



GBS | CIDP

Foundation International

Winter 2013

The Communicator

Providing Strength Through Support

Upcoming Meetings

Look for details on the web or in the mail.

**Charlotte, North Carolina
January 14, 2014**

**Peoria, Illinois
February 1, 2014**

**Regional Meeting
Boynton Beach, Florida
February 8, 2014**

**Raleigh, North Carolina
March 1, 2014**

Many meetings are in the planning process, please contact your local liaison for meetings being scheduled in your area.



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

Your information will not be shared with anyone outside the Foundation

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

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Ken's Korner



As the holiday season approaches, it is time to reflect back on the past year, to give thanks for all of our many blessings, and to wish the foundation community all the best wishes for a Happy Holiday and healthy New Year.

One might think, being in our 33rd year, we might sit back and rest on our laurels, however nothing could be further from the truth.

It is true, in 33 years, we have grown from a small support group held in the living room of our founders, Bob and Estelle Benson, to helping thousands of people each year in 190 Chapters in over 40 countries. It is true we have established 18 medical Centers of Excellence. It is also true we have and continue to fund research to find better treatments including possible cures for the challenges of GBS, CIDP, and MMN.

More importantly, as long as people are challenged with these disorders, either not yet diagnosed, acute, recovering, or recovered, our job is not finished. Patients let us know every day how important our work is and give thanks through their letters, emails, telephone calls, and support. Instead of sitting back, we are working harder than ever!

Looking back on the year, we have many new "Firsts" geared to expand our mission. They include:

- Our first Capitol Hill Day to provide a strong effective voice to inform and influence public policy as it pertains to the challenges of GBS, CIDP, and MMN.
- Our first National Institute of Health Day to educate the Institute about the challenges of Peripheral Inflammatory Neuropathy disorders, and to make recommendations regarding treatments and research initiatives.
- Our first signature Walk & Roll event, an event format planned to spread across the country to develop national recognition of our mission.
- The establishment of the Benson Fellowship for Peripheral Inflammatory Neuropathy, our first, to encourage professional training.
- The creation of our first Deputy Director position, which has been filled by Bob Nelson, who comes to us with over 30 years of leadership experience in the nonprofit sector.

In this newsletter you will see an announcement for this year's symposium, which will be held in Orlando, Florida, October 31 - November 2, 2014. The Symposium will be an outstanding event! As you can imagine, the program is already being developed, and will provide many opportunities for learning and networking. We expect a splendid time will be had for all. You can pre-register for the symposium at www.gbs-cidp.org and be first to receive "First notice" on symposium updates.

Without your very kind and generous support throughout the year, and during the holiday season, we would not be able to do all we do for so many people. You are part of the team that makes a difference in the lives of the GBS, CIDP, MMN community. 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!

See enclosed flyer for details on the 13th International Symposium!

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

Printed on recycled paper.

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We thank Kassandra Ulrich, Cecilia O'Neil, and Debbie Plimmer for their many years of service as Regional Directors, and for helping so many of our patients.

The following liaisons have accepted the expanded role of regional director and we thank them for their support:

- Kenneth Doehrman Northern Alabama
- Jonathan Toumey Indianapolis, Indiana
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- Yvonne Bishop Kansas City, Missouri
- Ginger Crooks St. Louis, Missouri
- Jim Yadlon Trenton, New Jersey
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- Margee McKenna Warren, Ohio
- Rick Forney Southwestern Virginia
- Glennys Sanders, MBE UK



From the German GBS/CIDP Support Group

On November 6th, 2013, our honorary member, Marianne Fels, passed away at the age of 91.

In 1987, Marianne was one of the founders of the first GBS support group in Germany. After her daughter, Eva Fels (now one of the Foundation's liaisons), was diagnosed with GBS, she realized that something had to be done and she became engaged in the support group. She wrote many documents for the support group, most of them she translated from English. These brochures would prove an invaluable source of information for those affected. Among other things, she created a communication board for ventilator-dependent patients and translated a brochure for long-term GBS patients. Many newsletters from the Foundation, especially the medical issues, were translated into German by her. Her co-founders greatly appreciated her hard work and dependability.

During a celebration in 2007 to mark the 20th anniversary of the GBS support group, Marianne Fels was awarded the Golden Badge of Honour of the German GBS Initiative e V for her services.

