



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) or related syndromes and variants suffers alone and when everyone has access to the right diagnosis and the right treatment, right away.



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Patient Story

I am Blessed

By Julie B. Bell

GBS | CIDP Liaison

My journey begins in October 1967, the year I was born. I was a child of two college students who wanted nothing but the best for me. Their love for me allowed me to be put up for adoption. Twenty-eight days later, I had a permanent home.

My life with CIDP began in December of 1995, at the age of 28. I was living in San Antonio, Texas, and flew home for Thanksgiving. As I was walking through the airport with my dad, a doctor of Pediatric Radiology, noticed that my gait was off. I attributed it to being a “post pregnancy” thing but told my dad that my hips were sore. He advised me to go see my primary doctor and get a referral to go see an orthopedic doctor. My doctor ran some tests and asked me to stand on my toes, but I could not do that, although I used to dance during my college years. I did not realize I had lost functioning. I left the doctor’s office with my referral. The next day I got a call saying that I had a 1:00 appointment with a neurologist. At this point, I remember being in a panic. I had hip pain and thought I needed an orthopedic doctor, not a neurologist.

I arrived at the neurologist’s office to find out that my blood test for muscle inflammation came back elevated. The neurologist wanted to conduct tests of his own that I began to refer to these tests as the “push me, pull me” tests. I had EMG’s, a spinal tap, and a muscle biopsy done. The doctor had narrowed his search to multiple sclerosis, muscular atrophy, multiple myeloma, or chronic Guillain-Barré. After Christmas of 1995, we got the results of all the testing. I had the chronic Guillain-Barré Syndrome.



The doctor said to look on the bright side, because the chronic GBS is treatable. Yeah, easy for him to say; he was not the one dealing with the devastating news.

After the diagnosis I was very depressed, angry, and scared. *Why me?* That is what we all have said at one point or another. Lucky? No way! I had my pity party. I was scared. I cried and I screamed. I am a young mother with two children. What am I going to do? At that point, my husband and I “took the bull by the horns” and began our research.

Treatment also began. I was sent to another doctor, a hematologist/oncologist. I began my marathon rounds of plasma pheresis, every day for 28 days in a row. I remember being so cold when the plasma was being removed. The tool for measuring the effectiveness was me. How did I feel? It was at this point that I began to learn to listen to my body and worked on being in touch with how I was feeling. I also began massive amounts of steroids. It was recommended that I eliminate all of the stress, so I stopped working full time as a special education teacher.

In my research, I was able to locate the GBS Foundation. I gathered information about this disease. I got in contact with Dr. Richard J. Barohn, who was on the medical advisory board, and visited Dallas, where he was

continued on page 2

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*Non-profit 501(c)(3)**continued from page 1*

practicing. Dr. Barohn was a great doctor. He confirmed and agreed that the chronic GBS was what I was dealing with. The second opinion from a doctor familiar with the disease helped me come to terms with the situation.

I continued on my journey as a patient with a rare disorder. The next several years were spent battling this monster. I had flare ups that would cause me to regress. Each time I recovered, I never made it back to where I once was. I soon found out that this monster would flare its temper and would strike back the next time with more vengeance. This would be my life. I soon adapted to this pattern, slowly losing functioning in my arms and legs. I still stayed in touch with the Foundation and looked forward to seeing the newest updates in treatments and progress. I made copies of the Foundation letters and took them to my doctors' offices. I became an expert about my disease and the educator of those around me.

Nine years into this disease, now named CIDP (Chronic Inflammatory Demyelinating Polyneuropathy), I faced a bigger battle. In October 2004, my husband, Phillip, was diagnosed with pancreatic cancer. How lucky we are...We sat together in the hematology oncology office, dripping together. I was getting IVIG and my husband chemo drugs. I knew my disease would not kill me; and as I sat by cancer patients and my husband, I knew they were not as lucky as I was.

I became the care provider for my dying husband, my 15-year-old daughter and 10-year-old son. In August of 2005, 10 months after the initial diagnosis, my husband lost his battle with cancer and died.

Dealing with a tremendous amount of stress, I continued to push on. At this point in my life, I began to get worse. I developed drop foot in both feet. The functioning in my hands deteriorated. I began to use ankle foot orthotics on both feet. As an adult, my choices were limited for "age appropriate" looking AFOs. I began to embrace the fact that I looked different. I chose to make the best of the situation, and I began buying crazy knee socks. I switched neurologists and began my infusions there. Along this journey, I met another woman who had this disease and we became drip buddies. We made it a point to have a "girls day" on infusion days. We would order lunch for delivery and we brought chick flicks and popcorn. Instead of being depressed, we made it a fun day.

