Summer 2015

GBS|CIDP Foundation International

The Communicator

Providing Strength Through Support

Working for a future when no one with Guillain-Barré syndrome (GBS), chronic inflammatory demyelinating polyneuropathy (CIDP), and related syndromes such as MMN suffers alone and that everyone has access to the right diagnosis and the right treatment, right away.

In This Issue

Patient Story

By Demi-Lee Pretorius
Bryan, New Jersey

At the age of 13 I was diagnosed with Guillain Barré syndrome.

I had to abandon classical ballet because I could no longer move my feet like a ballerina should and had lost all sensation below my knees. Similarly, I could also no longer partake in athletics or netball—sports I had competed in from an early age. My parents were informed that my condition would gradually progress to the point where I would end up in a wheelchair. Refusing to accept this diagnosis without further investigation, we packed our belongings and moved from South Africa to the United States where we settled in New Jersey.

Last year I experienced a relapse and my previous diagnosis of GBS was adjusted to CIDP. I recently completed a course of plasmapheresis at the New York Presbyterian Hospital in Manhattan. I also receive an IVIG infusion every four weeks at home for two days and undergo chemotherapy every three months.

I am now in my senior year at high school, and I am a member of the local high school rugby program where I also serve as a flag referee. Doctors are amazed that I am even able to walk, let alone run, which serves as testament to my determination to overcome this condition; I literally lift my lower legs with my quads when running. Even though there are certain key rugby skills that CIDP will continue to hamper, I remain an enthusiastic, albeit less mobile, athlete.

At school I am involved in our anti-bullying program to specifically raise awareness for students with similar disabilities. In the beginning of every school term, kids often stop and stare at my braces, which I then take as an opportunity to educate them about my illness. I have run a number of anti-bullying campaigns at my high school, including a recent CIDP awareness drive where I handed out CIDP bracelets in an effort to raise funds for the GBS|CIDP Foundation. I was also inducted into the high school National Honor Society, an amazing feat considering the amount of school I have missed out on when receiving my monthly IVIG infusions.

I love volunteering my time and recently coordinated a fundraising campaign to purchase teddy bears for the "Miss U-Can-Do-It" pageant. With the support of my high school, close friends, and family, I was able to send teddy bears to this national non-profit pageant created just for girls and women with special needs and challenges.

Recently I was met with great news! It has always been my dream to become a teacher, so you can imagine my surprise and delight when I received a letter from Kean University this week where I was accepted into the STEM program, a five-year combined Bachelor/Master's program in science, mathematics and technology.

I will not let this condition direct my life or keep me from doing what I love. I'm a fighter, and I'm bigger than this illness.

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

Meet Our Newly Elected President of the Board of Directors, Santo Garcia!

In 1980 Bob & Estelle Benson founded what is today the GBS|CIDP Foundation International to help fellow patients and families. They reached out to local doctors for their expertise and together created an organization that thirty-five years later continues serving those in need. We are the lucky benefactors of an undying commitment to improve the lives of all impacted by GBS, CIDP and the many variants such as MMN.

I challenge all of you reading this newsletter to come together to create the next thirty-five years. Whether you are a patient, caregiver or friend; a doctor, nurse or therapist; an industry partner or researcher; an elected official or one of our worldwide volunteers, you are the future of this foundation!

Our Mission

To improve the quality of life for individuals and families affected by GBS, CIDP, or related syndromes such as MMN by:

- Creating and nurturing a global network of volunteers, healthcare professionals, researchers and industry partners to provide those affected with GBS, CIDP, or related syndromes such as MMN with support and the most current available information;
- Designing and implementing public, medical and professional education programs to increase awareness and improve understanding;
- Funding research through grants, establishing fellowships and using other appropriate avenues to identify the causes of and discover treatments for GBS, CIDP, and related syndromes such as MMN;
- Structuring partnerships to engage in advocacy at the federal, state and grass roots levels to advance our vision and mission with legislators and government agencies.

I am your President of the Board of Directors, a liaison, a patient, and a therapist and I am committed to honoring the foresight of our founders by working tirelessly to make the next thirty-five years tremendous! Where do you fit into this mission statement? What are your talents? Which of our four pillars (Support, Education, Research, Advocacy) can you best serve?

Think big!

Going Green

The GBS|CIDP Foundation is Going Green! We are pleased to announce that we will be offering *The Communicator* in a convenient, easy-to-read electronic format. If you would like to receive *The Communicator* in your inbox rather than in your mailbox, let us know! Just send an email with "**Going Green Campaign**" as the subject line to info@gbs-cidp.org.

