

Summer 2011

GBS | CIDP

Foundation International

Providing Strength Through Support

The Communicator

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The Holly Building

104½ Forrest Avenue

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1.866.224.3301

1.610.667.0131

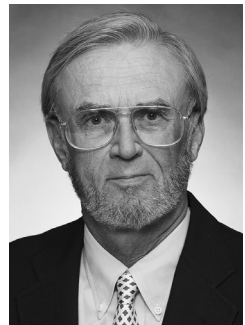
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Message from the President of the Board of Directors

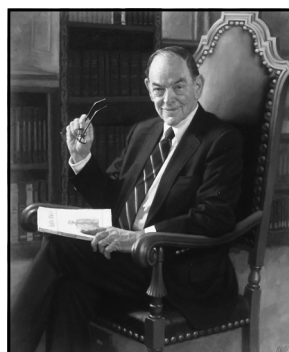
About twenty years ago, when I first began serving as a GBS/CIDP Foundation liaison in Hawaii, it never occurred to me that one day I, a 1985 GBS survivor, would be writing a column for *The Communicator* as your Board President! One thing led to another, however...meeting Estelle Benson in Honolulu when she was in town for a convention, a trip to Dallas for a regional liaison meeting, and suddenly the realization that I was meeting some of the most amazing and committed volunteers I had ever worked with. I was "hooked" and was honored to be asked to serve on your Board when I was approached several years ago.



Since then, it has been my pleasure to work with all of you to help the Foundation grow and fulfill its mission of serving the patients, families and caregivers impacted by GBS, CIDP and the variants. And I can assure you that the focus on patients will continue as we develop the additional technical, human and financial resources we need to sustain and improve our efforts on your behalf. Work is already underway on a project to vastly improve our web site and you will be seeing other new communications initiatives soon.

As we say in Hawaii, Mahalo! (Thank you!) for your support. We are making a difference!

Aloha,
Phil Kinnicutt
Board President



Save the Date!
CITIZEN OF THE YEAR AWARD

Presented to

DR. ARTHUR K. ASBURY

SPONSORED BY GBS/CIDP FOUNDATION INTERNATIONAL

Gala Dinner on October 28, 2011
at the College of Physicians of Philadelphia

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.

NYC Marathon

Dutch GBS patient Marc Burggraaf had a severe case a few years ago and spent considerable time in the ICU and on a respirator. Patricia Blomkwist, liaison for The Netherlands, visited him both in the ICU and in rehab. Fortunately Marc made a good recovery and eventually 'starred' in the Dutch GBS video!

Marc's friends, Maarten Vrij and Gaby Smeenk, decided to run the NYC Marathon on November 7, 2010 to raise funds for the Foundation in Marc's honor. They collected a total of \$ 3,000! Thank you so much!"



Letter from Patient

Melissa from St. Louis, Missouri wrote us the following story about her inspirational experience with GBS:

I was diagnosed with GBS on May 2, 2011. I had numbness in my legs, and was told, "It will get worse before it gets better." The next day I was taken to ICU due to respiratory failure and placed on a ventilator. My family was told it could be months before I showed improvement. I was induced into a coma for 10 days. I never lost the swallow reflex, so I was fighting the breathing tube in my throat. When I awoke I still had no feeling in my legs, but was recovering in other ways. After being in ICU for 25 days, I was recovering so fast I was sent to rehab. I was in there five days, and made a fast recovery. It is now a month later and I am back at work, walking with a cane; speech is almost normal, and the only side effect I have is some numbness in my feet and fingers. The doctors are amazed at how fast I came out of it.



Research Grants For 2011 Announced

The following research grants were awarded for the year 2011:

The Role of Osteopontin and Anti-osteopontin Antibodies in CIDP

....

Examining Antagonistic/Synergistic Effects of IVIG and Erythropoietin (EPO) in a Model of Autoimmune Neuropathy

....

Implementation of the International Guillain-Barré Syndrome Outcome Study (IGOS)

....

Peripheral Neuropathy Outcome Measures of Standardization (PeriNoms) Study

We look forward to sharing the results in a future issue of *The Communicator*.

Research Grants for Investigators

Letters of Intent for the next grant cycle are due to the foundation office on November 1, 2011 for funding in 2012. Letters of Intent should be sent to the GBS/CIDP Foundation International, The Holly Building, 104½ Forrest Avenue, Narberth, PA 19072. Questions can be answered by calling 610-667-0131 or emailing info@gb-cidp.org.

