preclinical models of GBS. For example, in experimental allergic neuritis (EAN), a widely used animal model for demyelinating GBS, complement is activated and prevention of complement activation ameliorates the nerve injury and disease course in this model. Complement is involved in experimental models of autoantibody-mediated nerve injury is demonstrated by a series of studies from Dr. Hugh Willison's group in Glasgow. Their group has shown that complement inhibition at different levels along complement cascade minimizes nerve injury in experimental models. In an important study, this group showed that Eculizumab prevents nerve injury in an animal model of antibody-mediated neuropathy. Overall, clinical and experimental data implicate complement activation in the pathogenesis of GBS and suggest that the blockade of complement activation by eculizumab, an FDA approved drug is a viable strategy to minimize nerve injury in this disorder.

Based on these clinical and preclinical observations, Dr. Hugh Willison's group is conducting a single site/center Phase II trial in patients with GBS. This trial of

continued on page 13

Eculizumab is one of the new and emerging treatments that offer promise to optimize therapy for GBS patients

United States
of America

Congressional Record

PROCEEDINGS AND DEBATES OF THE 113th CONGRESS, SECOND SESSION

House of Representatives

PERIPHERAL AUTOIMMUNE NEUROPATHIES AWARENESS

HONORABLE JOHN GARAMENDI

OF CALIFORNIA

IN THE UNITED STATES HOUSE OF REPRESENTATIVE

Mr. Speaker, I rise today to call attention to rare and serious autoimmune neuropathies such as Guillain-Barré syndrome (GBS), Chronic Inflammatory Demyelinating Polyneuropathy (CIDP), Multifocal Motor Neuropathy (MMN), and related conditions. These diseases cause the body's immune system to attack healthy organs and tissues. In the case of conditions like GBS, CIDP, and MMN, the immune system attacks the body's peripheral nervous system.

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. These conditions can be progressive, and any delays in medical intervention can result in the patient being completely immobilized and using a ventilator to breathe, with the potential for residual damage and disability. Essentially, the more damage that is done to the nervous system, the longer it takes to heal.

According to the National Institutes of Health (NIH), symptoms are related to the type of affected nerve and may be seen over a period of days, weeks, or years. Muscle weakness is the most common symptom of motor nerve damage. Other symptoms may include painful cramps and uncontrolled muscle twitching visible under the skin, muscle loss, bone degeneration, and changes in the skin, hair, and nails. NIH plays a crucial role in the effort to combat these conditions, as treatment options are limited and diagnosis can be difficult. While there are many known triggers for the conditions, the underlying causes have yet to be defined. Investment in medical research and scientific innovation is needed to identify the root cause of these conditions and to improve the lives of affected individuals.

This October, the GBS/CIDP Foundation International is coordinating the 13th International Symposium on GBS, CIDP, MMN, and related conditions. This event will bring leading scientific minds, patients, and other stakeholders together with the goal of advancing our understanding of these conditions and improving care for affected individuals. I urge my colleagues to join me in supporting this community's ongoing effort to raise awareness and advance medical research. We extend our sincerest gratitude and strong support as these dedicated individuals come together to collectively reach toward knowledge, cures, and the promise of healthier lives for all.

Thank you to Our Foundation Ambassadors

The Foundation gratefully acknowledges our Liaisons who held Chapter meetings in 2014!

Hannah Blanton ~ Charlotte, NC
 Jim Crone ~ Peoria, IL
 Harriette Lion ~ Boynton Beach, FL
 Ginger Crooks ~ St. Louis, MO
 Everett Nichols ~ Raleigh, NC
 Bruce Throckmorton ~ Phoenix, AZ
 Rick Forney ~ Salem, VA
 Bill Ansley ~ Columbus, OH
 Debbie Plimmer ~ Dallas, TX
 Jim Yadlon ~ Hamilton Square, NJ
 Steve Smith ~ Newburgh, NY
 Jon Toumey ~ Indianapolis, IN
 Yvonne Bishop ~ Kansas City, MO
 JoAnn Wettlaufer ~ Spanish Fort, AL
 Charlean Eggert ~ Elmhurst, IL
 Judi Jetson ~ Ashville, NC
 Aaron Clarke ~ St. Paul, MN
 Sibylle DeRosa ~ New Windsor, CT
 Noreen Reagan ~ Webster, NY
 Joan Armstrong ~ Manlius, NY
 Sheri Demple ~ Salt Lake City, UT
 Lizz Russell ~ San Diego, CA
 Tamara Foxen ~ Lafayette, LA
 Magee McKenna ~ Cleveland, OH
 Gina Sharpley ~ Egg Harbor, NJ
 Marilyn Macurak ~ Conway, SC
 John Schilke ~ Portland, OR
 Russell Walter ~ San Francisco, CA
 Bill Robbins ~ Atlanta, GA
 Vanessa Thomas ~ Dayton, OH
 Kim Koehlinger ~ Ft. Wayne, IN
 Estelle Benson ~ Philadelphia, PA
 Lisa Butler ~ Philadelphia, PA





Lizz Russell
Marilyn Pedesco Board of Directors Pittsburgh
Liaison partner! Hannah Iova Mary Iova



Congratulations to our dedicated Walk and Roll Chairmen!