Ken's Korner

Greetings!

One of many highlights of the GBS|CIDP Foundation is our biennial Symposium. We consistently receive an out-pouring of appreciation from attendees for offering such a unique experience for our patients, caregivers, families, and medical professionals. So, here we go again!

SAVE THE DATE: **SEPTEMBER 23 & 24, 2016 IN BEAUTIFUL SAN ANTONIO, TEXAS!**

This symposium will take place in the heart of downtown San Antonio, a city rich with culture and history. We will stay at the Hyatt Regency, San Antonio (reservation information to follow) which is a 16-story garden atrium hotel located eight miles from the San Antonio International Airport, and across from the historic Alamo. The Hyatt is set on the centerpiece of the city, the Riverwalk — a two-and-a-half mile cobblestone path (recently updated to be ADA compliant) along San Antonio River. Enjoy a riverboat cruise and the shops, sidewalk cafes, restaurants, and other attractions!

Symposium 2016 will feature a wide array of presentations and workshops led by our best medical professionals, and will offer a unique opportunity for those affected by GBS, CIDP, and variants to meet with other patients and families from around the world.

Symposium 2016 will take place on September 23 & 24 in San Antonio, Texas

We are designing an entirely **NEW CURRICULUM** for Symposium 2016, and we would love to hear *YOUR FEEDBACK!* Is there a specific topic you would like to have covered? Was there something at the last Symposium that we should offer again? We cannot incorporate every suggestion, but please know that we are busy at work hoping to address your thoughts whenever we can. Write us today: info@gbs-cidp.org with the subject line "Symposium 2016."

Hear Our Voices: Stories of Strength & Survival
A collection of patient stories from the GBS|CIDP and variant communities.

Announcing our soon-to-be-published book—a collection of patient stories! Your stories are unique, valuable, and insightful and we love to share them. Be a part of this inaugural collection and submit your edited story with a photo to: anna.yankelev@gbs-cidp.org. Stories should be between 500-1000 words in length; contact Anna for more details!

We have been busy with a variety of chapter meetings and fundraisers. Be sure to join a GBS|CIDP event in your area, and check out our "Year in Celebration" on page 11 for some recent highlights! As always, let us know what we can do for you. Have a wonderful summer and watch for our first Annual Report in the fall!

Ken Singleton
Executive Director

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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

Visit us on Facebook: www.facebook.com/gbscidp

Diagnosing and Treating CIDP

Reprinted with permission from *IG Living Magazine*

By Michelle Greer, RN and Gil I. Wolfe, MD

Professor of Neurology, SUNY Buffalo School of Medicine and Biomedical Sciences; Member, GBS|CIDP Medical Advisory Board

The primary function of the immune system is to differentiate between self and non-self, to keep self healthy and to destroy or neutralize non-self. When the immune system malfunctions and attacks itself, it is known as an autoimmune disease. CIDP is considered an autoimmune disease, and occurs when the myelin sheath that covers the nerves and assists with impulse transmission is attacked. This is known as demyelination. Because of the nature of the attack, there is usually inflammation. The result is an interruption in nerve signals between the peripheral nerves and the muscles they control.

CIDP presents slowly, usually over several months, unlike the acute form of demyelinating neuropathy known as GBS. GBS presents rapidly, usually over days, but sometimes even more quickly, and frequently occurs following some sort of infection or illness. Unlike GBS, CIDP is usually a chronically progressive neuropathy and is rarely associated with antecedent illnesses or respiratory failure.

Diagnosing CIDP

Usually, CIDP presents as a motor predominant neuropathy with prominent proximal weakness, meaning the muscles responsible for movement closest to the torso are affected first. The weakness is typically symmetrical, affecting both sides of the body equally. Occasionally, CIDP can present in the pattern of a mononeuropathy multiplex, large-fiber neuropathy with sensory ataxia, pure motor neuropathy, or small-fiber neuropathy.

It's not uncommon for CIDP to go undiagnosed for a while due to many factors. The symptoms may be vague and brushed off until they become more profound and/or interfere with everyday functioning. Once an individual does go to a physician, a definitive diagnosis still may not follow.

Neuropathy has many causes, and CIDP has several variants, therefore, it is important that a thorough health history, physical, and neurological examination be performed to determine the cause of the neuropathy. CIDP is rare, but its incidence ranges greatly due to the potential of over- or under-diagnosis. An individual may be thought to have CIDP when it is actually another form of neuropathy, and the reverse can happen as well. Many physicians and patient groups have worked on a standard way to identify CIDP more quickly and accurately, but appropriate diagnosis remains a challenge.