Both the German support group and the Foundation were close to Marianne's heart. Our thoughts and condolences are with the family.

Help Us Save The Trees

You can help us save the trees by selecting the "Paperless" option to receive our communications. Simply email bob.nelson@gbs-cidp.org and ask for the paperless option, and future communication from us will be through email.

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. Our CIDP and Miller-Fisher Groups share names only after a signed permission 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.

GBS/CIDP Foundation International announces the establishment of the Benson Fellowship to fund Peripheral Inflammatory Neuropathy Fellowships

NARBERTH, Pa., Nov. 8, 2013 -- The GBS/CIDP Foundation International has established the Benson Fellowship to fund Peripheral Neuropathy Fellowships in honor of Estelle Benson, and her husband Robert Benson, a survivor of Guillain-Barre Syndrome. The Foundation voted to endow over \$1,600,000 of its financial resources to initially fund the Fellowship.

The purpose of the Benson Fellowship is to encourage professional training for medical doctors in the peripheral inflammatory neuropathy area and to encourage philanthropic support to help address this significant challenge within the medical community.

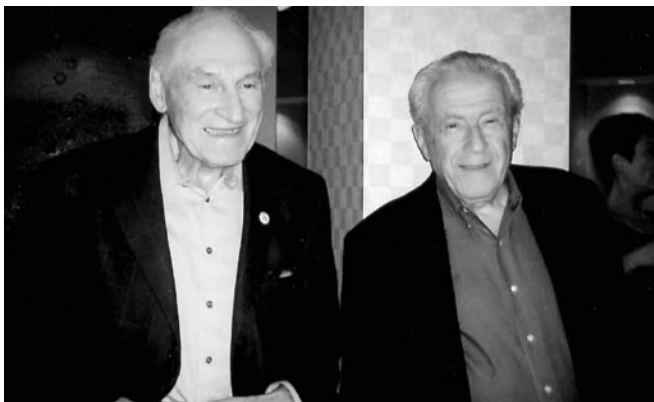
For further information, please contact: Ken Singleton, Executive Director
 (610) 667-0131 GBS/CIDP Foundation International
ken.singleton@gsb-cidp.org

How it All Started!

In December, 1979 Henry Friedman received a call from Estelle Benson asking him to visit her husband who had been diagnosed with GBS a few weeks before. She was told that Henry was a GBS survivor and, at the time, the only other person she knew - who had had the disorder! Sure enough, he showed up, actually on his way to a formal event, dressed in a tuxedo!

He told Bob that a year before he was suffering like Bob was and that there was a strong chance for a recovery. That had such a remarkable effect on Bob. It was that moment that prompted the Bensons to believe the doctors! It gave Bob and Estelle the seed for starting a "support group" to visit patients. "Hank" was the inspiration for this idea. He became the financial and investment officer and member of the Board of Directors until he retired in 2008.

Thank you, "Hank," and Happy 91st Birthday!



Pictured in 2004, Henry Friedman (left) with Bob Benson

To learn about the exciting
**PATH Study – CIDP Treatment with Subcutaneous
 Immunoglobulin (IgPro20),**
 please see our web site at www.gbs-cidp.org.



Dear IGOS Investigators,

Today, we can proudly announce that we have reached an important milestone in IGOS.

Dr. Zhahir Islam and Dr. Badrul Islam from the Dhaka Medical College Hospital in Bangladesh recently joined the IGOS. In this short time, they have already included two patients in IGOS. **These inclusions have resulted in a total amount of 250 patients included in IGOS! Congratulations to all!**

We are very delighted with this achievement and we hope that this news creates even more enthusiasm and energy to work on IGOS.

Below you can find an overview with amount of inclusions per country as of November 13th.

Country	Centers	Inclusions
UK	20	59
USA	32	53
Denmark	6	27
Italy	9	25
Netherlands	9	24
Spain	9	18
Germany	5	16
Japan	3	7
Argentina	7	6
France	1	4
Canada	3	3
Malaysia	1	3
Belgium	2	2
Bangladesh	2	2
Australia	1	1
Taiwan	1	0
India	0	0
Brazil	0	0
Total:	70	250

We want to thank everybody for their effort, hard work and enthusiasm for IGOS. On to inclusion number 500!

