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

FEBRUARY 29TH

GBS/CIDP Foundation International joined in with people from all over the globe to celebrate Rare Disease Day on the rarest of days, February 29th. Ken Singleton, Executive Director, went to Bethesda, Maryland and participated in the National Institutes of Health fifth annual Rare Disease Day with a day-long celebration and recognition of the various rare diseases research activities supported by the NIH Office of Rare Diseases Research, the NIH Clinical Center, other NIH Institutes and Centers, the Food & Drug Administration’s Office of Orphan Product Development (OOPD), the National Organization for Rare Disorders (NORD), and the Genetic Alliance. On March 1st, he joined in with others at the FDA Rare Disease Patient Advocacy Day in Silver Springs, Maryland. The purpose of the event was to enhance awareness of FDA’s roles and responsibilities in the development of products (drugs, biologics, and devices) for the diagnosis, prevention, and/or treatment of rare diseases and conditions.

Message from the Executive Director

CALL TO ACTION

State and Federal Level Advocacy
Volunteers Needed

Patient advocacy is an important part of the Foundation’s mission. With the upcoming implementation of the Federal Affordable Care Act, monitoring healthcare-related legislation at the Federal and State level is more critical than ever in ensuring access to quality and affordable healthcare for our patients and their families, and we could use your help.

Two issues have already started to surface in State Legislatures as they start to implement the act and deal with the creation of their individual “State Health Insurance Exchanges.”

1. One troubling concept is the possible transition from a fixed co-payment plan for prescription drugs to a co-insurance model that could result in an enormous increase in what our patients would have to pay for expensive drug therapies like IVIG.

2. Another problem is the possible adoption of a “fail first” or “step therapy” approach that would require medical personnel to use the least expensive drug or treatment procedure first upon a confirmed diagnosis. If it fails, they would then continue using approved less expensive interventions until deciding to use the more expensive alternative. Since early diagnosis and treatment of GBS, CIDP and variants is critical in limiting nerve damage, this approach could have a devastating impact on patient rehab and recovery.

It is vitally important for us to participate in the legislative process at both the Federal and State level. If you have an interest in helping out and are willing to have your voice heard on behalf of the Foundation, we would like to hear from you. Our Advocacy Director Ed Gdula and the office staff will provide the training and all necessary materials and information.

Please contact the office at info@gbs-cidp.org, (610) 667-0131 or toll free (866) 224-3301.

Looking forward to you joining us in our advocacy efforts,

Ken Singleton

In case you haven’t seen our newest publication, Guidelines for Physical and Occupational Therapy, check it out on our website www.gbs-cidp.org or contact the office for a copy at info@gbs-cidp.org or 610-667-0131. Also, in the summer, look for the announcement of the publication of Guillain-Barré Syndrome: An Acute Care Guide for Nurses and Therapists.
RELAPSE FROM GBS

**Question:** Mr. RB asks about a potential complication or aftermath of GBS that is likely on the minds of many former GBS patients. He expresses concerns about relapse and wonders how common it is, what the symptoms are, and what can be done about it. He relates experiencing, from time to time, tingling or numbness in the soles of the feet, wondering if this is a sign that GBS is coming back. He understands that about 10% of GBS patients have a relapse, and wonders how to distinguish tingling sensations that pass from those that presage an attack.

**Reply:** Mr. B raises important issues, of natural concern to former GBS patients. Let's first discuss ‘relapse’.

One can look upon a true ‘relapse’ as a deterioration or reversal of symptoms, in the form of recurrent weakness and/or abnormal sensations that is experienced early in the course of recovery from GBS. In the typical GBS case, the patient deteriorates, from their normal state, by developing progressive weakness, usually accompanied by abnormal sensations (tingling, numbness, formations [a sense of worms or ants crawling under the skin], even frank pain), over several days to at most four weeks, until this deterioration stops. In most patients, about two thirds of them, weakness ascends the body, leading to inability to walk and even weakness of the arms. In about a third of patients, weakness progresses up the body to involve the breathing muscles, requiring mechanical ventilation, with the use of a respirator, for days to weeks. In both situations, once weakness maximizes, the patient plateaus for hours, and barely noticeable, to days or longer. This is followed by steady recovery. During this recovery, often early on, within its first few days to weeks, that relapse can occur. And this relapse, which occurs in perhaps 10% of patients, can be severe enough to require re-intubation and mechanical ventilation. So relapse can be serious. Once the relapse has plateaued, improvement of strength again resumes, often steadily. It is helpful early in the recovery phase, for physicians to be on the lookout for deterioration, in case breathing collapses.

