



GBS/CIDP Foundation International

Serving patients of GBS, CIDP and Variants with support, education and research

Guillain-Barré Syndrome • Chronic Inflammatory Demyelinating Polyneuropathy

Winter 2009

The Communicator

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*Deceased



*May your holidays be filled with peace, joy, and love.
A very Happy New Year to everyone.*

THE STAFF OF THE GBS/CIDP FOUNDATION INTERNATIONAL



The holidays are a very special time of the year. We are busy preparing special meals for family and friends, reconnecting with those with whom we may have lost touch, traveling to enjoy being in the company of others, and we cannot forget shopping; not for ourselves but for others. In thinking of the needs of others and reaching out to see how we can be of help, we experience a sense of fulfillment that fills our hearts with joy!

In 2010 the Foundation will be celebrating its 30th anniversary. In 1980 Estelle and Robert Benson "reached out" to meet the needs of those suffering with Guillain-Barré Syndrome as a result of Bob's personal experience. Eight people meet around a kitchen table and the GBS/CIDP Foundation was born. Over the years it has grown to approximately 30,000 members in 174 chapters in 22 countries. The Foundation's mission remains steadfast – to insure that all who are suffering through GBS, CIDP and other related diseases are not alone. It is our privilege to work throughout the year in helping to meet the needs of our patients and their caregivers.

Since June of 2009 we have responded to over 900 inquiries via our website and more than 500 phone calls. In October we conducted a training session for 12 new liaisons. We are in the process of updating our *Overview for the Layperson*, *Caring for a Child with GBS or CIDP*, and our *Handbook for Caregivers*. In progress is a booklet on physical, occupational and speech therapies. Our advocacy efforts focus on insuring that all rare disease patients have access to early diagnosis, appropriate and affordable treatment particularly in relation to the current proposed changes in health care.

The Foundation's 11th International Symposium will take place in Valley Forge, Pennsylvania, November 5-7, 2010. Save the date! Come and celebrate 30 years of joy in being able to be there for others in need.

All the best,

Patricia A. Bryant
Executive Director

*Save
the
Dates*

11th International Symposium
November 5-7, 2010
in the Valley Forge, Pennsylvania area.

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.

Letter to the Editor



Dear GBS/CIDP Foundation International,

Thank you so much for all you do to eliminate this illness. My husband suffered from GBS after having his gall-bladder removed. It was a devastating time not only for him, but for the whole family. He was in the hospital plus rehab for 6 long months. I watched him go from a strapping man to a wasted and immobile being. He was paralyzed from the neck down and the only thing he was spared from was going on a ventilator.

The doctors were pessimistic about his recovery but the angels in rehab (the physical therapists) were encouraging. If there is just one lesson to be learned from this experience it's to always offer hope to the patient and family. He did walk out of the hospital and lived a decent life until a heart attack took his life.

I send you my story and my gratitude for all your efforts.

Alexandra Lambropoulos



Have you visited our website lately?

Get up-to-date information

www.gbs-cidp.org

CONTACT US

The Holly Building
104½ Forrest Avenue
Narberth, PA 19072
866.224.3301
610.667.0131
Fax: 610.667.7036
www.gbs-cidp.org
email: info@gbs-cidp.org

Welcome to the following newly elected members of the GBS/CIDP Foundation's Medical Advisory Board:

Peter D. Donofrio, MD
Department of Neurology, Vanderbilt University School of Medicine

Clifton L. Gooch, MD
Professor and Chairman, Department of Neurology,
University of South Florida, College of Medicine

David S. Saperstein, MD
Phoenix Neurological Associates, Ltd.

Kazim A. Sheikh, MD
Professor of Neurology, Department of Neurology,
University of Texas Health Sciences

Appreciated Stock Contributions

A wonderful way to contribute to the GBS/CIDP Foundation is to give highly appreciated stock, or low cost basis stock. If you are hesitant about selling them because of the resulting tax consequence, you can gift that stock to the Foundation in kind without any tax liability. The stock will be sold under the tax beneficial status of the 501c3 in GBS' name.

