

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.

## Patient Story

**By Kyle Van Mouwerik**

Liaison for South Lake Tahoe, California

On the 18th of August 2013, I was suddenly engulfed in a fight for my life. An illness that no one could pronounce laid claim to me, with a velocity and a determination that numbed everyone. I had come to a standstill. Within four days, my lungs, which had sustained me so well for 22 years, ceased to draw breath. My body became immobile.

Fueled with morphine and propofol, the acute phase of Guillain-Barré syndrome sought to do me in as I endured an induced coma. I waged my battle, traversing a twilighted landscape—jungles and deserts and high places, gunshot wounds, dark meeting places in rooms with no windows, ICU psychosis, and dimly lit passageways.

A heart that used to beat at 58, now found its angle of repose at 120 and more. A muscled 185-pounder diminished to 125 pounds in short weeks. A body that could not sustain the basics of life, like blood pressure and a normal temperature. Oh, what we take for granted! According to my parents, the only communication I provided within those first three weeks was a delirious shaking of my head: back and forth, forth and back.

My maniacal head-shaking is still woven into my parents' memories. I stayed in the hospital four months before my homecoming on December 23rd, and spent five months at home with my parents.

It took a while, but finally things started to come back. My mind and my sense of humor (though these had never fully departed), my weight,



and my will. A couple dozen prescriptions became a dozen, a half dozen, and finally no doses of anything. I kicked it all—opiates, morphine, and finally methadone. Mobility returned, and dexterity. Many things were discarded: Hoyer lift, hospital bed, and then, finally, my walker.

I still host a couple of scars: a stoma from my tracheostomy, a unique puncture in my abdomen where a feeding tube sustained me. I came to know what we understand as suffering, which “is really only life herself, making him unavoidably unique” (says Jim Harrison, in *Dalva*).

After another nine-month incubation under my belt, I felt reborn.

I drove north, on a path of reclamation. Armed with Blue Rockers (braces), hiking poles, a wheelchair, my Dodge and my dog, I was on my way to South Lake Tahoe, my home before the illness. On my 24th birthday this December, I made a spur-of-the-moment decision to try snowboarding again for



## In This Issue

Page

- 2** Meet our newest hero, **Hugh Williams**, who is running 52 races in one year, raising awareness and funds for the Foundation!
- 4** Liaison from France, **Jean-Philippe Plançon** reports on therapy study
- 9** PPTA announces the Patient Notification System
- 10** Liaison **Bill Ansley** deployed to Afghanistan... Meet **Ned the Nerve!**
- 11** Get your **Walk & Roll** on for 2015!

*continued on page 2*

**EXECUTIVE DIRECTOR**

Ken Singleton

**FOUNDER**

Estelle L. Benson

**OFFICERS**

Philip Kinnicutt

*President*

K. Robert Doehrman

*Vice President*

Patricia H. Blomkwist-Markens

*Vice President*

Ginger Crooks

*Treasurer*

Santo Garcia

*Secretary***BOARD OF DIRECTORS**

Sue D. Baier

David R. Cornblath, MD

James Crone

Elizabeth Emerson

Susan Keast

Laura E. Stegossi, Esq.

Joel S. Steinberg, MD, PhD

Marilyn Tedesco

Kassandra Ulrich

**MEDICAL ADVISORY BOARD**

Richard J. Barohn, MD

Vera Brill, MD

Mark J. Brown, MD

David R. Cornblath, MD

Marinos C. Dalakas, MD

Peter D. Donofrio, MD

John D. England, MD

Kenneth C. Gorson, MD

Michael C. Graves, MD

Hans-Peter Hartung, MD

Susan T. Iannaccone, MD

Bart C. Jacobs, MD, PhD

Jonathan Katz, MD

Carol Lee Koski, MD

Richard A. Lewis, MD

Robert Lisak, MD

Eduardo Nobile-Orazio, MD, PhD

Gareth J. Parry, MD

David S. Saperstein, MD

Kazim A. Sheikh, MD

Joel S. Steinberg, MD, PhD

Pieter A. van Doorn, MD, PhD

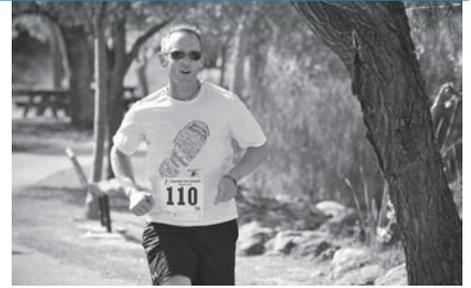
Professor Hugh J. Willison, MBBS, PhD, FRCP

