



Providing Strength Through Support

Regional Meeting in Florida

On a beautiful sunny day in February, 52 GBS and CIDP patients and their loved ones came together in Boynton Beach, Florida for the Chapter's annual meeting. The speaker was Santos Garcia, a CIDP patient, our liaison from Fort Myers, a member of the Foundation's Board of Directors, and an occupational therapist. Santos answered a myriad of questions and the audience really identified with him as one of their own. Estelle Benson, our Founding Director, was also in attendance and spoke about the Foundation's endeavors for upcoming research projects, advocacy and the next symposium which will be held in Orlando, Florida. In addition, liaisons Caroline Morrison from Miami, Kassandra Ulrich from Ohio, as well as Harriette Lion and Nancy Brown from the Boca Raton/Delray Beach host chapter were able to interact with the audience. All in all it was a wonderful informative meeting and well appreciated by the South Florida participants who attended.

Please update your contact information to make sure we have your current email address.

Contact us online at www.gbs-cidp.org or by emailing info@gbs-cidp.org



Ken's Korner

I hope you all like the name Ken's Korner. Each issue I will use this space to share things happening with the Foundation. Please feel free giving me your feedback at ken.singleton@gbs-cidp.org.

Walk and Roll for GBS-CIDP is our new national walk name. This year we will be piloting three locations for all friends of the Foundation. Enjoy a day of fun, friendship

and refreshment while raising awareness. Everyone throughout the Foundation will have the opportunity to participate and help. In addition to our three pilot sites there will be a virtual walk. You will be able to raise awareness in your community. Look for more information by email, our website or Facebook.



If you want to participate in the inaugural walks in the Greater Atlanta, Philadelphia or Pittsburgh areas, please contact the office at info@gbs-cidp.org.

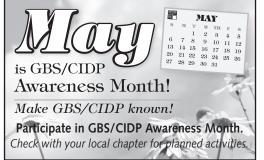
2013 Washington Lobby Day was held March 12th and 13th in Washington DC. The day and a half was spent educating Congress on who we are and all of our disorders. Special focus was made on the following areas.

- Support Funding for Federal Research and Patient Care Programs
- Co-Sponsor H.R. 460: The Patient Access to Treatments Act
- Ensure Patient Access through Proper Physician Reimbursement for Diagnostic Procedures

Look for this annual event and contact me if you have interest in participating in the future.

International Liaison Meeting in Berlin, Germany April 19th through 21st – look for more information in this newsletter. Since our Symposium in Fort Worth, Texas, the Foundation has added liaisons in Mexico, Bosnia and Herzegovina, Brazil, Bolivia

and Belgum.



Remember **May is GBS-CIDP Awareness Month**. I encourage everyone to raise awareness regarding our diseases.

The Foundation is trying to improve its communication at the same time while controlling our costs. Please provide your email address to info@gbs-cidp.org.

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

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Meet Board Member Kenneth R. (Bob) Doehrman

I was diagnosed with GBS when I was in my early sixties in 2001. When I was taken to the ER I had experienced cranial nerve involvement as well and looked like a stroke victim as the left side of my face drooped. A good ER doctor went through a series of tests and, after a spinal tap, diagnosed GBS. I was admitted to the hospital at 2:00 A.M. and had my first IVIG before noon followed by four more infusions. My GBS progressed up my extremities effecting



both my legs and arms, but stopped short of my diaphragm. I thank God for not having to have a tracheostomy.

I was lucky in that I made a rapid and good recovery. I spent nine-days in the hospital and 21-days in HealthSouth Acute Rehabilitation Hospital, walking out to go home using a straight cane. I had several weeks of outpatient therapy and went on my way. While I was in the rehab hospital, my OT brought a younger man to see me who had GBS the year before. He was walking upright with no apparent problems. He told me to give it six-months. I figured that if he could do it, so could I. I put the cane away after eleven-days at home and was fully recovered in less than six-months.

I was born and raised in northern Indiana. After I graduated from Indiana University (BS-Management), I was commissioned in the Army through the ROTC program. I spent 21 years in the Army serving in Germany (the cold war) and in Vietnam (the hot, wet war) and throughout the United States primarily in the eastern half of the country. During this time I earned a MA (Human Resources Management) from Pepperdine University. I am also a graduate of the U. S. Army Command and General Staff College.