For Appreciated Stock Contributions please instruct your financial institution to transfer the appropriate number of share of the stock of your choice via DTC as follows:

DTC #0226
Fidelity Investments
FBO: GBS/CIDP Foundation International
A/C #675-719692

Stillwater Capital Advisors, LLC will provide a letter acknowledging the gift for tax purposes.

For questions please call Doug Swope of Stillwater Capital Advisors, LLC (610) 848-6745 or Toll Free (877) 790-9904.

Disclaimer Information Presented in the GBS/CIDP Newsletter is 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.

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 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.

Immunization of Patients with prior GBS and CIDP: Advice to Patients

Peter D. Donofrio, M.D.
Medical Advisory Board
GBS/CIDP Foundation International

Each year, when flu season approaches, the issue of vaccination arises and to whom the vaccine should be recommended. The decision for patients with neurologic disorders would be simpler were it not for the association of Guillain-Barré Syndrome (GBS) with the 1976 influenza A (H1N1)/New Jersey vaccine, better known as swine influenza. At that time the swine flu vaccinations were suspended after only 10 weeks when 532 new cases of GBS were reported temporally associated with vaccination. Small increases in the incidence of GBS occurring after vaccinations were also noted in the 1992-1993 and 1993-1994 flu seasons.

What should health care workers advise to patients who have previously experienced GBS and chronic inflammatory demyelinating polyradiculoneuropathy (CIDP)?

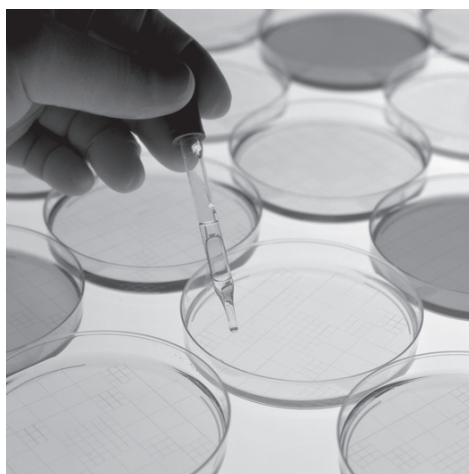
Unfortunately, little information is available to make a judgment. The best data comes from an article by Pritchard et al. (JNNP 2002;73:348-349). The authors distributed a questionnaire to members of the British Guillain-Barré Syndrome Support Group about their illness, immunizations given after their illness, and new symptoms developing within six weeks of these immunizations. Three hundred and eleven patients with prior GBS had received an immunization since recovering from GBS. Eleven patients reported new symptoms of fatigue, weakness, numbness and paresthesia, but, in most instances, the symptoms were mild and did not require hospitalization. One patient could not walk or drive for 6 weeks. The relapses were most associated with influenza, tetanus, and typhoid immunization, but some relapses were observed after immunizations with polio, hepatitis A and B, BCG, yellow fever, meningococcal, and diphtheria vaccines. Some patients received multiple vaccines making it more difficult to determine associations. In this same study, 65 patients who had had CIDP earlier in their lives received immunization. Five of the patients reported worsening of neurologic symptoms after the immunization and, in three of these, the symptoms were similar to earlier relapses of GBS. The authors concluded that in patients with prior GBS, the risk of disease relapse necessitating treatment or hospitalization was 1.18 % and only 0.3% worsened sufficiently to affect the patient's

Rankin score of disability. The data were more difficult to interpret in the CIDP patients because of the small numbers (only 65). Five patients noted some worsening of symptoms after immunization with influenza, tetanus, or pneumococcal vaccines. Some of the patients had received the vaccinations that precipitated relapses during earlier years and did not develop neurologic symptoms. The authors advised caution in interpreting the data because of the small response rate to the survey (37%) and the inherent selection bias of any survey where patients who experienced symptoms were more likely to complete the questions than those who were asymptomatic. The results of a similar survey of the GBS and CIDP members of the Dutch Society of Muscle Disorders published this year showed that none of 106 patients with GBS experienced recurrence

of symptoms after flu vaccination, but 5 of 24 CIDP patients reported worsening of symptoms after the flu vaccination (Kuitwaard K, et al. J Peripheral Nerv Syst 2009;14:81-82S).