The Foundation helped me feel like I was not alone on this journey. Over the years, I had read about the symposium in Fort Worth, Texas. This symposium was a life-changing experience for me. I felt like I was with family. Everyone understood. They got it. I realized at the symposium that many people were unaware of the daily living aids that were available. I began a new mission: to help others with my disease discover modification and tools that exist to help with daily functioning. I left the symposium with such a drive that I knew I needed to be a liaison so that I could help others.

I have learned to advocate for myself and want to help others advocate for themselves. In March of 2013, I tried a new device for drop foot. It is a neuroelectric stimulation system. I passed the screening, but I soon found out that the system was not covered by insurance. I knew that this system would keep me active and help me keep my leg muscles functioning. I began searching for an alternative funding. \$8,000 a leg was way out of my budget until I discovered DARS, the

continued on page 3

Disclaimer Information Questions presented in the GBS/CIDP Newsletter are intended for general educational purposes only, and should not be construed as advising on diagnosis or treatment of Guillain-Barré Syndrome or any other medical condition.

Privacy Policy In response to many queries: Intrusive practices are not used by the GBS/CIDP Foundation International. It does NOT sell its mailing list nor does it make available telephone numbers! The liaisons are listed in the chapter directory with their permission. We are proud that none of our members has ever been solicited or sent materials other than those concerning GBS, CIDP, and related syndromes and variants. We respect your privacy.

As many actors will testify, a little face-lift can make a big difference. The same goes for written communications. So in this issue of the *Communicator*, you will notice that we have refreshed our look! We are now two colors and have changed some of our fonts, which give us an easier-to-read Newsletter. You will notice that our cover now features our patient story. In our continued focus on a patient-first vision, we want you to hear from your patient peers first! We will continue to bring you all of the traditional content while presenting it in a new, cultivated look.

We are very busy working on bringing you the most informed, largest Symposium in our history. Our registration is now open on our website, and you all should have received the brochure in the mail in July. We have continued to feature Symposium topics and presenters in this issue. We hope you have taken advantage of our streamlined approach to registration.

The Benson Fellowship Committee has announced that they have reviewed all of the applications for the first Benson Fellowship and have selected three very talented and qualified specialists. Each of the finalist will present at the General Session on Saturday morning. The committee will then do their final review, select the finalist, and present their recommendation to the board of directors for final approval. The finalist will be presented later in the afternoon. Your generous support of the Foundation continues to enrich and fund this program which attracts young doctors to neuromuscular research!

As we continue to plan, we want to remind you of our featured entertainment, country singer, Laura Dodd, who has battled CIDP since the age of twelve and will perform for us on Saturday evening! Laura will also be available to talk and share her journey—a rare opportunity, not to be missed!

I want to acknowledge our Regional Directors and Liaisons who made Congressional visits to their local districts in August when Congress was in recess. Hearing from constituents is a priority for most representatives. Our message asked for support in increased NIH (National Institutes of Health) funding and support to co-sponsor and advance the bipartisan Patients' Access to Treatment Act (H.R. 460).

We look forward to seeing you at the symposium.

Have a wonderful fall,

Ken Singleton

Executive Director



In our continued focus on a patient-first vision, we want you to hear from your patient peers first!

continued from page 2

Department of Assistive Rehabilitation Services. I met with a caseworker and 10 months later I was fully funded for bilateral Bioness.

Today I work full-time as a special education teacher, completing 19 years of teaching. I have maintained my health and I still have IVIG infusions every 2 weeks. I hope to continue to help others on their journey. If you look at where I have been and then the things I have endured, my life is truly a blessing!

Amazon Smile

GBS|CIDP Foundation International is now a participant in **AmazonSmile**. 0.5% of the price on eligible Amazon purchases will be donated towards our Foundation. There is no limit to how much Amazon will donate, so take the opportunity to go on a shopping spree, and know that every purchase will lead to a donation for our cause. Simply visit smile.amazon.com and select GBS|CIDP as the foundation to which you choose to donate. All eligible products will be marked “Eligible for AmazonSmile donation” on the product detail page. Tell everyone about this amazing opportunity to give back with no additional cost! Shop the way you always do, and help make a difference at the same time!