Symptoms are first noticed as numbness, tingling, pain and weakness, which are vague and can be the initial symptoms of many conditions. This usually occurs first in the toes and feet, eventually resulting in foot drop or drag and increased difficulty in walking. The weakness and numbness are typically symmetrical—equal on both sides of the body—and sensory loss is often in a stocking and glove distribution.

A diagnosis of CIDP is based on an electrophysiologic pattern of multifocal demyelination identified through an EMG/nerve conduction study, elevated CSF (cerebral spinal fluid) protein and, when necessary, nerve biopsy. These tests, combined with a thorough health history and neurological exam, will help guide the physician to a correct diagnosis.

Treating CIDP

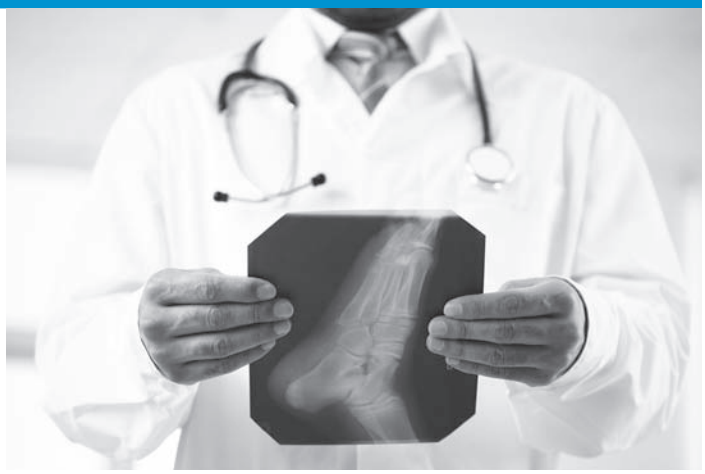
Once CIDP is diagnosed, treatment options are considered and discussed. The treatment of CIDP is based on immunomodulating therapies. Immunomodulation refers to suppression or alteration of the immune response so that attack on the self subsides and symptoms improve. CIDP does respond to corticosteroids; however, long-term use of high-dose steroids comes with its own set of issues. Side effects can be severe and affect multiple organ systems. Plasmapheresis is generally reserved for refractory patients—those who have tried all the standard therapies and the condition is still not controlled. The only treatment that has received FDA approval for the management of CIDP is intravenous immunoglobulin (IVIG).

Rare, But There Is Hope

Although CIDP is rare and difficult to diagnose, once it is accurately diagnosed, there are treatment options. CIDP can be treated with a variety of immunomodulatory therapies, including FDA-approved IVIG. Fortunately, CIDP can be managed to help patients live relatively normal and healthy lives, and there are many patient-to-patient support groups that include oversight by experts in neuromuscular disorders.

Foot Drop

By Peter D. Donofrio, M.D.
Professor of Neurology, Vanderbilt University Medical Center
Member, GBS|CIDP Foundation Medical Advisory Board



Foot drop (FD) is a term used by physicians and patients to describe weakness of the foot such that the patient cannot bend the ankle back toward the knee. Foot drop can affect one foot or both feet. When foot drop is mild, patients may notice weakness only when walking up stairs or stepping onto a curb or stool. If foot drop is more severe, the foot may flop down whenever they try to use the foot or ankle; it interferes with any use of the lower limb.

Because of the anatomy of the nerves in the lower limbs, foot drop can result from several conditions including a pinched nerve at the knee region (peroneal or fibular nerve palsy), a sciatic nerve lesion high or low in the posterior thigh, an abnormality of the lumbosacral plexus where the nerves cluster together in the region of the groin, or a compressed nerve in the lower back, usually the L5 root. Some patients with spinal cord disease or stroke can also have foot drop. Foot drop can develop slowly over weeks to months or may occur acutely. Foot drop is common in patients with underlying diffuse neuropathies, diabetes being the most common. Other causes of diffuse neuropathies where foot drop may arise include alcohol abuse, vitamin deficiencies, HIV infections, connective tissue disorders (such as a lupus, rheumatoid arthritis, Sjogren's syndrome), amyloidosis, vasculitis and other causes.

In GBS and CIDP, foot drop is often bilateral as the underlying illnesses affect both sides of the body and are relatively symmetric. In Guillain-Barré syndrome (GBS), foot drop may be seen within the first few days of the illness and may persist for months if the GBS is severe and protracted. In chronic inflammatory demyelinating polyradiculoneuropathy (CIDP), foot drop may not appear for several months to years, but again tends to be symmetric. Foot drop may or may not respond to treatments with IVIG, plasma exchange, cortical steroids, or other immune suppressants.