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 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.

Criteria For Diagnosing CIDP

David S. Saperstein, MD - Phoenix Neurological Associates, Phoenix, AZ

In a prior article in *The Communicator* I discussed, in general terms, how physicians diagnose CIDP. In this article I wish to focus on so-called diagnostic criteria. Beginning with the earliest descriptions of CIDP several decades ago, researchers have tried to determine specific sets of criteria that would allow a reliable diagnosis of CIDP. Criteria require certain clinical and laboratory findings to be present. The first formal set of criteria was devised in 1991 by a group of peripheral nerve specialists. These criteria, typically referred to as the "AAN criteria" (for the American Academy of Neurology), were created for research purposes. It was important to be sure that patients being studied truly had CIDP. As a consequence of this research focus, the AAN criteria are very stringent. People who meet these criteria almost certainly have CIDP, but a significant percentage of people who have CIDP will not meet these criteria.

Every diagnostic test or criterion can be described in terms of sensitivity and specificity. A test is highly sensitive if most people with a particular disease are identified by this test. In contrast, a test is highly specific if most everyone who tests positive has the disease. Unfortunately very few tests are 100% sensitive or specific. Therefore, people with a particular disease may have a negative test result (referred to as a false negative result) and some people who do not have the disease will test positive (false positive). Thus, every diagnostic test or criteria has to strike an acceptable balance between sensitivity and specificity.

The AAN criteria, created for research purposes, have a sensitivity of less than 50%. If a physician relied on the AAN criteria to diagnose CIDP in his or her patients, a large number of CIDP patients would not be diagnosed. Most CIDP specialists do not use specific criteria to diagnose CIDP; instead, based on experience, they intuitively synthesize symptoms, clinical exam findings and laboratory test results to determine who is or is not likely to have CIDP. In contrast, general neurologists are more likely to rely on criteria. Therefore, following the publication of the AAN criteria, the goal has been to develop criteria with a high likelihood of identifying people with CIDP (high sensitivity) but also will not diagnose CIDP in people who do not have it (high specificity). The most popular criteria devised after the AAN criteria are the so-called INCAT criteria (for the Inflammatory Neuropathy Classification And Treatment group). In some studies the INCAT criteria showed a sensitivity of greater than 85%, but other studies found sensitivities of less than 65%. Both the AAN and INCAT criteria have high specificities.

The main weakness of the AAN and INCAT criteria is that they focus almost exclusively on the findings of the EMG test. EMG is an important test for identifying the demyelination that occurs in the nerves of people with CIDP. However, for a number of reasons, many people with CIDP will not have clear-cut demyelinating features on their EMG.

More recently proposed CIDP criteria deemphasize EMG while giving more weight to clinical features like the pattern of weakness or numbness found on examination. For example, the presence of weakness throughout the arms and legs, as opposed to weakness restricted to the hands and feet, is highly suggestive of CIDP. In the presence of more diffuse weakness, only a small degree of abnormalities on EMG are needed to diagnose CIDP. In less clear-cut cases, analysis of spinal fluid protein or nerve biopsy can make the diagnosis. In 2009, the CIDP Validation Study Group, comprised of members of the GBS/CIDP Foundation International Medical Advisory Board, published CIDP criteria that were based on consensus opinion from the review of 150 patients. They found the presence of symmetrical, widespread weakness was a very accurate indicator of CIDP (regardless of whether EMG showed demyelinating findings). These criteria (often referred to as the Koski criteria) identify more than 83% of patients with CIDP.

At the recent Peripheral Nerve Society meeting in Maryland I presented the findings of a study of patients suspected of having CIDP but who did not meet AAN or INCAT criteria. Forty-three patients, from seven specialized neuropathy centers, were studied. Sixty-five percent responded to treatment with IVIg. Three quarters of these patients had diffuse weakness. However, improvement was seen in 6 of 12 patients with only sensory problems. In some of these patients, spinal fluid analysis or nerve biopsy helped clinch the diagnosis of CIDP. At the same meeting, Dr. Richard Lewis and colleagues presented additional data from the CIDP Validation Study Group. They described nine CIDP patients with just sensation symptoms. Most had demyelinating EMG and most improved with treatment.