In summary, the chance for relapse in GBS requiring treatment is about 1% after receiving an immunization and only 0.3% of patients will experience significant disability. The incidence of relapse appears to be higher in CIDP, particularly after a tetanus injection. Ultimately, the final decision to accept the immunization resides with the patient in consultation with a physician. The patient must

weigh the chances for relapses of GBS or CIDP after immunization to relapses from natural infections with the influenza virus and other pathogens, as well as the morbidity and mortality of influenza infection not affecting the peripheral nerves. The latter may be a more prominent risk, particularly if the patient is taking an immunosuppressant agent (for CIDP). Some data exist that the relative risk of developing GBS is considerably higher after the natural flu than after vaccination. A recent manuscript by a physician in England who had suffered from GBS eloquently expressed the pros and cons of vaccination (BMJ 2009;339:b3577). She has chosen to be revaccinated. Patients and physician must recognize that we know nothing about the potential for recurrence of GBS or CIDP after vaccination with the new H1N1 product. ■



My Bout with GBS

Phil Serpico – New York City, 2009

It struck me out of the blue. I was a healthy man of 67 years old who was still playing tennis weekly.

My symptoms began on a Friday afternoon; tingling sensations in my feet and a rubbery feeling in my legs that altered my gait. They grew worse the next day. It was a rapid onset and by Sunday morning I went to an emergency room on the arm of my brother.

I had already guessed at my GBS diagnosis on computer searches the day before. A spinal tap confirmed my diagnosis and I was admitted. During the next three weeks I received the customary treatments of intravenous immune globulin (IVIG) and plasmapheresis.

Despite all my rapid treatments, GBS raged on and after one week I was fully paralyzed and in the intensive care unit. I was shocked to say the least. EMG testing showed that my case was severe.

After all available treatments were done, I was sent to rehab at a nearby hospital. The next nine weeks would be hell for me. I contracted pneumonia after three days and required a tracheotomy and a ventilator to breath. My feedings were done through my nose and then my stomach. This was a major setback which I was lucky to eventually overcome. Unable to speak for weeks made things more

frustrating. But it was here that I met my first GBS representative who had to read my lips to answer my questions.

Three months had gone by since my diagnosis and I was off to rehab again, 20 pounds lighter than my previous 5'9", 150 pound frame. It was here that I was able to now hold a book from the Foundation and delve into GBS in-depth. I struggle to write this story with hands that are stiff and tingling. This tingling, in hands and feet, is more like surges of electricity. Just changing socks is a painful episode.

Enough about me. Here are some things I want to convey to others:

1. You will need support from family and friends and the GBS Foundation.
2. It is important to understand that recovery will be slow! You must adjust mentally to this fact. Anger and depression can slow your recovery.
3. Ask your caregivers to answer and explain any questions you have.
4. Check your insurance to see how many rehab days are covered. Medicare provides just 100 days and GBS recovery can exceed that easily. Recovery can range from six months to two years.

I write this piece while in my sixth month of rehab. I wait for my



nerves to heal, while I learn to walk again between the rails. I'm coming back slowly, but I'm coming back! I look forward to the day that I can stand bedside with a GBS patient who needs support and understanding. I hope it is sooner, rather than later.

In closing, I want to share with you some words I have in large print on the bulletin board in my room. They were said to the famous writer Joseph Heller who wrote "Catch 22" while he was flat on his back with GBS in 1981. Dr. Adam Bender, a 36 year old neurologist in New York City, looked at him as he was leaving and said: "You're going to get better, you know. Sooner or later you'll be able to do everything again."