After retiring from the Army, I was employed as program manager and systems analyst for a large corporation providing support to the Department of Defense and subordinate organizations. This job brought me to the leading hightech center of the deep south of Huntsville, Alabama where I have been since 1983. I have two children in the Huntsville area; a son - Eric - who is married and has four children ranging in age from 13 to 20 and a daughter - Kristen - who is married and has two children ranging in age from 4 to 13.

My hobbies include these six grandchildren, the Foundation, and Macintosh computers.

After having my life temporarily interrupted by GBS and making a good recovery, I felt a need to get involved in helping others. I joined the GBS/CIDP Foundation International organization at large in 2001 after I was diagnosed with Guillain-Barré Syndrome (GBS). I became a liaison for the State of Alabama in June 2003 and a Regional Director (Mid-Atlantic states) in May of 2005. Then I was elected to the Board of Directors in 2009. I am also a Co-Coordinator of Liaison Activities for the Foundation.

The Foundation has been dear to my heart since I became aware of it in 2001. I have seen its growth in the number of support group chapters and general membership over these years, in the United States and internationally. As I am directly involved in patient and caregiver support, I have witnessed the expansion of support we have been able to provide in this area.

We have increased our awareness of the needs of the caregiver, who can often become the second victim in the GBS patient family unit. The patient gets support from the medical and nursing staff, the therapists, and others, but the caregiver is often found without a support system. Caregivers need a support system as they may be working outside of the home, trying to manage the home in the absence of the patient, while trying to be attentive to the patient in the

Ask the Doctor

Joel S. Steinberg, MD, PhD (Dr. Steinberg is a former GBS patient, Vice President of the Foundation's Board of Directors and a member of the Medical Advisory Board)

NUMBNESS AND ANTS UNDER THE SKIN

Question: Physical therapy was suggested and I have been doing that and I am getting stronger, but I still have numbness in my toes and have a feeling of ants under my skin. It is not getting any better. I just had a nerve test and the nerves are slow. My doctor said yesterday that I had neuropathy and said to call him in about two months. I want to know what to do now.

Reply: The good news: you have lots of company. These paresthesias or abnormal sensations are quite common with GBS. The bad news, there is not much in the way of good treatments. Try over-the-counter pain meds (aspirin, a non-steroidal anti-inflammatory agent such as Advil or Aleve; or Tylenol). Or try a moist heating pad (K-pad or some store brand). You could try the newer meds used to treat neuropathic pain, but they don't seem to help much for numbness or formications (that sense of ants crawling under the skin). Examples are

gabapentin, sold as Neurontin, Lyrica (pregabalin) and Cymbalta. You would want to discuss using these meds with your neurologist or family doctor; they require a prescription. Trying more aggressive approaches, Lidocaine patch, transcutaneous electric nerve stimulator or TENS unit, or acupuncture, would likely be over kill. They are used for substantial pain.

The annoying paresthesias of GBS usually go away or diminish over time. It took years for my tingling to go away after otherwise recovering from GBS.

Kenneth R. (Bob) Doehrman continued from page 2

hospital and rehab. Sometimes it becomes too much for them. Our liaisons are addressing the caregiver as well as the patient. We have formed many former patient and caregiver teams to address this issue.

I am proud of the work we are doing in advocacy for GBS/CIDP with various government agencies. We are also performing significant work in direct patient advocacy assisting families with getting access to IVIG for long-term maintenance and solving insurance and benefit problems.

Our hope is that someday the cause and cure will be found and the need for our special foundation will no longer exist.



Arthur K. Asbury, MD,

a member of the Medical Advisory Board of the GBS/CIDP Foundation International has decided to step down from his role as an active member and been designated as an Emeritus member of the MAB.

Dr. Asbury is world-renown for his clinical and experimental studies of peripheral neuropathies, particularly GBS. The Foundation wishes Dr. Asbury well as he and his wife move onto a new chapter in their life, travelling and enjoying children and grandchildren.