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GBS|CIDP Foundation International

Benson Clinical Research Fellowship 2014

By Richard Hughes

Emeritus Professor of Neurology, King's College London; Honorary Member of Board of GBS|CIDP Foundation International

There is extraordinarily strong competition for the first Benson Clinical Research Fellowship. The scheme aims to provide funds (up to \$150,000 per year for three years) to enable young clinicians or non-clinical scientists to do a substantial research project in the field of inflammatory neuropathy.

The project must be done in a Centre or Centres of Excellence. Eventually 13 candidates, from Asia, Australia, Europe and the USA, submitted full applications. These have been considered by a 7 member selection committee who were hard pressed to select a short list of three candidates from an excellent field. The three chosen will present their proposals in public at the 13th International Symposium of the GBS|CIDP Foundation International on the morning of Saturday, November 1st at Disney's Coronado Springs Resort and Convention Center in Lake Buena Vista, Florida.

The audience will have the opportunity to vote in secret for the candidate they prefer. The Members of the Medical Advisory Board will have a separate vote. The selection committee will receive both sets of votes, interview the candidates and then recommend to the Foundation Board the most appropriate candidate for this prestigious award.

*Up to \$150,000 per year
for three years will be
awarded for a research
project in the field of
inflammatory neuropathy*

The announcement of the successful candidate will be made later on the same day.

In alphabetical order, the short-listed candidates and their project titles are:

Dr. Filip Eftimov, Amsterdam, The Netherlands:
"Long-term outcome of CIDP treatment strategies"

Dr. Ruth Huizinga, Rotterdam, The Netherlands:
"High innate responsiveness to microbial triggers predisposing to the Guillain-Barré syndrome: identification of genetic causal variants"

Dr. Rhona McGonigal, Glasgow, United Kingdom:

"Identifying new therapeutic targets in mouse models of GBS"

The Fellowship has been funded in memory of the late Robert Benson who had GBS. His wife Estelle founded the

GBS|CIDP Foundation International in 1980.

Benson Fellowship Selection Committee

Dr. Patsy Armati, Australia

Dr. David Cornblath, USA

Dr. Richard Hughes, UK (chair)

Dr. Eduardo Nobile-Orazio, Italy

Dr. Kazim Sheikh, USA

Dr. Betty Soliven, USA

13TH INTERNATIONAL GBS|CIDP SYMPOSIUM

We hope you have made your plans to join us for the Symposium in October! You still have time, however after 9/29, space is limited!

REMINDERS:

Make your transportation plans to and from the Orlando airport to the Coronado Springs Resort through Disney's Magical Express. This offers free transportation, but you must book in advance. This can be done on-line: <http://www.mydisneymeetings.com/gbscidp2014>

You can also book transportation on the Magical Express by calling: (407) 939-6244.

To expedite your arrival upon check-in you can pre-register at the Coronado. This is available starting 10 days prior to arrival and up to, and including arrival date. You can access on-line check-in through the website above or by calling: (407) 828-7128.

If you have purchased any theme park tickets or made reservations at any other Disney property, you can personalize your experience by using MyMagic+. This process allows you to connect to all of the Disney World experiences you selected. To access this service, simply visit: StartYourDisneyExperience.com.

We look forward to celebrating the start of the Symposium at the Thursday evening Welcome Reception! If you are traveling with children, please feel free to bring them to this kick-off; we will have supervised children's activities available!

Walk and Roll 2015

The Walk and Roll for GBS|CIDP Campaign is sweeping the nation for 2015.



Offering the chance to bring together patients and families to celebrate recovery and share stories, Walk and Roll for GBS|CIDP is a fun and heartwarming event for everyone involved. Not only does the campaign increase the public's awareness of GBS, CIDP, and related syndromes and variants, but also help to raise funds to support the Foundation's mission. Walks in Dallas TX, Chicago IL, Oklahoma City OK, New York City NY, Baltimore MD, Seattle WA, Bowling Green KY, Los Angeles CA, and Ocala FL are already in the works!

Help "old friends get together who have never met!" and let's get ready to Rock and Roll into 2015! Didn't see a city by you in that list? Contact allison.dadouris@gbs-cidp.org to start planning a walk near you!

Symposium Topics

In the June issue and this September issue of the *Communicator*, we feature some of the topics and highlight some of the presenters from our own Medical Advisory Board. We hope that this may inspire you to join us for this unique opportunity to meet our esteemed experts!