Gil I. Wolfe, MD, FAAN

Nobuhiro Yuki, MD, PhD

*Non-profit 501(c)(3)*

## Giving Back: Hugh Williams Races to Beat GBS



Have you ever met a real hero?

The dictionary defines a hero as a person of distinguished courage or ability, admired for brave deeds and noble qualities. Meet Hugh Williams, a GBS|CIDP Foundation International hero! After GBS ran through Hugh, Hugh is now running for GBS.

Hugh was diagnosed with GBS in 2009. In the course of a few days, he went from being a runner to struggling to walk to the mailbox. He met with several doctors who could not explain what was wrong with him until he was finally diagnosed at the UCSF Medical Center. The challenges that come with GBS weighed heavily on him: not knowing where to get help, not being able to look after his family, and not being able to work.

Over the next year, Hugh put on 25+ pounds and became horribly out of shape. He could not exercise, and he was not in the mood to eat right. He often woke in the night because of numb hands and tingling legs. He was phenomenally tired and easily exhausted. His balance was off, and he became dizzy easily. But Hugh steadily got better, and by mid-2010 he was thinking about getting gently back into exercise. It took Hugh over a year to get back to even close to normal, and more than two years to run again.

Fast forward to today. Hugh is fully recovered, and is turning the tables on GBS. Hugh has pledged to run 52 races in 2015 to raise both awareness for GBS and donations so that the Foundation can continue its work in helping others. His plan is to raise \$52,000 for the GBS|CIDP Foundation, or an average of \$1000 per race!

Please follow Hugh on his journey by visiting his blog to read about where he has been and where he may show up next. You can also get regular updates at his fundraiser page on Facebook. Even better, show up at a race, run with Hugh, cheer him on and meet this true hero!

Learn more about Hugh and his journey at his blog: <http://fiftytwofives.com> and on Facebook at <http://facebook.com/fiftytwofives>

Make a donation to his campaign: <http://igg.me/at/fiftytwofives>

*continued from page 1*

## Patient Story

the first time in two years.

The snowboard boots held my feet in position, so I did not use my braces (which I always wear when I walk). I did two runs with my friends, then hung out at the Heavenly Valley ski resort first aid station where I had worked as an EMT two years ago. As I did my third run of the day, I couldn't help smiling and thinking, "What was that doctor's name who said I'd work a desk job forever?"

**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 related syndromes such as MMN. We respect your privacy.

Dear Friends,

We hope this finds you well and beginning to see the promising signs of spring approaching!

In 2015, as we continue our emphasis on communications, we are always looking for innovative ways to communicate with all of you, our constituents. As good stewards of every dollar donated, we strive to bring you improvements in our communication both efficiently and economically. We'd like to draw your attention to the following initiatives involving communications.



- We have a growing presence on Facebook with over 7,000 weekly followers. There we post relevant news stories and updates on Foundation activities like upcoming Walk & Roll events and chapter meetings.
- Our newly re-formatted website also brings you new and current information. Recent additions of note include:
  - Symposium 2014 video – homepage slider
  - Three new Centers of Excellence – Get Support – Centers of Excellence
  - Assistive and Adaptive Equipment resources – Get Support – Resources – Publications
  - Walk & Roll dates – Homepage – Community Events
  - Chapter Meetings – Homepage – Community Events
  - Patient Stories – Homepage – My Story

To communicate with you we need to know how to reach you! Please let us know your phone number or email address changes, and send us your email if we do not currently have it. We love to hear from you and want to be able to respond! If we have your email address, you can expect to hear from us with quarterly emails and updates.