Liaison Development Meeting in Berlin

The Foundation will host a liaison development meeting for those liaisons from Europe and Africa from April 19th through the 21st in Berlin, Germany. This meeting is important to ensure that all chapters, regardless of location, are carrying out the mission set forth by the Foundation of support and education to GBS/ CIDP patients, present and future. It is also a wonderful opportunity for liaisons to meet, share experiences and interact with one another. The meeting will be hosted by Patricia Blomkwist-Markens, our liaison in The Netherlands and a member of the Foundation's Board of Directors, and Estelle Benson, our Founding Director. We are expecting over 20 countries to be represented. Look for the update and photos on what happened in the next "Communicator."

<u>Disclaimer Information</u> 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 the Guillain-Barré Syndrome or any other medical condition.

<u>Privacy Policy</u> 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. Our CIDP and Miller-Fisher Groups share names only after a signed permission slip is received. We are proud that none of our members has ever been solicited or sent materials other than those concerning GBS. We respect your privacy.

Influenza Vaccine and the GBS Patient

Joel S. Steinberg, MD, PhD (Dr. Steinberg is a former GBS patient, Vice President of the Foundation's Board of Directors and a member of the Medical Advisory Board)

Carol Lee Koski, MD, Medical Director, GBS/CIDP Foundation International

uillain-Barré syndrome (GBS) **r**is a rare disorder that occurs in 1-2 patients per 100,000 population, or about 3,000 to 6,000 patients in the United States each year. This disorder is potentially a medical emergency because it causes muscular weakness that can lead to difficulty breathing and swallowing. Any age group can be affected although it is more common in the 5th and 6th decades of life. About two thirds of patients are men and about one third are women. Most patients recover well although 20% develop persistent nerve damage with associated weakness such as difficulty walking.

GBS is the result of damage to the peripheral nerves caused by the patient's own immune system. In approximately 60%-80% of patients the disorder is triggered by a preceding infection. In the USA 75% of these infections are respiratory, frequently due to Cytomegalovirus or Epstein Barr virus while 25% are triggered by diarrhea due most commonly to the bacterium, Campylobacter jejuni. In other areas of the world, poor sanitation results in many more cases of GBS from diarrheal infections. Other triggers include various vaccines, surgery,

trauma, and autoimmune disorders including Sjögren's syndrome and systemic lupus erythematosis.

The swine flu vaccine program of 1976 was halted due to reports of excess cases of GBS in vaccinated patients. A scientific review of the situation by the Institute of Medicine determined that the 1976 vaccine administration was associated with an additional risk of approximately 1 case of GBS per 100,000 population. A second study in 1993 and 1994 showed an even smaller, 10-fold less additional risk or 1 extra case per 1,000,000. One can thus conclude that the risk of developing GBS from the influenza vaccine is very small and that it might vary with different vaccine preparations. However, there are sporadic or anecdotal reports of patients who developed GBS following an influenza vaccination, and then went on to have a recurrence when revaccinated in subsequent years.

Influenza affects 36% or 1 out of 3 people in the United States per year during the months of November through March. 25% of influenza patients develop an associated illness such as pneumonia that results in 20,000 to 40,000 deaths each year. This is particularly true in older patients,

greater than 70 years of age, and those with chronic disease. Vaccination has been found to reduce the rate of hospitalization and mortality from heart attack and stroke that can occur in flu patients. Because of the increased risk of severe illness and death with the flu, the following recommendations are made concerning the use of Influenza vaccine in patients who had GBS in the past.

An annual Influenza vaccine is not contraindicated in patients with a prior episode of GBS unless they had the vaccination within 6 weeks of the onset of their initial GBS symptoms. This is particularly true in older patients and those with chronic disease such as diabetes, heart and lung disease who have a higher incidence of mortality with influenza.

We do not recommend vaccination for patients whose prior GBS had started within 6 weeks of receiving a flu vaccine. Instead on exposure to an individual with influenza, they should start a course of one of the two FDA (Food and Drug Administration) approved drugs for Influenza such as zanamivir (sold as Relenza®) or oseltamivir (sold as Tamiflu®). This should be discussed with your primary physician.

Rare Disease Day Celebration • FEBRUARY 28TH

BS/CIDP Foundation
International was
a partner with
people and organizations
from all over the globe
to celebrate Rare Disease
Day on February 28th.
The slogan for the day is:
"ALONE WE ARE RARE.
TOGETHER WE ARE

STRONG". A rare disease is one that affects fewer than 200,000 Americans. There are nearly 7,000 such diseases affecting nearly 30 million Americans. There are 3,000 to 6,000 new cases of GBS annually in the United States. At



any one time up to 40,000 people in the U.S. may be affected by CIDP.