Pain and Fatigue in GBS and CIDP

By Pieter Van Doorn and Gareth J. Parry

Pain occurs frequently in GBS and may occur at any stage in the disease, even occasionally preceding the onset of weakness. In the earliest stages pain is caused by direct inflammation of the nerves. It is a poorly localized pain of a deep aching quality and occurs mainly in the region of the spine, hips and shoulders. It is generally proportional to the severity of the weakness and is often made worse by movement. This early pain tends to subside over a few days as the weakness evolves and may improve when treatment with IVIG or PLEX is started. Later pain is different in quality and location and is due to nerve damage and is called neuropathic pain. It is usually located in the hands and feet more than the torso and has a burning or tingling quality. It also improves with time but tends to last much longer, often for many months, occasionally permanently. The early pain, if sufficiently severe, may need to be treated with narcotic analgesics such as morphine which carries some risk of respiratory depression and lead to artificial ventilation. Narcotics should be used with great caution in neuropathic pain because it is chronic and usually needs long-term treatment with attendant risks of addiction. Instead, treatment with drugs such as nortriptyline or gabapentin is preferable. Pain is not as common in CIDP and is of the neuropathic variety. It only occasionally is sufficiently severe to need treatment. Fatigue is very common in patients with CIDP or those who have suffered from GBS, occurring in 60%-80% of patients. It may persist for many years after GBS and is not necessarily related to severe weakness. Fatigue may be related to other conditions such as depression or medication use. Many drugs used to treat pain have fatigue as a common side effect. It is difficult to treat. Stimulants are modestly effective but can lead to dependence. A combination of energy conservation and light exercise is beneficial.



Gareth J. Parry, MD

Dr. Parry is emeritus professor of neurology at the University of Minnesota in Minneapolis. He was formerly the head of neurology, medical director of the University of Minnesota Neuromuscular Program, University of Minnesota-Fairview Multiple Sclerosis Center, the MS Achievement Center and the Clinical Neuroscience Research Unit. He is also a consultant neurologist at the

Wellington Hospital in New Zealand. His clinical and research interests focus on neuroimmunology, including immune-mediated neuromuscular diseases and CNS demyelinating diseases. He is a fellow of the Royal Australasian College of Physicians and a diplomate of the American Board of Psychiatry and Neurology. Dr. Parry serves on the Medical Advisory Board of the GBS/CIDP Foundation International and is the Chair of the New Zealand GBS Foundation Medical Advisory Board. He is author of over 100 journal articles and more than 20 books and book chapters, including two books on GBS, one for medical professionals and the other, co-authored with Dr. Joel Steinberg, for patients and caregivers.



Pieter A. van Doorn, MD

Pieter A. van Doorn, MD, is professor of neuromuscular disorders at Erasmus University Medical Center in Rotterdam,

the Netherlands. He coordinates the Neurology outpatient clinic and heads the neuromuscular branch. Dr. van Doorn received his MD at Erasmus University, where he was trained in neurology and clinical neurophysiology. He started his research in immune-mediated neuropathies at the department of immunohematology at Leiden State University in the Netherlands. In 1990, he completed his thesis on intravenous immunoglobulin in chronic inflammatory demyelinating polyneuropathy (CIDP).

Dr. van Doorn's main fields of interest are neuromuscular disorders, especially Guillain-Barré syndrome (GBS) and CIDP; and Pompe's disease, a muscle disease due to an enzyme (alpha-glucosidase) deficiency. He is pursuing studies that examine the relationships between antecedent infections, immune reaction/antiganglioside antibodies, and the effect of IVIG treatment. He is involved in studies on outcome measures and prognostic modelling in GBS and CIDP. Dr. van Doorn has initiated and conducted several randomized controlled trials and surveys in GBS and CIDP, including the ongoing second-dose IVIg trial in GBS patients with a poor prognosis.

He is a member of the medical advisory board of the Prinses Beatrix Spierfonds and the GBS-CIDP Foundation International. Dr. van Doorn is board member of the Peripheral Nerve Society (PNS), and chair of the Inflammatory Neuropathy Consortium (INC). He chaired the organisation of the PNS/INC meeting 2012 in Rotterdam.


Susan T. Iannaccone, MD

Susan T. Iannaccone, MD, FAAN, is the Jimmy Elizabeth Westcott Distinguished Chair in Pediatric Neurology, Professor of Neurology and Pediatrics at the University of Texas Southwestern Medical Center and Director of Child Neurology at Children's Medical Center

Dallas. She specializes in pediatric neuromuscular disease and has been Medical Director for the Dallas Pediatric MDA clinic since 1991. Her multidisciplinary Pediatric Neuromuscular Medicine clinic serves a population of over 500 children with neuromuscular diseases, including 130 with hereditary neuropathies.