Newer CIDP diagnostic criteria have been helpful. However, ways to accurately diagnose CIDP in people with mainly sensory manifestations are still needed. Most of these people will have a neuropathy other than CIDP, but we do not want to miss anyone with a potentially treatable condition like CIDP. Researchers continue to work on this problem.

Study	# of pts	AAN	INCAT	Saperstein	EFNS/PNS	Koski
Saperstein	26	47%	69%	88%	81%	92%
Van Den Bergh	28	35%	43%	-	-	-
Rajabally	20	50%	-	-	-	-
Tackenberg	76	52%	-	83%	95%	-
Koski	267	11%	64%	-	34%	83%

Table. Comparison of the Sensitivities of Different CIDP Criteria*

*Adapted from Saperstein et al, *J Peripher Nerv Syst* 2007;12 (Suppl. 1):75-76.

Definitions: AAN = American Academy of Neurology, INCAT = Inflammatory Neuropathy Classification and Treatment group, EFNS/PNS = European Federation of Neurology/Peripheral Nerve Society



Peripheral Nerve Society Meeting

Estelle Benson, our Founding Director, and Carol Lee Koski, MD, our Director of Medical Affairs, represented the organization at the annual meeting of the Peripheral Nerve Society held in Potomac, MD from June 25th to June 29th. We were proud to be a sponsor of the "GBS/CIDP Day." Involved in the Program Day were:

Bernd C. Kieseier, MD
 Hans-Peter Hartung, MD
 Richard A.C. Hughes, MD,
 FRCP, FMedSci
 Robert R. Myers, PhD
 Angelo Quattrini, MD
 Robert Baloh, MD, PhD
 Chiara Briani, MD
 Wilson Marques, Jr., MD, PhD
 Klaus V. Toyka, MD
 Hugh J. Willison, MD, PhD
 Jean-Marc Léger, MD
 Peter J. Dyck, MD
 Pieter A. van Doorn, MD, PhD
 Cindy Shin-Yi Lin, PhD

Where We Have Been!



On June 22, 2011 the GBS/CIDP Foundation International participated in the 5th Annual Neuropathy Action Awareness Day in Sacramento, CA. Representing the organization were Marilyn Tedesco from the Board of Directors, and liaisons Betty Donelson from Granite Bay, CA and Rose Nagao from Sacramento. They had a table in the Exhibition Hall and were able to attend sessions offered to participants. A member of our Medical Advisory Board, Jonathan Katz, MD, Chief of Neuromuscular Services at California Pacific Medical Center, participated in a panel "The Whole Body Experience: Neuropathy from Head to Toe and Medical Laws: From the Courts to Your Nerves."



From June 20th to June 23rd the Foundation was represented at the World Physical Therapy Congress in Amsterdam, The Netherlands. Two members of the Board of Directors, Patricia H. Blomkwist-Markens from Amsterdam and Glennys Sanders from Lincolnshire, England represented the Foundation. There were approximately 5,000 people in attendance (mainly physiotherapists), of which about 3,500 came from outside The Netherlands. At our booth in the Exhibition Hall, we introduced our new pamphlet, "Guidelines for Physical and Occupational Therapy." Mrs. Blomkwist-Markens reported, "We went through the first box of the wonderful new booklet within the first few hours!" People stopped by the booth from around the world, including Kuwait, Congo, Nigeria, Bermuda, Trinidad, the United States, Canada, New Zealand, Australia, Germany, Switzerland, Belgium, South Africa, Chile, Brazil, Denmark, Sweden, Norway, Iceland, Zimbabwe, Saudi Arabia, Lebanon, Venezuela, Guatemala, Indonesia, Malta, India, Pakistan, Iraq, Poland, Israel, Greece, Spain, Portugal, Italy, Turkey, Latvia, Finland, France, the Czech Republic, Ireland, the United Kingdom, Hungary, Malaysia, Croatia, Japan and Hong Kong. "The translations of the GBS and CIDP trifolds were a great hit as well. It was fantastic to see how impressed people were when we were able to provide them with literature in their own language."



Patricia H. Blomkwist-Markens
and Glennys Sanders

TO HONOR THE FOUNDERS OF THE GBS/CIDP FOUNDATION INTERNATIONAL

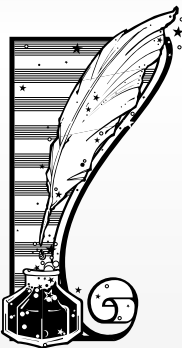
THE ROBERT & ESTELLE BENSON FELLOWSHIP

HAS BEEN ESTABLISHED.