Amirah Henry of Newark, NJ, one of our members, joined Handprints Across America Gallery by sending in a picture of herself with the flier

celebrating Rare Disease Day after her IVIG treatment for CIDP at the Children's Hospital of Philadelphia. The smile says it all!

On our Facebook page we asked people to click on the "Raise Your

Hand" banner to support research on rare diseases so that \$1 would be donated for each click! Over 1,000 people from our Facebook page visited the site. Thanks to all who participated in this great effort.

Three of our members, Rick Forney from Virginia, Rose Gallegos from New Mexico and Karl Kingan of Texas requested that their states designate February 28, 2013 as Rare Disease Day. A proclamation was issued by each of these states declaring such. We appreciate the efforts of each individual who raises awareness for rare diseases.

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International Guillain-Barre Outcomes Study (IGOS): Update for U.S. Centers

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he International Guillain-Barré Outcomes Study (IGOS) is the largest and longest prospective trial designed to collect extensive data from patients afflicted with GBS in a systematic manner. Clinical information regarding antecedent triggers, beside examination of cranial nerve findings, respiratory abnormalities, autonomic dysfunction, strength and sensory testing, disability and quality of life measures, pain, fatigue, electrophysiological parameters, treatment response and medical complications throughout the course of the illness and recovery will be obtained at regular intervals from the initial presentation through one to three years in followup. This is the first study that also will prospectively obtain critical information from blood testing, assessing serum antibodies and genetic markers throughout the course of the illness. This information will allow the development of more precise prognostic models regarding long-term outcome and possibly identify features that predict a response to treatment with intravenous immunoglobulin (IVIg), plasma exchange, or novel approaches to treatment (such as a second dose of IVIg in patients with a more severe disease course or other experimental therapies). This international trial was designed and implemented by Professor Bart Jacobs and colleagues from Erasmus University, in Rotterdam, The Netherlands, and involved an enormous collaborative effort from the inception of the study, protocol development, web-based data collection, and recruitment of participating centers across the world. It is anticipated that there will be over 200 centers participating in more than 20 countries. The goal is to recruit 1000 GBS patients of all ages, including "classic" as well as variant

clinical presentations (for example, the Miller Fisher variant, acute motor axonal neuropathy, acute motor and sensory axonal neuropathy, etc.) from around the world. Thus far, 40 patients have been enrolled internationally.

In many countries health care is highly centralized (for example, The United Kingdom, Denmark, The Netherlands) and allows for the efficient development of participating GBS referral networks involving academic medical centers for patient enrollment across the country. In contrast, health care in the United States is decentralized and therefore more dependent upon the willingness and sustained motivation of highly skilled neuromuscular clinicians across the country caring for patients with GBS. We have been very fortunate to receive financial and organizational support to fund this trial in the United States through the GBS/CIDP Foundation International, along with generous support from Baxter, CSL Behring, NuFactor, and from GBS patients and their family members. There are currently 47 centers across the United States who have committed to the IGOS trial. Six centers (Mazen Dimachkie, M.D. at Kansas University Medical Center; Nick Silvestri, M.D. at University of Buffalo; Sasha Zivkovic, M.D. at University of Pittsburgh; Bob Pascuzzi, M.D. at University of Indiana; Russell Chin, M.D., at Cornell University; and Kazim Sheikh, M.D. at University of Texas, Houston) have received formal Institutional Review Board (IRB) approval and may enroll patients; Sasha Zivkovic, M.D., deserves special congratulations for enrolling the first U.S. patient at the University of Pittsburgh. Six other centers have the IGOS protocol under IRB review and anticipate approval within weeks, and



the remainder are in various stages of protocol submission for IRB approval. There will be an organizational meeting for the U.S. IGOS investigators at this year's American Academy of Neurology meeting in San Diego. We anticipate that through 2013 all current U.S. IGOS centers will have IRB approval and begin enrolling patients and hope to involve additional investigators to further expand the U.S. IGOS network.