Best regards,
 The IGOS team
www.gbsstudies.org

Multifocal Motor Neuropathy: Progress and Challenges

by Richard Lewis

Overview

Multifocal Motor Neuropathy (MMN) is a rare condition that causes weakness without significant loss of sensation. The disorder affects less than 1 person per 100,000 people. Men are almost twice as likely as women to develop the illness and most people contract the disease between the ages of 35 and 70. With very rare exceptions, MMN does not shorten life, or cause major problems with breathing or swallowing. However, it can cause a great deal of dysfunction and disability and the disorder appears to persist indefinitely and rarely goes into a long-term remission.

The initial symptoms are typically in one hand or arm in the distribution of one or two nerves. Other nerves become involved in either arm or in the legs and muscles become atrophied and may have muscle twitching, called fasciculations. Fasciculations are a prominent finding in amyotrophic lateral sclerosis (ALS), an untreatable progressive disorder that dramatically shortens life. It is crucial for doctors to determine if someone with fasciculations and weakness has MMN instead of ALS since MMN is potentially treatable and has a much better prognosis. In contrast to ALS, MMN does not affect the brain or the central nervous system tracts (upper motor neuron tracts) that send the signals to the motor neurons. MMN is a disorder only of the lower motor nerve fibers, the axons that originate in the motor neurons- but the cell bodies themselves (motor neurons) are not affected by the disease.

The diagnosis of MMN is based on the pure motor symptoms and signs, and the lack of upper motor neuron signs. The hallmark of the disorder is the finding of "conduction block" on the nerve conduction studies. Conduction block (CB) is the phenomenon of the failure of the electrophysiologic impulse to travel all the way down the nerve because the transmission is impeded by changes that do not destroy the nerve fiber (axon). In practice, this is demonstrated on nerve conduction testing by finding a strong response when stimulating the nerve close to the muscle but a weak response when the stimulus is given to a portion of the nerve that is above (proximal to) the nerve lesion causing the block of transmission.

There are a number of studies that support the idea that MMN is due to abnormalities of the patient's immune system. Specific proteins, called antibodies have been found in a significant number of MMN patients. These antibodies attack a constituent of the nerve fiber, called GM 1. Detecting very high amounts of this antibody in the blood of someone suspected of having MMN strongly supports this diagnosis.

It is now well established that treating patients with intravenous immunoglobulin (IVIg) benefits patients with MMN. It can reverse the conduction block, reduce the chances of developing new nerve lesions and most likely slows progression of deficits. However, it does not

cure the disease, requires repeated treatments and may lose its efficacy over time. No other treatment has been convincingly shown to be effective although there are case reports and small series of patients that suggest some benefit with a number of immunosuppressive agents.

Despite responses to IVIg, many patients will get progressive destruction of the axons causing permanent weakness. The search for treatments that can prevent this axonal loss is ongoing and is a major goal of investigators.

Challenges and Progress

There is much to learn and understand about this disease and there is clearly a need to improve our therapies. The following are a few of the questions that need to be answered and some of the progress that has been made in the past few years.

Question 1: What is the cause of the conduction block?

Since CB is the major physiologic phenomenon underlying MMN, understanding the cause of the block can lead to treatments directed at the specific target.

Progress: Initially the CB in MMN was thought to be caused by the stripping off of the insulation of the axon (myelin). This demyelination is known to cause CB in other diseases including the demyelinating form of GBS as well as CIDP. However, we know that the acute motor axonal form (AMAN) form of GBS has CB without demyelination. It has been shown in AMAN that the target of the antibodies in AMAN are directed at a region of the axon that produces the fast transmission of impulses down the nerve- the Node of Ranvier. AMAN has similar antibodies to those found in MMN and there is now increasing evidence that the CB in MMN is also due to an attack of the Node of Ranvier or its adjacent regions. This knowledge is likely to provide investigators the opportunity to develop treatments directed at specific targets in this region.

Questions 2: Why is MMN purely motor? Why are the sensory nerve fibers spared?

Progress: Although challenges remain, it is clear that there are aspects of the anatomy and electrophysiologic properties of the nerve fibers that are different between motor and sensory nerves. This makes the motor fibers more vulnerable to the immunologic attack as well as to development of CB.