Dr. Iannaccone is known for her work as a clinical trialist for spinal muscular atrophy and Duchenne muscular dystrophy. She was a major contributor for the international consensus statements for standards of care for children with several neuromuscular diseases. She is also a mentor for a pediatric NMM fellow each year and Program Director of the annual Carrell-Krusen Neuromuscular Symposium.

Inflammatory Neuropathy in Teens and Young Adults

By Susan Iannaccone and Diana Castro

Drs Susan Iannaccone and Diana Castro are very pleased to be invited to participate in the 2014 International Symposium sponsored by the GBS/CIDP Foundation International. We will represent the University of Texas Southwestern Medical Center of Excellence Clinic and in particular, the Pediatric Clinic based at Children's Medical Center Dallas. As co-directors of the Pediatric Neuromuscular service at CMC, we diagnose and manage more than a dozen new cases each year. Many suffer from monophasic illness, recovering quickly after one course of IVIG. However, at least once a year we are referred a patient with protracted weakness and evidence of CIDP. We look forward to meeting everyone at the meeting and to sharing our experiences as you share yours with us.


Vera Bril, BSc, FRCPC, MD

Vera Bril is a Professor of Medicine (Neurology) at the University of Toronto, Director of Neurology at University Health Network and Mount Sinai Hospital and holds the Krembil Family Chair in Neurology. She is the Interim Director of

the Krembil Neuroscience Program at the University Health Network. She has particular expertise in the diagnosis and management of patients with complex neuromuscular disorders. Her research interests have centered on the diagnosis and evidence-based treatment of myasthenia gravis, inflammatory polyneuropathies, and diabetic sensorimotor polyneuropathy. Her work has helped set the standards for electrophysiological investigations in the definition and evaluation of the progression of chronic polyneuropathies. Her research has helped establish the role of intravenous immunoglobulin in the treatment of myasthenia gravis and the Guillain-Barré Syndrome, and the long-term treatment of chronic inflammatory demyelinating polyneuropathy.

She has acted in an advisory capacity to Health Canada and the FDA. Dr. Bril also serves as the Deputy Physician-in-Chief for Economic Affairs for the Department of Medicine at the University Health Network and Mount Sinai Hospital and Chair of the Economics committee. She is part of the Department of Medicine Executive Committee and helps administer this group of 300 physicians.

Anesthesia and Patients with Inflammatory Neuropathy

By Vera Bril

What happens when someone with GBS or CIDP needs surgery? Is it safe to have a general anesthetic? Is it safe to have a local anesthetic? Are there more risks because of the GBS or CIDP? What should I ask the anesthetist and surgeon about before the surgery? Is the recovery complicated? These are some of the questions that we will talk about during my presentation.

Symposium Topics

Immunizations and Vaccinations

By Peter Donofrio and David Cornblath

The presenters will discuss broadly the implications of undergoing flu vaccinations and other vaccinations in patients with prior Guillain-Barré Syndrome and CIDP and will review the development of Guillain-Barré Syndrome in patients who received the influenza vaccine in 1976-1977. They will also discuss the lack of any significant evidence relating to flu vaccinations and Guillain-Barré after 1977 and will emphasize the higher incidence of Guillain-Barré after the natural influenza illness. Patients are more likely to develop Guillain-Barré after a natural flu infection than by flu vaccination. They will review the flu vaccination guidelines which have been proposed by the GBS|CIDP Foundation International, the Neuropathy Association, and the CDC, then will conclude the lecture by contrasting the morbidity and mortality of the natural influenza compared to complications of flu vaccination.



David R. Cornblath, MD

David R. Cornblath, MD, is Professor of Neurology at The Johns Hopkins University School of Medicine and Director of the Neurology EMG Unit at Johns Hopkins Hospital. His specialty interests are neuromuscular diseases and neuropathies. He is currently involved in a number of clinical trials of neurotrophic agents for ALS and neuropathy. He received his MD degree

from Case Western Reserve University in 1977 and completed his internship at University Hospitals in Cleveland in 1978. His neurology residency was undertaken at the Hospital of the University of Pennsylvania, under the direction of Dr. Arthur K. Asbury and was an MDA Neuromuscular fellow at the same institution. In 1982, he went to the Department of Neurology of the Johns Hopkins University School of Medicine to start and develop the Neurology EMG Unit at the Johns Hopkins Hospital.