This is one of the most important GBS studies ever to be conducted and is the largest research project supported by GBS/CIDP FI. The data generated from IGOS may fundamentally change how we care for patients with GBS and hasten research for more effective therapies. What can you do to help support IGOS in the United States? First, speak to your treating neurologist and encourage their participation: we encourage clinical investigators to participate and especially those at academic, tertiary neuromuscular referral centers who care for 5 or more patients with GBS per year. Researchers who are interested can contact GBS/ CIDP FI or the IGOS website (https:// www.gbsstudies.org) for additional information. Second, help the GBS/ CIDP Foundation International with continued financial support to allow them to sustain their support for this crucial research. We will keep you posted on our progress.



How one person can make a difference in fundraising on her own personal walkathon in Zimbabwe.

Chengetai Chiguwa, our liaison in Zimbabwe, held her own personal walkathon (walking to church) on the same morning that the Foundation held its walk in Fort Worth at the 12th International Symposium, October 28, 2012. She decided to have her family participate in a walk together, including her husband, son and daughter, and her daughter-in-law and granddaughter. She wrote to us, "I am glad that my daughter whom I left home at 4 months when I was down with GBS is now 5 and also participated in the family walkathon. She is the one in an orange dress and the other little cute girl in red top is our granddaughter. The final walkathon figure is US\$375."

One of our Board members, Ginger Crooks commented, "Thank you for sharing. This is truly awesome and very touching. It means so much more to see the actions of other countries and the fact that GBS has no boundaries.



GBS/CIDP Foundation Research Grant Program reaches \$1 million mark!

In less than 10 years the GBS/CIDP Foundation International went over the \$1,000,000 mark in research grants in 2012. The Foundation awards 3-4 yearly grants per year ranging from \$40,000 to \$60,000 each. It is anticipated that information generated by these seed grants will lead to additional funding through agencies in the USA and Europe. Some of the recent grants have yielded promising results. This data is being used to support a clinical trial in GBS patients. Other work demonstrated that CIDP is associated with abnormal chronic activation in CIDP leading to more focused genetic studies. The Foundation has supported the development and ongoing effort to prospectively study the characteristics (clinical, therapeutic, and genetic) of an international cohort of 1,000 GBS patients which will provide direction for better treatment and more focused research.

The Research Grant Program which awards funds worldwide for study of the causes, prevention and treatment of inflammatory neuropathies including Guillain-Barré Syndrome, a self-limiting symmetrical paralysis that can lead to respiratory failure, Chronic Inflammatory Demyelination Polyneuropathy, a relatively symmetrical motor weakness with sensory loss that can progress for years, and Multifocal Motor Neuropathy, an asymmetric multifocal neuropathy that must be distinguished from amyotrophic lateral sclerosis (ALS) or Lou Gehrig's disease. Although all of these are treatable disorders, delayed diagnosis and treatment can lead to significant disability and mortality.

The Foundation will be accepting grant requests in November 2013 for the 2014 grant year. Please contact the Foundation at info@gbs-cidp.org or (610) 667-0131. Additional information is also available at http://www.gbs-cidp.org/grants/

Chapter Meetings

Our liaisons have been busy over the last six months hosting meetings across the country. We would like to recognize the following individuals who held meetings and all the people who participated to make them such a great success:



Kathie Pomykala and Rick Epifani, Las Vegas, NV on Saturday, September 15th Charlean Eggert and Shannon Boyer, Chicago, IL on Sunday, September 16th Audrey Brucker, St. Paul/Minneapolis, MN on Saturday, October 6th Steven Smith, Newburgh, NY on Tuesday, October 17th Rhonda Vega, Reno, NV on Saturday, October 20th T. Everett Nichols, Raleigh, NC on Sunday, November 4th Hannah Blanton, Charlotte, NC on Tuesday, November 6th Jim Crone, Peoria, IL on Saturday, November 10th Jim Yadlon, Central/Southern NJ, Saturday, November 10th Bill Robbins, Atlanta, GA on Saturday, November 10th Rick Forney, Southwestern VA on Saturday, November 10th John Schilke, Portland, OR on Saturday, November 17th Kristin Bueb, Denver, CO on Saturday, December 1st George Evanick, Greater Hartford, CT on Tuesday, December 4th Yvonne Bishop, Kansas City, MO on Saturday, December 15th John Schilke, Portland, OR on Saturday, January 13th Harriette Lion, Boynton Beach, FL on Saturday, February 9th



facebook

Have you been on our Facebook page lately? Are you one of the over 2,500 people who have "liked" us. It is a great place to communicate with other patients and caregivers. It is place where we post upcoming events including chapter meetings, inspirational stories about individuals that have triumphed over GBS and CIDP, and educational resources.