Questions 3: Do the GM 1 antibodies cause the disease? If so, why do we not detect the antibodies in all patients with MMN?

Progress: It is still not entirely clear whether the GM1 antibodies are the specific cause of MMN. However, it is known that GM1 is prominent at the nodes of Ranvier and is different in structure in sensory nerve fibers compared to the motor nerves which would potentially make the motor

fibers more vulnerable to antibody attacks and that similar antibodies cause AMAN, a purely motor disorder. However, reproducing MMN in animals has not been accomplished by either giving them GM1 antibodies or stimulating the animal to make the antibodies.

The fact that only 35-50% of patients with MMN had the antibodies (in most reports) was particularly troubling. This issue may have been resolved with a recent study from Dr. Hugh Willison's laboratory (MAB member) that the antibodies are detected in over 85% of patients with MMN if the test combines MMN with other similar glycoproteins (gangliosides). This detection of antibodies to complexes of gangliosides, if confirmed, will not only give us a better understanding of the disease but also provide an important diagnostic test that will more definitively determine if someone has MMN.

Questions 4: What causes the progressive axonal loss in MMN? How can we prevent it?

Progress: There remains a great deal of work that is needed to answer these questions but progress is being made. Recognizing that the primary site of attack in MMN is at the Node of Ranvier now points to the axon as being primarily involved. Attack on the nodes does not only cause CB, but also affects the energy transport down the nerve fiber which over time can cause degeneration of the most vulnerable aspects of the nerve, the distal twigs that are farthest from the cell body. This concept is being considered in other disorders that affect the nodes but need further study in MMN. Some of the axonal elements at the nodes of ranvier may be amenable to therapy.

Question 5: Are other treatments available for MMN?

Challenges: The fact that there are no treatments other than IVIg that have been proven to be effective has been very disappointing. There are a number of challenges to identifying new treatments.

1. MMN is a hard disorder to study treatments. It is very rare and requires many centers to recruit patients. This is very expensive and it is difficult to obtain funding to support such an effort.
2. Developing outcome measures that can accurately and sensitively determine if a treatment is effective is an important requirement for good clinical trials. The GBS-CIDP FI supported Peripheral Neuropathy Outcome Measure Study (PERINOMS) has developed and validated a number of outcome measures that can be used in clinical trials in MMN and other immune neuropathies.
3. We know that MMN is both under-diagnosed and mis-diagnosed. The potential for the antibody testing against GM1 complexes providing specific and sensitive diagnostic information will help improve our diagnostic accuracy which will improve our ability to determine if a treatment is effective.
4. We need a better understanding of the natural history of the disease, the different symptoms and signs that encompass MMN. Having a more specific way of determining who has MMN will be a big step in this regard. Some larger series have provided important information but an international registry and database is needed.

CONCLUSIONS: We have learned a great deal about MMN and the recent progress is very encouraging but the search for new and better treatment is ongoing. A concerted effort by investigators, partnering with patient organizations such as the GBS-CIDP FI is crucial to make further progress.

End of the Year Giving

Make the greatest charitable impact while maximizing tax savings!

During the holiday season, with the ending of one year and the beginning of another year quickly approaching, many people express thankfulness for their blessings by making a charitable contribution. Of course, this can also be a smart tax-saving move at the end of the year which can be used to help an individual maximize their charitable impact.

Please remember the following IRS tips when making an end of the year charitable contribution:

- Only taxpayers who itemize their deductions on Form 1040 Schedule A can claim deductions for charitable contributions.
- Contributions are only deductible in the year made. In other words, only contributions made in 2013 can be used for tax purposes for 2013.
- Get a receipt. To deduct any charitable donation of money, regardless of amount, taxpayers must have a bank record or a written communication from the charity showing the name of the charity and the date and amount of the contribution. For each deductible donation of \$250 or more, taxpayers must obtain an acknowledgment from a charity.
- Only donations to IRS qualified organizations are tax-deductible. As a 501 (c)(3) nonprofit, the GBS/CIDP Foundation International is an IRS qualified organization.

There are many ways you can support the mission of GBS/CIDP Foundation International. You can make a direct donation, or a donation in memory or in honor of a loved one. This can be done on our donation page on our web site at www.gbs-cidp.org. You may also consider donating through your estate plan or life insurance policy.