The fellowship encourages junior faculty to develop academic excellence in the field of inflammatory neuropathy.

To contribute to this Fellowship, please make checks payable to:

GBS/CIDP Foundation International
 104 1/2 Forrest Avenue, Narberth, PA 19072



Chapter Events

Enjoying an Afternoon of Fashion and Tea

The San Diego Chapter held a Fashion Tea at The Westgate Hotel, benefitting The GBS/CIDP Foundation International, on May 27th. Lizz Russell-Parker, a 27 year survivor and the head of the local chapter, organized this event. Guests in attendance included Julie Jukich, another liaison from the San Diego chapter, Marilyn Tedesco, a GBS/CIDP Foundation International board member, and many others.

Guests enjoyed a wonderful tea and a beautiful fashion show featuring the designs of Lizz Russell (purses, jewelry, gowns and clothing) while supporting the efforts of the local chapter to bring awareness of GBS and CIDP. All in all it was a fun day of tea, fashion, shopping and wonderful food to benefit GBS/CIDP. Lizz Russell said her mission is, "to inform as many people as I can about this disease and early diagnosis is key." We want to thank Lizz for a successful event.



Charlotte

"Running for Those Who Can't"

This is the 5th year that Hannah Blanton, our liaison in Charlotte, has organized the Annual GBS/CIDP 5K and Miracle Mile. It is an opportunity for those who run, or even walk, to join in an event that focuses on "running for those who can't" while raising money for the GBS/CIDP Foundation International. This year over 300 runners came out to support this event. The number of runners coming out for this day of family fun, food and entertainment has grown every year.

Non-Chapter Events

Think of Raising \$5,800 Just by Sitting!

Each year since 2008, William "Bill" Shirey of Estes Park, Colorado has been a great supporter of the GBS/CIDP Foundation International. Bill has organized a fundraiser in a unique manner. His mission was to find a way for others to participate and bring home the idea that patients with GBS or CIDP may look healthy but can still have problems with walking caused by damage to their nerves. He also wanted to build awareness of these rare syndromes so that others can learn about them.

Bill's solution was to have a "sit-in." He along with the Men of St. Bart's meet each year to show their support in a clever method. The "sitters" are asked to get donors to sponsor their sitting. The men will cook and serve breakfast to all of the sitters. The time is spent bringing awareness and support to others while having a lot of fun.

Each year Bill's group has grown and so has their support for others who want to find a cure for GBS or CIDP. The Foundation wants to express gratitude for Bill and his "merry band" for all their devotion to helping others and bringing awareness along the way. They have been responsible for collecting \$1,800 this year and over \$5,800 for research, support and advocacy since they began their sit-ins four years ago. They truly demonstrate fellowship for others and we thank them!

10 Year Old in Montana Organizes Fundraiser at School

Hailey Cannon came down with CIDP last year when she was only 9 years old. Hailey, who lives in Montana, decided that she wanted to hold a fundraiser to support the Foundation from which she and her family received so much support. She decided that she could raise money from the children at her school. The principal was awesome in his support of the project. So every Friday this past year at Hailey's school they held a fundraiser during lunch. Children paid a dollar to shoot a free throw. If they made the shot, they received a Gatorade (which was donated by Pepsi). Over the past school year a total of \$700 was raised by the students at Hardin Intermediate School. Our thanks go out to all of the students, parents, teachers, administrators and Pepsi - and particularly to Hailey and her family - all of whom made this fundraiser a success.

Miracle Mile Walk in Arizona

On May 7, 2011 the Arizona GBS/CIDP Support Group held its annual Awareness Month Miracle Mile Walk and Celebration. It was set in beautiful Chaparral Park. In charge of the walk was Gene DeMart, liaison representative for the Foundation, and his wife, Mina. Gene organizes this event each year to bring awareness and support to those who have GBS and CIDP.

This year's event met with a few obstacles. A water main break on the main road made it necessary for those attending to find a way around the flood. Add to that the 99 degree temperature (in early May) to make it a challenging walk! In the name of a good cause, the walkers persevered through the heat. Waiting for the group at the end of the walk was a picnic complete with all the cool drinks they could consume. With hearts lightened, stomachs filled and thirsts quenched, all enjoyed the camaraderie.