After the patient has recovered, which in most people (up to 75%) can be a full recovery, there are some potential further scenarios.

A small percentage of ‘recovered’ patients may experience ongoing fatigue and/or abnormal sensations, such as tingling. Fatigue is often treated with paced activities. Abnormal sensations are sometimes improved with such medications as gabapentin (Neurontin) or pregabalim (Lyrica).

Up to 3% of recovered GBS patients may incur a true second episode or case of GBS.

And occasionally a recovered patient may experience a recurrence of abnormal sensations and/or weakness and think it is their GBS coming back again, when it is actually something else. These patients, essentially all patients who have recovered from GBS and again get sensation abnormalities, warrant a new look and evaluation of their symptoms. Do not automatically expect the recurrent symptoms to be due to a recurrence of GBS. Sometimes new weakness and/or sensations changes can reflect newly evolving CIDP, the chronic cousin of GBS. Or an entirely different disorder may be developing. The diagnostic possibilities are not that small, including diabetes, underactive thyroid gland, etc. It is often wise to have a physician familiar with GBS examine the patient, to look for these various disorders that could in part mimic a recurrence of GBS.

**MEMORY LOSS AFTER GBS**

**Question:** I want know if memory loss is associated with Guillain-Barre Syndrome (GBS).

My husband was diagnosed and hospitalized last November 3, 2011 in the Netherlands with GBS, was treated with immunoglobulin for 6 days (approximately 700 ml per day). He is now on a course for rehabilitation (physical therapy), has not recovered the movements well in the hands, but in the last month has shown some memory loss. We talk about something and then he does not remember it. Has this to do with the disease?

**Reply:** GBS fortunately does not affect the brain, the site of memory. So it may be helpful to look for other explanations of this change. Depending in part on the patient’s age and general medical condition, it may be helpful to check for the usual causes of poor memory, such as hypothyroidism, vitamin B12 deficiency, loss of nerve cells in the brain, and so forth. A fresh look by a family physician or neurologist may be helpful, in part by looking for new issues rather than the GBS.
Shining Inspiration Story of Dale Torgerson of Viroqua, Wisconsin

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ale Torgerson spent 62 days in the hospital after being stricken with Guillain-Barré Syndrome in February, unable to walk or feed himself and his body in a state of 85 percent paralysis for weeks. He was unable to hug his wife, Brenda, or hold his three daughters, Erin, 7, Katy Jo, 4, and Myle, 22 months. His career was put on hold; something not easily done as a dairy farmer. His family played board games with Dale in the hospital as part of his rehabilitation from the body-paralyzing disease. His complete recovery could take one to three years.

At the age of 34, Dale was always healthy and rarely suffered from any of the common illnesses. In January though, he came down with a cold that held on for a couple of weeks and left him struggling to feel better. On Feb. 10, he began having a tingling sensation in the bottom of his feet. At midnight on Feb. 11, he woke freezing. He felt cold as ice inside, but his body was warm to the touch on the outside. By 3 a.m., when he was ready to head to the farm to milk, he was feeling extremely weak and thought maybe he had the flu. At the farm, Torgerson began feeling sluggish and everything seemed to be moving in slow motion. He managed to finish chores, but they took twice as long as normal to complete. He called Brenda and said he needed to go to the doctor, something he has never done in their nine years of marriage, she said.