In addition to the foot and ankle weakness, patients with foot drop may have neuropathic pain, numbness, and tingling. If only one nerve or root is the cause of the foot drop, the numbness and tingling may be present only over the anterior and lateral portion of the shin and top of the foot. If the foot drop is part of a diffuse and symmetric process, the numbness, tingling, and pain may involve the entire leg from the knee downward or even higher up the leg if the underlying process is severe and chronic.

The evaluation of foot drop should begin with a thorough neurologic examination, preferably provided by a neurologist or another physician skilled in neuroanatomy of the leg, such as a neurosurgeon, orthopedic surgeon or physical medicine doctor. Those physicians will often order nerve conduction studies and electromyography (EMG) to assist in localizing the lesion and determining if the abnormality is in the peroneal nerve only or higher up the leg in the sciatic nerve, lumbosacral plexus, or nerve root. An MRI scan of the lumbosacral spine will often be necessary, particularly if a lumbar root abnormality is suspected. Further imaging studies of the lumbosacral plexus, thigh, or knee region may be needed if the localization by examination, nerve conduction studies, or EMG suggest an abnormality in those regions.

Treatment of foot drop depends upon the cause and localization of the abnormality. Foot drop in one limb may be amenable to surgery at the level of the knee, shin, or thigh. If the foot drop is due to a lumbar radiculopathy (pinched nerve), surgical decompression would be necessary in most patients. An ankle foot orthosis (AFO) is commonly prescribed by physicians or therapists to mechanically bend the foot at the ankle so the patient can walk more easily without the dropped foot interfering with foot clearance. The newer types of AFOs are light and strong and permit the patient to walk with many types of shoes. In some patients, the wearing of lightweight boots that lace up to the mid shin can maintain the foot at close to 90 degrees of ankle flexion and make walking easier, similar to the benefit of an AFO.

If the foot drop affects both legs and is a complication of GBS, CIDP, or diabetes, surgical treatment would probably not be needed. In those conditions, medical treatment might improve the foot drop. Some patients with GBS or CIDP may need an AFO applied to both lower limbs to permit walking. Pain arising from the foot drop would be treated with medications commonly prescribed for neuropathic pain (nerve pain) including gabapentin, pregabalin, amitriptyline, nortriptyline, duloxetine, and other medications.

No, You Shouldn't Let Fears of a Scary Nervous System Disease Stop You From Getting a Flu Shot*

By Kiera Butler

Reprinted with permission from *Mother Jones*, January 19, 2015

Despite abundant evidence that flu vaccines are safe and effective, only about a third of Americans get the shots each season. Public health experts believe that one reason for the low immunization rates is misinformation about side effects of the vaccine. One is the belief that the vaccine can actually give you the flu (false); another is that it can cause autism in children (also false, as we've said many times).

Add that to the worry that it will cause a rare but serious nervous-system disorder called Guillain-Barré syndrome (GBS), an autoimmune disease in which the immune system attacks the nervous system, resulting in muscle weakness, or even temporary paralysis. This fear is not completely unfounded — several studies, including a recent one by Italian researchers about the 2010-2011 vaccine — have found that getting a flu shot can indeed very slightly elevate one's risk of contracting the disease, by about one additional case per million people.

But here's where things get complicated: While it's true that the flu vaccine can raise your GBS risk, so can the flu itself. So which is more likely to lead to GBS: Getting the vaccine or getting the flu?

That's the question that Steven Hawken and Kumanan Wilson, epidemiologists from The Ottawa Hospital, set out to answer. The researchers developed a calculator that took into account baseline GBS risk (overall, it's about 10 in a million, through it varies with age and sex — GBS affects more men than women and more elderly people than young adults and children), vaccine effectiveness, and overall incidence of flu. Their findings: For most people, in a flu season where the flu incidence is greater than five percent and the vaccine is more than 60 percent effective, says Wilson, "your risk of GBS actually goes down when you get the vaccine because it prevents the flu."

That's good news in most years, when the flu vaccine is well over 60 percent effective. Here's the problem: This year's flu vaccine [was] only about 23 percent effective. Still, according to Wilson, while this year's total flu incidence isn't yet known, it appears to be greater than that of an average year — much higher than five percent. That means that even with the reduced effectiveness of the vaccine, the overall GBS risk is likely still greater for people who contract the flu than for those who get immunized, says Wilson.