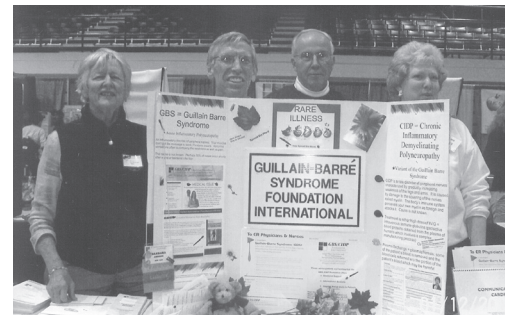
He was right. Heller recovered to write the book "No Laughing Matter" which is a chronicle of his illness. Everyone should read it, along with the Foundation's booklet on GBS. My best wishes to you.

Rochester Health Fair

20th Annual Free Family Health & Fitness Fair sponsored by Senator Jim Alesi. It was held Thursday, Oct 15th, 2009 at the Dome Arena at the Fair and Expo Center in Rochester, New York.



Photo: Left to right - Barbara Amering (Foundation liaison in Rochester, NY), Marcella Morgan (volunteer), Thomas Reichardt (volunteer). Marcella and Thomas are former GBS patients as is Barbara Amering.





A Special Shining Star ★

Bill Werling, Liaison, Dayton, Ohio

Interviewed by Cassandra Ulrich, Regional Director and Board of Directors

Once you have lived through Guillain-Barré Syndrome, you tend to find the joy in the little things in life. You breathe deeper, live, laugh and love more passionately.

Once you go through your own trials and tribulations you see the change in others who have been through what you have, and you come to realize the difference between victims and survivors.

Bill Werling was one of these people who you could tell right away was a survivor.

January 11, 2001 is a day that will forever change the way Bill Werling lives his life. That fateful morning Bill was no longer able to walk or use his lower extremities to even stand up on his own. A quick trip to the local emergency room found Bill in a place where all too many of us have been. Luckily there was a neurologist near by who happened to be paying attention to the man who was complaining of all the tell-tale signs of GBS and demanded that Bill be admitted immediately.

One day later the lumbar puncture report returned from the lab and confirmed the neurologist's hunch that Bill did in fact have Guillain-Barré Syndrome. A total of four months and 85 pounds later, Bill was able to return home with the careful attention of round the clock nursing.

A little more than a month later Bill was able to walk 30 feet with the aid of a walker, and at the end of 10 weeks of therapy Bill was walking short distances with a walker or even a cane. Bill promised to keep up his therapy on his own after the 10 weeks of monitored therapy.

When I asked Bill what was something that he took from his GBS experience he said this; "The realization that we all take so many things in life for granted allows me, and I hope others, to appreciate life more than I ever would have prior to my GBS.

I will never again take for granted things such as being able to sit, get out of bed, being able to stand. Just to be able to walk across a room is such a miracle. To be able to communicate (even if I sound different); to have eyesight; to have family and friends who love you, and care about you. These are things I give thanks for each day."

Dayton, Ohio could not be luckier to have Bill as their liaison. Since becoming a liaison, Bill has held very successful chapter meetings and has worked hard to further the growth of the GBS/CIDP Foundation in the Southwest Ohio area.

Bill's support group successful meetings are the result of his meticulous preparation and follow-up. When asked why all of the preparation? Why do you spend countless hours toiling over statistics of who attended and who responded to your meeting Bill's answer was simple; "All of the above is for one reason; this is why I became a liaison. The joy and the rewards come when you are able to visit with a patient and family in the hospital. You do not have to do much, just be there let them know you have some idea of what they are going through. Let them know that support is available, answer any questions you can and promise to try to get answers if you are not sure or do not feel comfortable in answering. I wish there would have been someone available for my family when we went through this experience.

Bill could have done what a lot of people do when faced with adversity. He could have buried himself in a blanket of self pity and doubt. He could have given up. Bill chose life, learning and survival. For this, we are grateful.

Words of wisdom from Bill, "Enjoy life!"



Reversal

Elaine Sparrow - 9/23/09

The acrid smell of alcohol
Burned her sensitive nose.

Grey-green walls and floor to ceiling
windows

With automatic blinds that closed
against the bright sunshine
casting shadows of machines, desks,
chairs, beds and a tube.

A breathing tube
cycling on and off
Breathing in, breathing out
Keeping a young girl alive.