If you are 70½ years old or older, you can direct a distribution from your IRA to GBS/CIDP Foundation International without incurring income tax on the withdrawal. You may have your IRA administrator transfer up to \$100,000 directly from your IRA through December 31, 2013. There is no guarantee that the IRS will extend this opportunity into 2014.

If you have any questions about how to make an end of the year contribution, please call or email: Ken Singleton, Executive Director

(610) 667-0131 or ken.singleton@gbs-cidp.org

A Son's Story

by Eric Marx, McLean, Virginia

Little did my family know in March of 1993, that our world would soon be rocked by a rare illness. The call came one August afternoon as I sat at my desk - it was my mother phoning from Rome where she and Dad were spending a couple of days on vacation. Clearly panicked, Mom explained that my father was in a hospital, paralyzed and on a respirator - the doctors didn't know what was wrong and the illness had progressed at an alarming pace - just that morning he'd awoken merely complaining of weakness in his legs.

Within a day my brother, Ken, and I were on our way to Italy. Both of us in shock, we worried that Dad would die before we arrived. During our first few days abroad we watched helplessly as Dad's vital signs swung from one extreme to another, and attempted to calm Dad as he lay there, fully-conscious and unable to communicate anything other than terror through his eyes. This seemed an especially cruel irony for such a warm and gregarious man who had a highly successful federal government executive career in public relations. Such was our introduction to a disease eventually labelled Guillain Barré syndrome (GBS).

I remember that day turned to night and back to day over and over again as we took shifts sleeping at the hospital. Early on, we learned that lack of movement led to pneumonia - a vicious cycle of onset, treatment, and recovery, sometimes back-to-back, each time bringing renewed concern about whether he'd make it through. This prolonged Dad's suffering and increased the life-threatening nature of his condition.

The staff at the private hospital was professional, friendly, and concerned, doing their best to treat the symptoms while consulting externally about what this bizarre illness could be. It took the team providing his care the better part of a week to put a name to the rare illness. This also delayed IViG and plasmapheresis therapies, though we'll never know if this delay was critical.

Unable to speak or write, Ken devised a method for Dad to communicate through blinking, the only movement he was capable of performing. We would begin with the letter "a" and progress through the alphabet until Dad gave an extended blink. We'd continue one letter at a time until we had spelled a word, and then began the second. After a while, we were able to short-cut words and even whole requests, for example, beginning with the letter "g" often meant "get" and we'd follow up with "get the nurse?," "get Mom?"

We were incredibly fortunate to have top-notch medical connections in the family, including Ken, then a hospital administrator at the University of Iowa. Ultimately diagnosed and realizing the only remaining "cure" was time, attention turned to how we could get Dad home. Ken used his ties to "scramble" the University of Alabama at Birmingham air medical team who flew to Rome to "rescue" Dad. With home

an ocean away, it really did feel like a rescue when the men in white suits, adorned with American flags, came into his room and whisked him away to "safety." Finally, we thought, Dad is coming home and we can all help him through recovery.

The relief we felt was short-lived as bouts of pneumonia continued and the regimen of medications grew. Things did, however, improve in certain ways. We were back in familiar surroundings, and we learned we weren't alone and that, in fact, there was an organization, the GBS/CIDP Foundation International, devoted to providing information, communicating with families similarly afflicted, and conducting research. Through the Foundation, we learned more about GBS, which brought significant relief to our need for information about what our father and family were going through, and helped prepare us for the future. The Foundation provided a tremendous source of hope for us.

Dad remained in the intensive care unit in George Washington University Hospital in DC for five months. Staff took wonderful care of Dad. My wife and I traded evenings and weekend days with Dad. While together, we'd talk largely about "normal" things - new "firsts" for his grandson, when Ken was coming back, how things were going with my new job.

Dad was very gradually regaining movement - facial expressions began to return, he started being able to turn his head, and could shrug. The medical staff also began to wean him from the ventilator, so thinking about next moves seemed appropriate. Once Dad was breathing on his own and his health otherwise appearing to improve, we determined that a rehabilitation facility was the way to go, and on Valentine's Day, 1994, Dad was transferred to Mount Vernon Hospital, roughly a mile from Mom's house. Finally, Mom wouldn't have to trek back and forth to DC each day, and it was more convenient for me to swing by on my way home from work.