Blood tests completed on Torgerson all came back negative, and he was given a large dose of Benadryl to fight what doctors thought might be an allergic reaction. Brenda questioned the diagnosis, especially after he returned home to rest and failed to show any signs of improvement when he woke up. Torgerson tried to shrug it off and headed back to the farm, where his condition began deteriorating fast. He found himself unable to do simple motions and was unable to climb a ladder in the barn, feed the cows and kept clenching his fists, which felt like they were sleeping. “A bag of barn lime felt like it weighed 500 pounds,” Torgerson said.

As the road to recovery began, rehabilitation was long and extensive, requiring at least three hours of therapy a day. “I was like a kid having to learn everything all over again, but harder since I couldn’t feel anything even if I was touching it,” Dale said. Torgerson worked overtime on his therapy and was released from the hospital on April 15, two months after entering the facility. Leaving the hospital was bittersweet for Torgerson, who was fearful he wasn’t ready to be on his own. Since that time he has made significant strides. He still walks with a cane and he attends therapy four days a week.

Brenda awaits the day her husband can walk without his cane, play with their children like he did before, farm without fear of falling and she will never forget their youngest daughter, Myle, was 14 months old and took her first steps in life walking next to her dad, as he was learning to stand and walk all over again.

Together they are trying to rebuild their lives and move forward with their dreams, many of which have been put on hold for the past months. They are forever grateful to all the people who helped them through this difficult time. They know the importance of family, friends and the countless strangers who helped them when they needed it most. “Sometimes it takes a family to go through something like this before you realize what you have. It has made me love things so much more and cherish things daily,” Brenda said.
May is GBS/CIDP Awareness Month

During the month of May, in an effort to increase awareness in each of our communities, we encourage everyone to organize activities that highlight GBS, CIDP and their variants.

In the past, members have sponsored educational events, contacted politicians, and held local fundraising events.

Throughout the world individuals and groups have organized fundraising/awareness events such as walks, runs, bake sales, food sales, fashion shows, afternoon teas, cocktail receptions, art sales, sports outings and “sitting-ins” for those who cannot walk. The included insert highlights two annual events held in North Carolina and the Virtual Miracle Mile Walk. Awareness and fundraising events can be big or small – what’s important is that as a community we are able to advance our mission in whatever way we can by educating people about GBS and CIDP.

If you are interested in participating please contact us at info@gbs-cidp.org, 610-667-0131 or your local affiliate.

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Letter from St. Odilia Catholic School Class of 2012

February 23, 2012

Dear Guillain-Barré Syndrome Foundation,

Last Fall, just after school started, one of our classmates, Rachel Stowman came down with GBS. Rachel was out of school for quite a while and when she was in school she missed classes due to her many doctor appointments. Each day we witnessed the continuing effects of GBS as Rachel struggled to walk. Shortly after we returned to school after Christmas break, Rachel again had to leave school due to GBS. Throughout all of this, Rachel has remained the same funny, outgoing and kind young woman we have always known.

Teachers have missed having Rachel in class and the students have missed her silliness and her friendship. As an eighth grade class, the students and advisors decided to donate all of the funds raised through our annual Valegram Day activities, in Rachel’s name to the Guillain-Barré Syndrome Foundation. We sell “Valegrams” which are like Valentines but are delivered to students throughout our school. The most fun part is the singing Valegrams. A group of eighth grade students sing a special singing valentine greeting to the student who has received the Valegram! It is so much fun! Rachel had talked often of being one of the Valegram Day singers. Due to her having GBS she was not able to be with us at school that day. We hope Rachel will be able to return to school and her friends soon! We are sending a picture of some of Rachel’s eighth grade friends getting ready to sing to students and teachers!

Please accept our donation of $570.00 in honor of our classmate and friend, Rachel Stowman.

Sincerely,

The Eighth Grade Students of St. Odilia Catholic School – Class of 2012

Mrs. Munson – Valegram Day and Class Advisor
When Worlds Come Apart
My GBS/Miller-Fisher Story
By Norm Huie ~ Reprint of 2000 story with 2012 update

Hi, my name is Norm. I’m a 49 year old elementary school teacher in San Clemente, CA. People say I am an active person, married for 27 years, with two grown boys, one granddaughter, still surf regularly, teach piano lessons on the side, and restore old cars in the summer. However (you know what’s coming!), all of this came to a grinding halt on March 14 of this year.