White coats and green scrubs
"Martians working from outside the
spaceship", she thought.

"Where am I?"

A young girl, 19, paralyzed.
Smelling, hearing
Unable to move.

Tears on my face
Trapped inside

People on the outside
poking and prodding
working to keep me alive.

Stuck, trapped in this room
the tube room
my life support.

Voices described my condition,
staff dressed in white
caring for my basic needs.

Eyes not seeing.
Mouth not speaking.
Skin not feeling.

Ears hearing, mind fearing,
I left.
All went black.
In fear I left.

Nutrients dripping into my veins
flowing through my body.

I waited.

In the unknown and
unknowable darkness

I waited alone for this unnamed illness
to reverse its hold on my body.

I waited.

For my body to accept itself.
To own itself once more.

And then one day the sun came out ~

My finger moved
I wiggled my ear

Emotions, so many emotions.

The long road back had begun.



GBS/CIDP
Foundation
International

Tell us your story



I would like to up-date my progress with GBS. I was stricken in 2000, and had very little usage of arms legs, or movement of any kind for almost a year. Slowly some movement came back but was very limited for the next two years. Then there was no improvement for the next five years. One day I found I could close my left hand and make a fist, which seemed wonderful to me. By that time I could manage a walker for a short distance but was very weak and shaky. In the summer of 2008 I had a heart attack and open-heart surgery, which really took a toll on my strength and my entire body. I started therapy in August of 2008 and have been taking it three times a week since that time. I have been getting stronger and on March 18 of this year I took my first steps with a cane. My therapist would hold on to me with a gate-belt. However, this week I have started walking with the cane and no one holding on to me. It is a wonderful feeling for me, after nine years, to be walking even though I'm very weak and shaky. Through prayers and determination I am finally becoming a human being and can function in the real world. Tell your readers to never give up and keep trying. Oh, yes I didn't tell you, I am 80 years old. Thank you for letting me express my feelings.

Billie Scott, Fredonia, Kansas

In March 2001 I was in my 8th grade year ready to go to high school. I was leader of the dance team. One day it all changed. I woke up to go to the bathroom and could not walk or move my arms or hands. Me being only 13 years old, I had no clue what happened, CIDP took over me. I went through the most tragic time in my life, but could not let it keep me down. I worked very hard with a positive attitude and one of the news stations did a whole session on me for working hard and staying positive. Doctors and therapists had no clue as to what caused my condition but long term treatment was ahead for me. Its been 8 years, I have not fully recovered but I am up walking with Afos and am currently getting feelings in my legs, feet and hands and am looking forward to a complete recovery with my mind set, anything is possible. I'm getting better every day!

Angel Green, Katy, Texas

I was diagnosed with GBS a couple of years ago. It was a very difficult time for me and my family. I took comfort in the information from your foundation. I am well now and happy to give back.

Best regards,

Ed Ryan

C.A.R.E.



To Whom It May Concern:

The members of the C.A.R.E. (Complementary and Alternative Research and Education) Club at the Western University of Health Sciences in Pomona, CA would like to present this donation of \$418.50 to your cause. As students, faculty and staff of the health professions, we are supportive of the mission and vision at the GBS/CIDP Foundation.

Just as we did last year, our club held a Powder Puff Football game to raise money for the fight against Guillain-Barré Syndrome. We have included some pictures from the game. To encourage participation in this event, it is becoming tradition that the female medical students play football, while the men cheer the women on from the sidelines. We all had a blast playing, cheering for our teams, and, most importantly, raising money and awareness!



On behalf of our school and club, we would like to say thank you for your continued support to patients and families who suffer from GBS.

Sincerely,

Andrea Lombardo, May Sun (Co-Presidents)

Louise Ye (Vice President)

Jung Hee Han and Kaori Nakasone (Treasurer and Secretary)



Students Giving Back

June 14, 2009

Hello:

We are Mr. Skolnik's 4th grade class from North Shore Synagogue in Syosset, New York. Our class project this year was to raise money for Guillain-Barré research and awareness. We did this by making bracelets to sell throughout the year. These bracelets were reminders to do *Mitzvot*, or good deeds, every day. One *Mitzvah* we learned about was the obligation to visit the sick. Our teacher, Mr. Skolnik, was sick with GBS last year. We thought it was important to learn about this disease and give back to such an important cause.