In 1993, Dr. Cornblath was an Honorary Professor of Neurology, Hebei Medical College and the Second Teaching Hospital of Hebei Medical College, Shijiazhuang, PRC. He is an active Member of numerous professional associations including the European Neurological Society and the editorial board of *Annals of Neurology* and *Muscle & Nerve*.

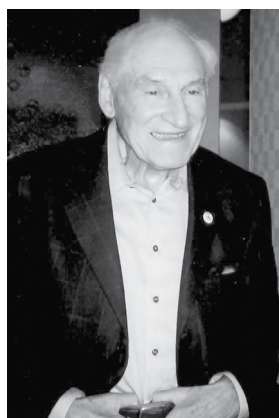


Peter D. Donofrio, MD

Peter D. Donofrio, MD, received his undergraduate training at the University of Notre Dame and medical school at Ohio State

University. He completed a medicine residency at Good Samaritan Hospital in Cincinnati, Ohio, and subsequently a neurology residency and neuromuscular fellowship at the University of Michigan. He has held faculty positions at the University of Michigan, Wake Forest University School of Medicine, and Vanderbilt University Medical Center.

Dr. Donofrio is presently Professor of Neurology, Chief of the Neuromuscular Section, and Director of the EMG Laboratory at the latter institution. He is also Director of the Neuropathy Association Center at Vanderbilt and Director of the MDA-sponsored ALS Clinic. He has a special interest in peripheral neuropathy, GBS, CIDP, and motor neuron disease and is the author or co-author of numerous journal articles, abstracts, and book chapters on subjects related to neuromuscular disorders. He is past president of the American Association of Neuromuscular and Electrodiagnostic Medicine, the North Carolina Neurologic Association and is active on several committees of the American Academy of Neurology and the American Neurological Association.



It is with much sadness that we announce the passing of Henry (Hank) Friedman, on Monday, August 11, 2014. He was one of the "original eight" who gathered as a small GBS support group and grew to what is now an international organization. Hank was the one who visited Bob Benson when he was hospitalized and paralyzed with GBS. His visit planted the seed for why the organization exists — to support patients.

Hank Friedman served on the Board of Directors for many years and expertly guided us with his business acumen.

We acknowledge Hank Friedman as someone who understood our passion and worked to ensure our legacy.

Why I Give

By *Kassandra Ulrich*

GBS|CIDP Foundation International Co-Coordinator Liaison Activities

Seven days prior to the birth of my son Will, my feet and hands started to tingle. I got weaker and my doctor said just to rest, and this would help. I delivered March 23rd, 1981, and by April 1st I was paralyzed. It wasn't a funny April 1st joke! The hospital was my home for the next 4 months. Will and I learned to walk together 9 months later. My family, friends, church members and neighbors helped us with Will, our home, food and transportation to physical therapy/occupational therapy. We were truly blessed.

I found out about the Foundation in 1987. It was the first time in 6 years that we received any information on GBS. That was the first time I met my mentor and good friend, Estelle Benson. She changed my life. I became a liaison in 1991, and then a Regional Director in 2005.

Every time I have met a patient or caregiver, I know that the information we are giving them is life changing for the patient as well as the caregiver. It fills my heart to know I helped them feel the same way I felt when I first met Estelle and Robert Benson. The Foundation was the only place you could get information and support.

When I started getting involved with the Foundation, I talked to people on the Foundation's website and did some minor telephone work. Now two decades later, I'm a liaison and a Board of Director's member.

The Foundation has changed my life. I couldn't go back to work after GBS. The "work" I have done with the Foundation, talking to patients, their families and the medical community has fulfilled my life. I always say, "it isn't me, it's the Foundation people need to thank."

I give to the Foundation because I know that every penny that is donated is put to good use. The Foundation never wastes a donation. We pay for support, research, keeping the medical community informed and advocacy. The dollars we generate do not go to keep the lights on or fund a vacation for the board, but to make sure people who were affected with this disease are getting the same type of opportunity to make themselves better that I received.



The Foundation supports IgNS: Immunoglobulin Nursing Society

The IgNS is dedicated to nursing professionals in education, clinical practice, and research in the field of Immunoglobulin therapy. The Foundation proudly supports and attends IgNS events to raise awareness and to promote our mission.