I had come home from a car show on Sunday, and was finishing up some paper-correcting for school. It was good to get out, for I had just recovered from three colds in a row, which had really beaten me down. In fact, I had taken the previous Friday off because of a stubborn case of “pink-eye.” I noticed while washing the dishes after supper, that my vision was a bit blurry. My wife mentioned it must be a reaction to the eye-drops I was taking, and didn’t think much of it. However, I woke up in the middle of the night to check the time on my digital clock and (yikes) I saw two clocks. In denial I went back to sleep, only to discover the next morning everything was way double. After my wife drove me down to school to drop off lesson plans for my substitute, I remember leaving my classroom thinking, “I may not see you for a while…” Little did I know.

I checked into my HMO walk-in at 7 a.m., and they referred me to an ophthalmologist. She looked me over, thinking of possible stroke, tumor, etc. and sent me to radiology for an MRI. This all came out normal, and my physician said this was indeed an eye problem, and to go back to the eye doctor the next day. The following morning my double vision was worse, and I lost equilibrium. I could not walk without holding on to someone or something. I had a hard time figuring out where my feet were. The eye specialist, of course, was mystified and remarked, “This is not an eye thing. This is neurological!” I was immediately referred to internal medicine and neurology and, by nightfall, was in ICU. After many blood tests, CT scans, lumbar tap (which didn’t reveal much at the time but a slight protein elevation), I was diagnosed with GBS – Miller-Fisher variant, by a neurologist and my physician, who warned me that this could develop into full-on GBS with very short notice. Needless to say, we were in shock! I was immediately put on a 5-day IVIG treatment, which seemed to curb further symptoms. I was being watched around the clock, and after 5 days was transferred to acute care.

Paralysis, thankfully, never set in. I was visited by a gentleman (a retired schoolteacher in my district), who had severe GBS in the same ICU three years ago, who shared his story and complete recovery with me. He came several times and offered vital encouragement to me. He was there for me, and his company and prayerful support was invaluable. He and I shared much common ground; I clearly would have felt very alone without him.

I must say I went through somewhat of a personal spiritual awakening during those days. We all encounter “storms” in life, where we become truly desperate. Separations, loss, and illness are but a few.

My doctors agreed that I had plateaued after a week, and moved me to transitional care for the remainder of my hospital stay. I went home with severe double vision, ataxia (loss of balance), and areflexia (loss of all deep-tendon reflexes). No cause, no treatment, no therapy, no medication, just time.

It has been 8 ½ months now, and I am still on disability and in recovery. My double vision still persists with no improvement. I went to the Doheny Eye Institute at USC, where I was seen by top neuro-opthalmologists. They have seen several Miller-Fisher patients in their experience, and said I had the “classic” symptoms. They’ve given me these stick-on prism lenses which help with maintaining stereo vision, but tend to give me massive headaches if I wear them for too long. My optometrist has designed an “occluder,” which is a contact lens with a black dot in the middle that acts as an eye patch on my right eye, eliminating the double-images. Non-patching results in dizziness, vertigo, and prolonged nausea. The nerve healing process, they say, is somewhat of a mystery. Something about the 6th cranial nerve, in my case, can take from 6 months to a year to recover. They said, after time has elapsed and no recovery has taken place, chances are there is permanent axonal damage. At that time, they say surgery is appropriate (muscular, like that done for lazy-eye), which is low-risk and remarkably successful. It seems like a relatively safe option in the long run.

Diplopia (double vision) is fairly common with Miller-Fisher. My dominant left eye is fully functional and 20/20, and I even drive fine (I trust other drivers think the same!). As far as strength, my reflexes have returned up to my waist, and I can go for a long walk, no problem. But any upper-body stuff, i.e. washing the car, vacuuming, doing push-ups, leaves me totally fatigued, unable to even get out of the chair! I really have to watch myself. I am told Miller-Fisher is a “descending” syndrome. The recovery is, hence, “ascending,” with cranial nerve damage healing last.