Sue Salzmann ~ Bernardsville, NJ
Kristen Weaver ~ Pittsburgh, PA
Kelly Pavlak ~ St. Louis, MO
Brenda Velantzas ~ Boston, MA
Tammy Hammonds ~ Atlanta, GA

Thank you to everyone who creatively planned their own fundraisers!

Ofir Brizinov ~ Selling Awareness Bracelets

Shane Sumlin ~ Movie Night

Brenda Wieckhorst ~ Selling Awareness Bracelets

William Shirey ~ Sit In

Lizz Russell Parker ~ Fashion Show

Hailey Cannon ~ Basketball Free Throw Toss

Pamela Wilson ~ Community Retail Event

Julie Bell ~ Twist Challenge

Jason Zenk ~ Blue Jean Day at the Marco Consulting Group

Catherine Showerman ~ Tractor, Motorcycle, Trunk & Car Show

Renee Canfield ~ Designing and Selling T-shirts

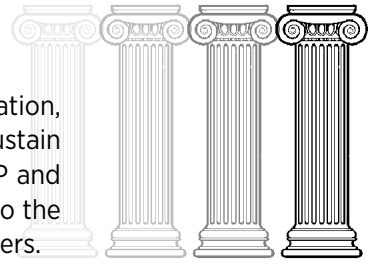
Stephanie Stamatelos ~ Fundraiser with Wells Fargo

Emily Fruik ~ Wine and Cheese Event

If you have an idea for a fundraiser, or would like to get involved in our Walk and Roll or Liaison Programs, please contact the office at allison.dadouris@gb-cidp.org!

The GBS|CIDP Pillar Society

The GBS|CIDP Foundation remains committed to our four mission pillars: support, education, research and advocacy. Your participation in the Pillar Society allows the Foundation to sustain its dedication to impactful programs that improve the lives of those affected by GBS, CIDP and related variants such as MMN. Join the Pillar Society today and confirm your commitment to the longstanding generosity of philanthropic-minded patients, families, caregivers, and supporters.



1. President's Circle

The President's Circle recognizes cumulative gifts that reach \$10,000 or more.

President's Circle members demonstrate leadership in philanthropy. This group of leadership donors makes financial commitments of gifts that enable the greatest impact for the Foundation.

In appreciation for their gifts, President's Circle members receive special recognition throughout the year.



2. 1980 Society

The 1980 Society recognizes donors who have given more than twenty donations.

Since its founding in 1980, the Foundation has relied on the generosity of friends to grow into the outstanding organization that it is today. The 1980 Society donors are the most loyal donors and play a significant role in the past, present, and future of the Foundation.

In appreciation for their loyalty, 1980 Society members will receive special recognition throughout the year.



3. Legacy Circle

The Legacy Circle recognizes individuals who have named the Foundation as a beneficiary in their estate plans and have named the Foundation as a beneficiary in their will, charitable gift annuity, charitable trust, or similar vehicle.

All individuals who have included the Foundation in their estate plans and have made their intentions known are invited into membership. Legacy Circle members will receive special recognition.



4. Ambassadors

These Special donors give the gift of time and leadership. Ambassadors are individuals who have engaged the community in the name of the Foundation.

This includes, but is not limited to, the following: chairing a chapter meeting, chairing a Walk & Roll, chairing a specific fundraiser and conducting an advocacy event by making a Congressional visit.

In recognition of their dedication to the Foundation, Ambassadors will receive special recognition for the events they lead.

As a token of gratitude, all members of the Pillar Society receive a Pillar Society pin to signify membership to this compassionate group of donors.

Why I Give

by *Santo Garcia*

GBS|CIDP Board of Directors Secretary

The day after my daughter was born I couldn't hold her without dropping her. Within a two weeks I was rendered as functional as a sofa cushion. Two weeks later I was told that I probably had ALS. I was haunted by the thought that my daughter would never remember her daddy.

Within three months of my first symptom, several doctors, countless tests, two hospital admissions and many tears held back so as to not burden my family any more, I was diagnosed with MMN/CIDP and immediately treated. The recovery has been slow and steady. Today I am back, fully functional and my daughter and I have many memories to share many years from now.

I discovered the Foundation through the internet and placed a call. The most compelling quality of the Foundation is the human connection it provides. As a patient, I was vulnerable, scared, frustrated, angry, alone, but hopeful. I needed a person(s) who understood to hear me and guide me. There is no substitute for the human voice or a comforting hand on your shoulder.

I serve on the Board of Directors as the Secretary. I am also a liaison in southwest Florida and enjoy speaking with anyone who has a question about the population we serve or ideas on how to make the Foundation bigger and better.

If I have a motto it's "Fill your life with meaning and purpose." The Foundation has provided me hundreds if not thousands of people worldwide to support and educate. Every year I'm given the opportunity to engage legislators

on the local, state and federal level to advocate on behalf of our members. Finally, I make it a personal mission to help raise money for

research to make sure that in the future no one has to lose the use of his limbs, a job or a home, as I did.