Rehab was both slow to progress and painful. Dad began to move his fingers and was actually able to make a sound. We were so hopeful as winter began to release its icy grip - when could he come home? Our thoughts about whether Dad would survive had faded, and we weren't so much worried about how much or how quickly he would regain control of his body, we just wanted him home. On Sunday, March 6, 1994, my son (grandson number two, Danny) and I went to see Dad at Mount Vernon. It was, in one way, an incredibly heartening visit as Danny had learned to say his full name and proudly proclaimed to grandpa "My name is Danny Marx!" While visibly happy with his grandson's accomplishment, Dad was unusually nonchalant when it came to what he wanted to talk about, watch on TV, etc. It was his shrugs that I wished I'd picked up on as a sign that he didn't have any fight left.

Early Tuesday morning on March 8, 1994, the phone rang around 5 AM - Mom just said, "He died." Oh my god!

How?! It couldn't be! What happened?! I had let my guard down (we all had), believing we were beyond worrying about mere survival. We were just waiting for him to awaken a bit more, like the spring flowers. Just waiting until we could bring him home. The shock was unlike any we'd ever experienced; and our world would never be the same.

As much as Ken and I miss our dad, it was always the fact that he and his grandchildren would never get to know each other that hurt the most. Our two eldest, Dagan and Danny, have no memories, and our two youngest, both named for him (Neal Robert and Robin Marguerite) weren't even on the scene. We know he would have loved each of his grandkids and they would have loved him.

Of course, Mom was devastated - Dad had been her one true love and they had remained very much in love. As brave a face as she tried to put on and as much as she attempted to show that she could be strong and independent, Mom was never the same.

While our story is an extreme and very rare example of GBS, we remain grateful for the hope and sense of "community" the GBS/CIDP Foundation International provided our family in our times of greatest need. We've remained connected to the Foundation for 20 years because we continue to be inspired by its mission of sharing, caring, and fostering research that will, hopefully, one day lead to a cure.

Our Walk and Roll Pilot Year Was a Big Success!



Our new signature event, *Walk and Roll for GBS, CIDP, and MMN*, was a great success for our first year. A year ago, the idea was a concept...today, it is a reality! In the Philadelphia, Pittsburgh, and Greater Atlanta areas, events were held, hundreds of people participated, and good times were shared by all. There was even a virtual walk on the internet where people, who could not participate on the day of the events, but still wanted to participate, could "Walk On-Line!" Participants with GBS and CIDP had the opportunity to meet one another and felt connected in ways they were missing. These connections will continue.

The lead goal for *Walk and Roll* was to raise public awareness about GBS, CIDP, MMN and their variants so that when a person develops one of these medical disorders, they can get the right diagnosis and the right treatment, right away. In addition to all the word of mouth and social networking associated with these events, newspaper articles and other media outlets broadened our communications and reach.

Our vision for *Walk and Roll 2014* is to expand the event from three to ten Walk and Roll events that will stretch from coast to coast. In order to accomplish this, we need members who are interested in helping us expand our mission by volunteering to help manage the events. Volunteering opportunities will include: chairing the event, participating on the Walk and Roll event planning team, assisting with event related communications, and, of course, helping out on the day of the event.

Locations we are seeking volunteer support include:

- | | |
|----------------------------|---------------------|
| San Francisco, CA | Los Angeles, CA |
| San Diego, CA | Northern New Jersey |
| New York Metropolitan area | Boston, MA |
| Philadelphia, PA | Chicago, IL |
| Dallas, TX | Washington, DC |
| Raleigh, NC | Orlando, FL |

If you have interest in helping expand the Foundation's reach and would like to volunteer for a *Walk and Roll* event, please contact Bob Nelson at 610-677-0131, or by email at bob.nelson@gsb-cidp.org.



We Welcome Lisa Butler, Community Engagement Coordinator

Lisa Butler, who has worked with the Foundation for years as a liaison for families who have children with GBS, has accepted the Foundation's newly created Community Engagement Coordinator position. Lisa brings extensive marketing and fundraising experience to our management team at the foundation.

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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.
- **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.
- **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
4313 Shawn Drive
Traverse City, MI 49685
Email: GBSTeenPenPal@hotmail.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.
- **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.