I am blessed to have family and friends close by to accompany me. I have stayed in touch with my 4th grade class and faculty at school, and many of these people have been so kind and thoughtful. I’ve come to value companionship and Christian fellowship more now than ever. Consider those who have been with you through all of this...we really owe them huge gratitude. My wife and sons have been so endearing and patient; their little
kindnesses go a long way these days.

I have come to realize, via interaction with countless other GBS folks online, that my experience is not only unique like everyone else’s, but rather “shallow-end” compared to what many others have endured. Although filled with days of discomfort and fatigue, I’ve been spared the sensory involvement and all kinds of abnormal sensations which many GBS patients experience. I’m so thankful for the GBS website and support groups such as this. Just knowing I’m not alone in all of this brings tremendous comfort.

People’s worlds do come apart. Adversity for everyone is inevitable in this life. I believe God calms many of these storms and gives some folks complete relief. With others, such as perhaps you and me, he allows the storm to rage on, and it ends up calming us as our quietness and trust become our strength.

Note: This was written in December of 2000. I’d like to give you an update. My double vision did not resolve, and I went forward with the eye surgery in February of 2001. This corrected my vision to a degree, but nerve damage still persisted. The GBS had permanently taken out my oculovestibular nerves on my entire right side, so I was left with extreme balance and motion issues. Chronic motion sickness and vertigo spells resulted, and still remain to this day. Symptoms have, however, become tolerable, and my brain has since accepted this damage as also have chronic fatigue, which really hits me every day in the mid-afternoon. I have to watch my activities and make sure I don’t over-do it, for it takes me days to recover.

There is, however, much good news! Although I did end up retiring from the classroom and resigning from my school district, I now have over 30 piano students who come to my home for instruction each week. I still have my “class,” yet they now come one at a time, and love coming! I also have a vintage automotive trim restoration business which allows me to work with my hands in a whole different way when I’m not teaching piano lessons. I’m able to spend much more time with my wife and family than ever before, and I appreciate the wonders of “stereo” vision now in nature and the world around me, more than I ever dreamed. God has, in my case, truly brought beauty from ashes, and only by his grace have I come thus far.

Fellow GBS sufferers, especially those of you who are newcomers to this “cruise,” please do not lose heart. There is hope for you even in your darkest of times. We are here for you in your ordinary days, filled as they are with times of waiting and wondering. Please connect with those in your local chapter. We’d love to hear from you!
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.
Join us for all
Miracle Mile Walks
May 2012
only 5,280 feet to go!
(for those counting, that’s how many are in a mile)

Want to donate online?
Visit us at www.gbs-cidp.org today!
Or you can mail in your donation.

Please make checks payable to:
GBS/CIDP Foundation International

Please cut and return the lower portion of this page to:
GBS/CIDP Foundation International
104 1/2 Forrest Avenue, Narberth, PA 19072-2215

I cannot participate in a “Walk,” but can support the “Miracle Miles” others are walking.

Here is my contribution to help with the awareness for GBS/CIDP!

Name ________________________________________________________________
Address ______________________________________________________________
City __________________________ State ______ Zip ________________
Phone __________________________ Email ______________________________
Amount Enclosed __________________________________ Check    Credit Card
Credit # __________________________ Expires __________ Security Code _______
Join us for our

6th Annual GBS/CIDP 5K and Miracle Mile

Saturday, May 12, 2012
Southpark Area, Charlotte, NC
register at www.gbs-cidp.org

*Family Fun, Food, and Entertainment*

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carolina art Soirée

3rd Annual Carolina Art Soirée

Thursday, May 10, 2012, 6-9 pm
Metropolitan Penthouse, Charlotte, NC
http://squarespace.carolinartsoiree.com

exhibition continues
Friday, May 11th 11-3 pm

40% of proceeds benefit the GBS-CIDP Foundation