Each year that Gene and Mina have held the walk attendance has grown steadily and so has the support. This year's event raised \$1,900! Thank you to Gene, Mina and all who that attended and raised awareness to support research, education and advocacy for our patients. See you next year!

Using Artists to Help a Cause

Art Sale Raised \$30,000 for Guillain-Barré Research

Jennifer Ford

Hannah Blanton's life changed one day when she was out for a walk.

In 2003, Hannah was strolling her young children through her Foxcroft neighborhood when her feet became numb. A registered nurse, Blanton knew the numbness was cause for concern.

Over the following week, the numbness and weakness moved up her body until she could barely walk, and paralysis set in from her chest down.

Doctors diagnosed Blanton with Guillain-Barré syndrome. According to the GBS/CIDP Foundation International website, GBS is an inflammatory disorder of the peripheral nerves outside the brain and spinal cord.

Affecting one to two people in every 100,000, GBS is characterized by a rapid onset of weakness and, often, paralysis of the legs, arms, breathing muscles and face.

It took more than two months of treatment and intense occupational, physical and speech therapy for Blanton to relearn how to sit, stand and walk. Fortunately, most with GBS recover; however, the length of the illness and recovery can vary. For some, paralysis can be permanent.

After her experience, Blanton was determined to help others overcome the challenges of the disease.

In November 2009, a sermon by the Rev. Bob Henderson at Blanton's church, Covenant Presbyterian, guided her to help other GBS sufferers.

Henderson shared the story of a local artist who was homeless and disabled. The real message of the artist's life was that she gave the money earned from her art back to her homeless neighbors.

Shortly after the sermon, Blanton and her family were serving dinner to homeless people and families at Room in the Inn at their church when she met the artist Henderson had spoken about.

The chance meeting sparked Blanton's imagination, and Carolina Art Soiree was born.

"We are all survivors of something or another; mine happens to be GBS," said Blanton, 41. "We are given challenges and it's how we use those circumstances and our own gifts that becomes the blessing in blessing others."

Carolina Art Soiree is an exhibition of local artists



Nancy Maloney (l) and Hannah Blanton (r) are co-chairwomen of the Carolina Art Soiree. Photo courtesy of Ron Deshaines Treasured Events of Charlotte

benefiting GBS/CIDP Advocacy. Similar to GBS, Chronic Inflammatory Demyelinating Polyneuropathy is also a disorder of the peripheral nerves that causes weakness in the legs and sometimes in the arms.

Blanton and event co-chairwoman Nancy Maloney, 48, designer and owner of Good Manors Inc., share a connection to GBS: Maloney's husband developed GBS more than 10 years ago.

Together, Blanton and Maloney connect local artists with patrons through Carolina Art Soiree and raise money for the GBS/CIDP Foundation.

"The Soiree is like baking a cake," said Blanton. "I gather the ingredients needed and bake the cake, but Nancy is the icing and detailing on the cake. She has the eye, the expert design, the touch with flowers and handles the grouping of the artwork. She

creates the ambience.

"We are a great team. Many of these artists have tremendous talents but need another venue to be seen and appreciated."

This year's event took place May 5 at Morrison SouthPark. Guests enjoyed food and drinks from sponsors Petit Phillippe, Delish Gourmet Cupcakes, Penny's Pimento Cheese, Earth Fare, Olde Mecklenburg Brewery, Southern Artisan Spirits and the wine department of the Morrocroft Harris Teeter.

Forty percent of each tax-deductible purchase went directly to the GBS/CIDP Foundation. More than 30 artists participated this year, including artists from Urban Ministry Center's Artworks945 program. The event raised \$30,000.

"The Carolina Art Soiree is the largest fundraiser for the foundation," said Blanton. "The money raised helps the foundation support advocacy, education, awareness and research for the disease."

The Charlotte GBS/CIDP Support Group also hosts an annual 5K and Miracle Mile to raise money. That fundraiser, which was held May 7, had 385 participants.

This year's Mother's Day was a joyous one for Blanton, spent with family and friends and with the realization she is making a difference in the lives of others.

Read more: <http://www.charlotteobserver.com/2011/06/01/2332141/using-artists-to-help-a-cause.html#ixzz1U9wjamQ7>

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From Mule Train to eMail – The Time is Now...

As always, the Foundation strives to keep you informed and up-to-date on medical issues related to GBS, CIDP, and variants.