"Robert" called me in a panic because his adult son was confined to a bed in an assisted living facility and I was there for him. "Maria" couldn't find a doctor in all of Guatemala to talk to but I was there for her. Contributions make it possible to have the systems in place to help support, educate, advocate and fund research for anyone and everyone anywhere in the world. Until we can find a way to pay for all that we do with solar or wind power, we need - and are tremendously grateful for - the contributions we receive.

I can say with great confidence and pride that this Foundation does more for its membership than any other. And for this to continue, we must support the Foundation with ideas for improvement, with volunteering of our time, and with donations. I care about the lives I touch because it is necessary to care. I give because caring alone is not enough.



continued from page 4

Eculizumab Enters a Clinical Trial in Guillain-Barré Syndrome (GBS)

"Inhibition of Complement Activation (Eculizumab) in Guillain-Barré Syndrome Study (ICA-GBS)" is registered at ClinicalTrials.gov (NCT02029378). The trial intends to recruit 30 patients and divide them into two groups, one group will receive IVIg and eculizumab and the control group will receive IVIg and placebo. Primary safety and efficacy outcome measures include determination of incidence of adverse events within six months from time of treatment (safety) and improvement of one or more grade in function on the six point GBS disability scale at four weeks (efficacy). The results of this trial will be eagerly awaited.

In summary, eculizumab is one of the new and emerging treatments that offer promise to optimize therapy for GBS patients, especially those who are refractory to currently used treatments in the acute phase of the

disease and are at higher risk of developing permanent neurological deficits. This progress has been possible primarily due to international research efforts aimed at understanding the mechanisms of inflammation and nerve injury in GBS.

Correspondence to:

Dr. Kazim Sheikh
Department of Neurology
University of Texas-Medical School at Houston
6431 Fannin Street
Houston, TX 77030 U.S.A
E-mail: kazim.sheikh@uth.tmc.edu
Phone: +1 713 500 6784
Fax: +1 713 500 0773

GBS | CIDP Foundation International SYMPOSIUM ORLANDO FLORIDA 2014

KEYNOTE ADDRESS,
presented by **Bart Jacobs**,
can now be found on our website
under **Latest News**

SYMPOSIUM FAST FACTS:

- 600 Attendees
- 20 Members of our
Medical Advisory Board
- 10 Regional Directors
- 75 US Liaisons
- 13 International Liaisons

13TH INTERNATIONAL SYMPOSIUM FIRSTS:

- First Presentation and
Selection of the Benson
Fellowship Research Grant
(see page 2)
- First Curriculum with two
"Ask the Experts" Sessions
- First attendance over 500,
with 250 "first timers"
- First viewing of
Foundation produced videos
(available on website)
- First "Wiggle it" hosted by
our own Santo Garcia!

*"Great experience,
great family, thank you!"*

*"Loved the inspirational
videos."*

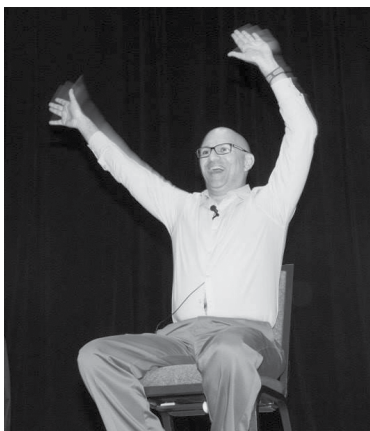


*"I felt so honored to be a part
of the Benson Fellowship,
I look forward to updates!"*

*"Immunizations and
Vaccinations was
down-to-earth and
answered my questions!"*



*"Most fun=
Chairobics with Santo!"*



"New research was interesting, chairiobics relevant to actual life"



"Exceeded my expectations!"



"Beautiful...warm, caring people...an incredible first experience, thank you!"

"...lots of networking with great information"



"The variety and fast pace were excellent!"





International Office
The Holly Building
104 ½ Forrest Avenue
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Directory

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

"CIDP" Group

For those with a diagnosis of chronic inflammatory demyelinating polyneuropathy. Please identify yourself to the National Office in order to be placed on the CIDP list for special mailings, etc.

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 chronic inflammatory demyelinating polyneuropathy. A separate registry has been created. Please contact the National Office for details.

Group for Having GBS Two Separate Times

Please call the National Office for contact with others.

Wheelchair Limited Group

Please call the National Office for contact with others.

AMSAN Group

Please call the National Office for contact with others.

A Teenage Pen Pal Group

Arielle Challander, 231-946-7256
4313 Shawn Drive
Traverse City, MI 49685
Email: ariellegiggles@gmail.com
Arielle had GBS in 2006 at age 13. She is willing to share her experiences so others might understand. To have teenage GBS'er pen pal, write, call or e-mail Arielle.

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. We have many such cases and reassurance from someone who has gone through this is needed support.

Bereavement Group

A group for anyone who has lost a loved one due to GBS|CIDP complications. Please contact: Bereavement Group at the National Office.

The "Campy" Group

Those whose GBS onset was identified as a result of the campylobacter bacteria. Numbers to be used for research purposes.