Philadelphia, July 2014

The Foundation representative attended the Ig Academy, a rigorous, one-day course that offered in-depth, evidenced-based education on the most critical and relevant aspects of Ig nursing. Designed for nurses, this program provided the following objectives:

- Prepared for Ig credentialing
- Provided an overview of Ig therapy
- Discussed relevant clinical uses



Las Vegas, September 2014

The Foundation representative will attend this 3rd Annual National Conference which provides in-depth Ig education reflecting the wide spectrum of clinical indications and sites of care. This program offers advanced-level topics for Ig nurses.

The FORCIDP Trial

By *Richard Hughes*

Emeritus Professor of Neurology, King's College London

Honorary Member of Board of GBS|CIDP Foundation International

The hunt is on for a simple, safe drug to treat CIDP (chronic inflammatory demyelinating polyradiculoneuropathy) to give it its full title. Corticosteroids, intravenous immunoglobulin (IVIg) and plasma exchange (otherwise known as plasmapheresis) are all first line treatment options endorsed by international guidelines [Van Den Bergh et al. 2010]. Immunosuppressive drugs such as azathioprine, cyclophosphamide, methotrexate and mycophenolate are sometimes tried in people with hard-to-treat CIDP but none of them have been proved to work in randomized controlled trials. In fact small investigator-led trials of azathioprine and methotrexate gave negative results. Against this background, the pharmaceutical company Novartis has launched a trial of fingolimod in CIDP, the FORCIDP trial.¹

Fingolimod is a proven treatment for multiple sclerosis, a disease which causes inflammation and nervous tissue damage in the brain and spinal cord, somewhat similar to the peripheral nerve damage in CIDP. Fingolimod works by blocking the escape of harmful lymphocytes from the lymph nodes. This lowers the blood lymphocyte count. Taking fingolimod is easy, one 0.5 mg tablet to swallow every day. It does have some side effects. Like all immunosuppressive drugs, it runs the risk of increasing susceptibility to infections. In addition, it has to be started carefully, with the first dose taken under supervision in hospital. This is because starting treatment may occasionally slow the pulse to low levels, especially right after the first dose and especially in some people. There are other side-effects as well but in more than 147000 patient years in multiple sclerosis, fingolimod has turned out to be reasonably safe.

The FORCIDP trial is comparing the effect of one fingolimod 0.5 mg tablet a day with that of a placebo tablet (one which looks the same but is inactive). To take part, people have to:

1. definitely have CIDP;
2. be taking either IVIg or prednisone (or equivalent) in a stable dose; and
3. have worsened during the past year when the dose of either of these was reduced.

On entering the trial, participants start the study drug and stop their IVIg or tail off their prednisone. If they worsen, they stop the trial tablet and are immediately treated with IVIg or prednisone again. If they do not, they stay on the trial tablet until the end of the trial and, if eligible, have the option to enter a longer study. The critical test for a successful result will be the time taken to

worsen on a special disability scale. The trial also measures grip strength, strength of 12 limb muscles and a second measure of disability using a new, probably more sensitive, scale. Fifty people have already started the trial and the intention is to include more than 150 people. This total will make it the largest trial of any immunosuppressant drug ever done in CIDP.

The trial is going on in many countries around the world. More information including the names and locations of participating centres can be obtained from the [clinicaltrials.gov](https://clinicaltrials.gov/ct2/show/record/NCT01625182?term=CIDP&rank=5v) website:

<https://clinicaltrials.gov/ct2/show/record/NCT01625182?term=CIDP&rank=5v>

The complexity and expense of conducting trials of new drugs in such a rare condition has made it necessary to look to the major pharmaceutical companies to lead the hunt for new treatments. It is very encouraging for the CIDP world that major pharmaceutical companies, such as Novartis, are taking an interest in our disease.



Disclosure

Professor Hughes is a consultant for Novartis and co-Chair of the Scientific Committee of the FORCIDP trial.

Reference List

Van Den Bergh PY, Hadden RD, Bouche P *et al.* European Federation of Neurological Societies/Peripheral Nerve Society guideline on management of chronic inflammatory demyelinating polyradiculoneuropathy: report of a joint task force of the European Federation of Neurological Societies and the Peripheral Nerve Society - first revision. [47 refs]. *European Journal of Neurology* 2010; 17: 356-363.

¹ The acronym for a double-blind, randomized, multicenter, placebo controlled, parallel-group study to evaluate the efficacy and safety of fingolimod 0.5 mg administered orally once daily versus placebo in patients with CIDP.



We Welcome Allison Dadouris, Marketing and Development

Allison just joined the Foundation this summer! She recently graduated from Lafayette College where she earned a BA in International Business, concentration in Economics and Spanish with a minor in Writing.