The telephone is great but is not effective for reaching many people quickly. At one time, there were mule trains crossing America making communications a long and slow undertaking. This was followed by government-regulated postal service - which still required at least a day for communications to reach their final destination. As time marched on, the need developed for even quicker methods of communication without using the telephone; independent businesses such as FedEx, UPS, DHL and others quickly stepped in to satisfy that need in the United States. Now, the only remaining mule train is the one that runs up and down the Grand Canyon, and in our busy society, the need for instant communications has grown exponentially.

So how can we quickly reach out to our members when important information should be shared? Fortunately, there's electronic mail (email) which is very effective in reaching large numbers of people quickly.

The Foundation's goal is to send time-sensitive requests and information via email to keep patients and their families well informed. In the future, as in the past, we will be partnering with companies that want to make improvements in treatment; keeping your email current and active will allow the Foundation to let you know the most up-to-date information and keep you informed about surveys, studies, medical updates and trials, which could benefit you as a patient. Email can also be used to quickly communicate messages about changes within the GBS/CIDP arena such as Washington legislative "call to action" notices and provide instant access to our newsletters and special announcements.

Won't you consider joining us in keeping up with important information and issues regarding GBS, CIDP and variants through email? It's time to consider it. If you haven't already provided your email address, please send it to us at info@gb-cidp.org. If and when your email address changes, updating your email address is as easy as going on our website - www.gbs-cidp.org - and clicking on "Contact Us" to complete a change of address form which is located at the bottom of the "Contact Us" page. Please join us in the cyber age of instant access to communications about GBS, CIDP and variants!

Afternoon at the Vineyard

A Benefit for the GBS/CIDP Foundation International

Saturday, September 10, 2011 ~ 11:30 am - 3:00 pm

Ruth Elster and her husband Bob, in gratitude for her recovery from Guillain-Barré Syndrome, are hosting an afternoon at their vineyard, at Arrowhead Mountain.

A catered lunch will be served along with wine tasting. Dr. Carol Lee Koski, renowned neurologist and member of the GBS/CIDP Medical Advisory Board, will make a presentation and be available for questions and discussion.

The facility is not handicapped accessible and accommodates only 40 persons.

Cost per person is \$50.00. Please make checks payable to: GBS/CIDP Foundation International

Mail to: GBS/CIDP Foundation International, The Holly Building, 104 1/2 Forrest Ave., Narberth, PA 19072-2215

Transportation will be provided from a designated parking location in Sonoma.

The location details and event schedule will be sent to you upon receipt of your reservation.

Letter from Patient

Hi, my name is Jacki Bastien. I was in a doctor's office in January 1994 in Gatineau, Quebec. I had a cold, fever and was coughing. The doctor said I had a virus and to take some syrop and Tylenol. A few days later I had no energy and went to the emergency room. The doctor said I had pneumonia, so they gave medication for that. In the middle of the night that day I started to have shortness of breath and some numbness and tingling under my feet. I went back to the emergency room and they kept me in the hospital. They told me that a specialist would come and see me and they admitted me finally. Well I thought I would see the specialist that day. Well guess what - I saw the specialist one week later. I was not impressed, but anyway he asked me what was wrong with me. I explained my situation, so he asked me if I could stand up and I told him I don't feel my legs. He insisted that I stand up, so I did and next thing I was on the ground, my two feet under my bum. By then my feet were swollen and along with numbness and tingling. He said okay, they didn't have the tools at the hospital to do the necessary test so they sent me by ambulance to another hospital in Ottawa. When I got to the hospital in Ottawa they did an electric shock test. At that point I was not feeling anything through my body, and I basically stopped breathing. The doctor did a breathing test, and I was told that I had stopped breathing so they put a machine in my mouth to help me breathe. Then I was in the ICU for one week or more. I couldn't walk, and was breathing slowly. My family was very scared to lose me and I had three lovely daughters at home. Then in March 1994 I started my physiotherapy. I could not walk. I had to start walking again. I went through some plasmapheresis treatment, lots of those, and they filtered my blood. It took me until May 6, 1994 for me to start walking. That was some experience. And today I thank the doctor from the hospital in Ottawa that saved my life. This is the doctor who told me I had Guillain-Barré Syndrome. I thank GOD for giving me a second chance of life. And today I work for Canadian Blood Services, for 11 1/2 years. I met the nurses that gave me my treatment at the hospital at that time. Thank you God for being with me through those times.

Jacki Bastien, Rockland, Ontario



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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 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.