What's more, he adds, it's important to keep in mind that the risk of serious complications from the flu outweighs that of acquiring GBS. Last year, according to the CDC, 9,635 people were hospitalized with the flu in the United States. According to the CDC there are between 3,000-6,000 cases of GBS annually (though no hospitalization data is available). Most of those cases aren't caused by flu vaccines or the flu itself; the most common cause of GBS is infection with the bacterium *Campylobacter jejeuni*, usually the result of eating contaminated food.

The takeaway: The GBS risk from the flu itself is most likely greater than that of the vaccine. And while GBS can be a scary disease, it's much less common than scary complications FROM the flu.

*__Disclaimer__: The information in this article is intended for general educational purposes only. Any decisions regarding vaccinations should be made in consultation with your neurologist or doctor.

GBS|CIDP Foundation International WALK AND ROLL

Walk & Roll Update:

8 walks held to date, 6 walks to go!

Over 1,000 participants with 145 teams, and $150,000 raised!

Thank YOU for making this happen!

Upcoming walks:

Pittsburgh, PA - 9/19
Myrtle Beach, SC - 9/19
Huntington, WV - 9/26
Boston, MA - 10/3
Atlanta, GA - 10/17
Newburgh, NY- 10/18

Team Sam at Walk & Roll Dallas, 2015

PSI President's Award Awarded to Estelle Benson

On April 22, 2015, Estelle Benson was awarded the President's Award from Patient Services, Inc. (PSI) at the Rayburn House Office Building in Washington DC. This award recognizes a leader in the patient advocacy community who embodies the strength, wisdom, and vision of PSI's Founder and President, Dana A. Kuhn, PhD. Estelle exemplifies these qualities and has devoted her time, energy, and passion to the service of patients with GBS, CIDP, and other variants for 35 years.

Patient Services, Inc. helps patients with expensive chronic illnesses and conditions access their treatments and therapies. Through private donations they can subsidize health insurance premiums, pharmacy and treatment co-payments, and expenses associated with Medicare Part D.

Right to left: Dana Kuhn, Estelle Benson, Gary Cross, Jim Romano

Congressman John Garamendi

Happy 35th Anniversary to the Foundation!

SAVE THE DATE: NOVEMBER 4, 2015

Join us at our 35th Anniversary Gala as we honor Congressman John Garamendi as the GBS|CIDP Foundation International Legislator of the Year. The Congressman has two daughters who had GBS.

This is only the fourth "Person of the Year" event the Foundation has sponsored in 35 years. We hope you will come and celebrate with us at the spectacular Andrew Mellon Auditorium, 1301 Constitution Avenue, NW, Washington DC.

This special evening also will feature the announcement and first recipients of the Estelle Benson volunteer award.

JOIN US IN DC to commemorate this very special occasion!

Capitol Hill Advocacy Day

In April, the Foundation was thrilled to host our biggest delegation yet in Washington, DC for our annual Capitol Hill Advocacy Day! Our 40 advocates received comprehensive advocacy training and a review of the issues before meeting with the offices of their congressional representatives. These visits with elected officials review bills and policies related to issues such as access to care and physician reimbursements, and help us raise awareness for GBS and CIDP. If you would like to participate in local advocacy efforts, please contact Anna Yankelev (anna.yankelev@gbs-cidp.org).

Some of our Regional Directors at the White House during Advocacy Day

GBS | CIDP
Foundation International

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CHANGE SERVICE REQUESTED

Directory

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

Diagnosed with MMN?
Contact: Dominick Spatafora
dominck@dvsconsultants.com

Miller Fisher Variant Group
Please call the National Office for contact with others.

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 CIDP contact Holly Cannon whose daughter Hailey has CIDP.
Holly.cannon@gbs-cidp.org

Looking for a 20-Something Contact?
Contact: Kyle Van Mouwerik
kyle.vanmouwerik@gbs-cidp.org

A Teenage Pen Pal Group
Arielle Challander, 231-946-7256
4313 Shawn Drive
Traverse City, MI 49685
Email: ariellegiggles@gmail.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.

National Office: 610-667-0131

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.

Advocacy
If you are interested in advocacy activities on a federal, state, or local level contact Anna Yankelev at the international office.
Anna.Yankelev@gbs-cidp.org

Be sure to inform the International Office if you have been diagnosed with one of the following. This will add you to condition-specific communication.

- **AMAN**
- **AMSAN**
- **Anti-Mag**
- **Campylobacter**
- **GBS X2**
- **Miller Fisher**
- **MMN**