Some of the recommendations that have been posted are:

"This group page and the people who were kind enough to reach out and give me hope during my darkest days in the hospital were a Godsend."

"I think that if more people knew about this web page it would be over filled. It made me feel good knowing how many people over came this when they were so close to death."

"This foundation has helped me find some great friends to help me deal with my illness and to help me understand it more!!"

"This website provides information, inspiration and hope for those dealing with the disease as well as for those dealing with victims of the disease."

"This page is an excellent resource for people with GBS or CIDP and the friends and family of people who are living with either Guillain-Barré Syndrome or Chronic Inflammatory Demyelinating Polyneuropathy (that is the condition I have + dysautonomia). It offers a warm, welcoming and supportive online community."

"Finding this page has made a huge impact on me in that I now have a "family" of Great Brothers and Sisters who truly understand what I am feeling. Through those who have been dealing with GBS and CIDP for a longer period of time than me, I have been able to validate my issues as being normal, educate my family and friends, and support and encourage others on here just as they have done for me. Thank you to all those responsible for the creation of this. Lots of love and healing from Jacksonville, Florida."

"This page is a great resource for anyone going through this scary frustrating disease. Check it out."

"I had no idea there was a FB page for CIDP! I am so excited to find this awesome support!!! Thanks so much!"

"This Facebook page is the greatest tool ever to me. Being able to talk to other people (GBS = Great Brothers and Sisters) who know how you feel, know what you are going through. It is a family of support people. Thank You GBS-CIPD Foundation!:) "

"I just discovered this page & I LOVE it! Thank you to whoever created it!!! It helps to unite us & inform us as well as everyone else."

"So much helpful information on this site for CIDP! I will continue to recommend it to my friends. Thank You!!!"

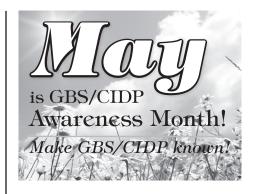
"This is the site for those who wish to dig deeper into learning what GBS-CIDP is really all about. No better person to learn from than someone going through it themselves, or their family members going through it with them. Excellent educational resource for all!"

"This foundation explains my disease and helped me get in touch with other like me. Thanks to sites like this I do not feel alone. xoxo"

"Thank you for doing research on GBS. Not many people know about GBS and without the doctors that knew how to finally diagnose me after a week I wouldn't be here today."

"Pure Excellence!"

Don't miss out - visit us at www.facebook.com/gbscidp.



Remember May is GBS/CIDP Awareness Month

During the month of May, in an effort to increase awareness in each of our communities, we encourage everyone to organize activities that highlight GBS, CIDP and their variants. In the past, members have sponsored educational events, contacted politicians, and held local fundraising events.

Throughout the world individuals and groups have organized fundraising/awareness events such as walks, runs, bake sales, food sales, fashion shows, afternoon teas, cocktail receptions, art sales, sports outings and "sit-ins" for those who cannot walk. This year the Carolina Art Soiree will be held in Charlotte on May 2nd – look for details on our website and Facebook.

We are also launching our "Walk & Roll for GBS/CIDP" this spring –look for details about these events in your community on the website and Facebook. Awareness and fundraising events can be big or small – what's important is that as a community we are able to advance our mission in whatever way we can by educating people about GBS and CIDP. If you are interested in participating please contact us at info@gbs-cidp.org, 610-667-0131 or your local affiliate.





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CHANGE SERVICE REQUESTED



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 poly-neuropathy. Please identify yourself to the National Office in order to be put in contact with others around the country.

Children with GBS

Call Lisa Butler, 215-628-2771 670 Penllyn Blue Bell Pike Blue Bell, PA 19422 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.

Miller Fisher Variant Group

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 413 Shawn Drive Traverse City, MI 49684

E-mail: GBSTeenPenPal@hotmail.com

Arielle had GBS in 2006 at age 13. She is willing to share experiences that others might not understand. To have a teenage GBS'er pen pal, write, call or e-mail to Arielle.

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/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.