While at Lafayette, Allison played field hockey and wrote for the college newspaper. Allison joins us to support fundraising and communications.

We Love to Hear From You!

Please send us your stories, "Letters to the Editor," and questions for the Medical Advisory Board.

Direct your inquiries to Lisa Butler in the Foundation office at lisa.butler@gb-cidp.org.

GBS/CIDP Foundation Supports the 7th Meeting of the Inflammatory Neuropathy Consortium

Dusseldorf, Germany

The Foundation was represented by Ken Singleton, Estelle Benson and Carol Lee Koski, as well as several members of our Medical Advisory Board. We are exceptionally proud of the MAB members Hans-Peter Hartung, this year's Chair, and Pieter van Doorn, President of INC, which hosts a gathering of a growing number of clinicians, clinical scientists as well as basic researchers in the field of peripheral nerve research. The presenters shared the most recent advances in the research of the pathogenesis, diagnosis and treatment of inflammatory neuropathies. In the words of the INC:

The use of steroids, plasma exchange, intravenous immunoglobulins and various immunosuppressive drugs for the treatment of inflammatory neuropathies is well established. However, the clinical heterogeneity of this group of diseases suggests different mechanisms in the underlying immunopathogenesis making treatment decisions sometimes difficult. We are currently at the beginning of an era to better understand these differences, which ultimately will enable us to identify the right treatment modality for the right patient at the right time. In addition, modern molecular technologies enable us to decipher a growing number of novel pathways involved in peripheral nerve and myelin repair that might translate into better regenerative strategies in the near future. Collecting larger patient cohorts and sharing experience among clinicians is becoming key to better understand inflammatory neuropathies and to establish individualized treatment strategies. This INC meeting provided the forum for all these activities.



Top Row (left to right): Eduardo Nobile, Italy; Kenneth Gorson, Boston, MA, USA; Hugh Willison, Glasgow, Scotland; Richard Lewis, LA, CA, USA; Hans-Peter Hartung, Germany; Pieter Van Doorn, Netherlands; Richard Hughes, London, England; Bart Jacobs, Netherlands; David Cornblath, Baltimore, MD, USA

Seated: Nobuhiro Yuki, Hong Kong; Carol Lee Koski, USA; Estelle Benson, Founding Director; Angelika Hahn, Toronto, Canada

The Walk and Roll Greater Delaware Valley, on Sunday, June 22nd, 2014 brought together friends and families to support the mission of GBS/CIDP Foundation International for with food, fun, and festivities!

"Just another way of saying I love you [...] How do I love thee? Let me count the steps"



"The walk and Roll for GBS was a success, not just for the money that was raised, but also for the fellowship and the love that was all around us"

"We had the information she was looking for in the last 6 months. We see this everyday. This is the reason I dedicate my time with the Foundation. Seeing how they were helped just coming to the walk is why we do what we do."

"There is always a new day and a new reason to be involved with the Foundation as we gain so much from others. Friends are everywhere"



"People are really confused about what it is and how it affects me. The walk was a good resource/excuse to bring it up to people without their feeling awkward about asking questions. Meet with others with the disease, raise awareness and money for the Foundation. It's a win-win situation"

"As an employee of one of the walk's sponsors, CSL Behring, I have had a chance to get to know many people with GBS and CIDP and have come to greatly respect the efforts of the Foundation. This particular walk, which occurred 10 minutes from my home, allowed me the opportunity to bring my family and share with them the pride and joy of the work we do to bring therapies to market to treat these conditions"



"The recent Walk & Roll in Philadelphia was a perfect example of how the Foundation brings people together for the common benefit of all those who have been impacted by GBS, CIDP and related syndromes and variants. The shared spirit in the air was tangible and the many smiles spoke for themselves. It was great to be there to participate."



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Directory

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

"CIDP" Group

For those with a diagnosis of chronic inflammatory demyelinating polyneuropathy. Please identify yourself to the National Office in order to be placed on the CIDP list for special mailings, etc.

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 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.

Wheelchair Limited Group

Please call the National Office for contact with others.

AMSAN Group

Please call the National Office for contact with others.

A Teenage Pen Pal Group

Arielle Challander, 231-946-7256
4313 Shawn Drive
Traverse City, MI 49685
Email: 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.

Bereavement Group

A group for anyone who has lost a loved one due to GBS|CIDP complications. Please contact: Bereavement Group at the National Office.

The "Campy" Group

Those whose GBS onset was identified as a result of the campylobacter bacteria. Numbers to be used for research purposes.