Enclosed, please find a check for the money we raised this year as well as our class picture.

Sincerely,
Les Skolnik and Class



May 26, 2009

To: The GBS/CIDP Foundation

From: Stone Mountain Elementary

A fifth grade class in Highlands Ranch, Colorado has had a very interesting year! The school year started like any other for Ms. Gehringer's fifth grade class. In September something happened that would impact the entire year. Ms. Gehringer woke up unable to move her arms and legs and she was diagnosed with GBS. Ms. G was unable to join the class as she worked through her rehabilitation process.

Ms. G's class remained concerned and hopeful for her as she worked on her recovery. In January 2009 she returned to school in a wheelchair and taught math. Another teacher, Ms. Johnson, was brought in to teach the remaining of the day. It is now May and Ms. G is walking using a walker and has made a very successful recovery. She has taught the class determination, perseverance, drive, and an extremely positive attitude.

This fifth grade class has focused on leadership, responsibility and community service. With their hard work the class decided to have a bake sale. The parents helped the class to prepare an awesome spread! With lots of hard work we successfully raised \$700.00 in two days. We would like to donate our proceeds to help research and aid all those that are affected by GBS! As a class, we are so thankful for the opportunity to learn from Mr. Gehringer and her experience as it has helped us all to be stronger, smarter, and more thoughtful fifth graders.

Sincerely,
Ms. Gehringer and Ms. Johnson's Fifth Grade Class
(Julia, Kylee, Erik, Jaclyn, Joey, Lauren, Lizzie, Megan, JJ, Johnny,
Karli, John, Tatum, Carter, Jared, Maggie, Hunter, Dominique,
Harrison, James, Brianna, Clay, and Zach)

**Tell us
your story**



I was visiting my family in California during July 2005 after my first year of college. Two days into my trip I began to feel very weak with a strong tingling sensation in my toes and hands. On my third day there, I started to feel horrible pains in my legs and back. Doctors didn't know what was wrong so they sent me home. On the fourth day I could barely walk on my own. I went back to the ER where I was diagnosed with GBS. I was immediately admitted into the ICU. I slowly became partially paralyzed from the waist down over the course of the next two days. I was in the hospital for a total of two weeks where doctors aggressively combatted the GBS with IVIG and plasmapheresis treatments.

I couldn't believe that I was a 19 year old first year college student who had the world by the tail and was now barely able to walk, shower, and even eat on my own. I was determined to get better and return to school in August, against all advice from the doctors who said that I would have to take a semester off. I pushed myself through many physical therapy sessions and with the help from my friends, family and faith, I returned to school on time to begin my second year of college. I am now so proud to say that I was able to graduate in four years and have just started my first job at an amazing company in Atlanta GA.

I'm now 22 and healthier and stronger than I've ever been. I will forever be a changed person after winning my battle with GBS.

*Amanda Smets,
Alpharetta, Georgia*

DIRECTORY

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

- **"CIDP" Group**

For those having diagnosis of chronic inflammatory demyelinating polyneuropathy. 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 those children diagnosed with chronic inflammatory demyelinating polyneuropathy. A separate registry has been created. Please contact the National Office for details.

- **Pen Pals (for all ages)**

Faith & Jeffrey Aronsky, GBS Pen Pal Coordinators
P.O. Box 802954 • Santa Clarita, CA 91380

- **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.

- **A Teenage Pen Pal Group**

Arielle Challander • 413 Shawn Drive, Traverse City, MI 49684 • 231-946-7256

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, 264 Oenoke Ridge,
New Canaan, CT 06840 • (203) 972-2744

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.

- **AMSAN Group**

Please call the National Office for contact with others.

- **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.



Guillain-Barré Syndrome • Chronic Inflammatory Demyelinating Polyneuropathy

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