Look for 2015 to bring the following:

- Please remember that May is GBS|CIDP Awareness Month. Get involved by attending or planning a Walk & Roll in your area or create your own event! Contact Allison Dadouris at the National office: Allison.dadouris@gbs-cidp.org
- For the first time in ten years, this fall you will receive an annual report which will include our financial position, a statement of our mission pillars, and a tribute to our supporters!
- Keep an eye on Facebook and on our website for a spring announcement of the location for our 14th International Symposium which will celebrate the 100th anniversary of the identification of GBS!

Have a wonderful spring, and let us hear from you!

*Ken Singleton*  
Executive Director

*As good stewards of every dollar donated, we strive to bring you improvements in our communication both efficiently and economically.*



**CONTACT US**  
International Office  
The Holly Building  
104½ Forrest Avenue  
Narberth, PA 19072

1.866.224.3301  
1.610.667.0131  
Fax: 1.610.667.7036  
www.gbs-cidp.org  
email: info@gbs-cidp.org

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](http://www.gbs-cidp.org)  
or by emailing [info@gbs-cidp.org](mailto:info@gbs-cidp.org)

Visit us on Facebook: [www.facebook.com/gbscidp](http://www.facebook.com/gbscidp)



# Coping with CIDP - Linking Exercise Practices with Physical and Emotional Quality of Life

By **Jean-Philippe Plançon**

President of French Association against Peripheral Neuropathies and the GBS|CIDP Foundation International Liaison in France



*Not Just Sweat: Outcomes of Exercising*

New research led by Jean-Philippe Plançon in Paris, France, explores the impact of chronic immune mediated neuropathies (CIMN) such as CIDP on health-related quality of life. This study highlights the direct link between self-esteem and physical ability with physical activity, and shows physical activity as a possible method of improving health-related quality of life in CIDP patients.

The results of this study indicate that the most significant aspects of health-related quality of life affected by CIMN are fatigue (65%), pain (39%), mobility (38%), and sleep (26%). In comparing patients with CIMN to healthy subjects, the study found that patients with CIMN view their health as 5.8 times worse than a subject without CIMN. Subjects with CIMN also perceived their endurance to be 40% lower and their athletic competence to be 48% lower than their unaffected counterparts.

In addition to affecting physical health, CIMN can also have a serious impact on emotional health. 56% of subjects with CIMN reported that their disease impacted their emotional reactions, and 47% reported being affected by social isolation.

This relationship between physical and emotional health is clearly documented in Plançon's research. As illustrated in this graphic, the functional disability associated with CIMN diagnoses can lead to a

downward spiral of decreased physical ability and self-esteem, resulting in a decreased quality of life.

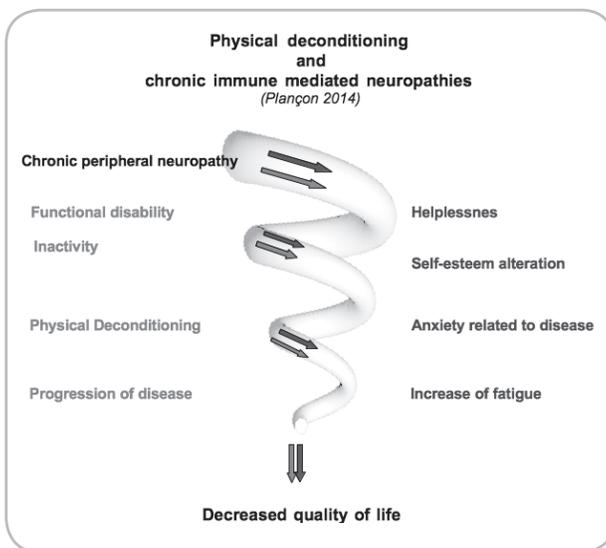
The benefits of exercising in CIMN patients are both significant and numerous. From the physical perspective, exercising can decrease fatigue and pain, and can increase energy and improve sleep quality. Exercising can allow patients to better cope emotionally with the effects of their disease, and can improve self-esteem and confidence. Finally, and perhaps most importantly, exercising allows individuals to maintain social ties and increase their social interactions on a regular basis, thus alleviating feelings of social isolation.

There has yet to be much literature published about the types of physical activity that best benefit patients, although

Plançon's experience has shown that patients who seem to derive the greatest benefits practice aerobic activities such as walking, running, swimming, and cycling. Targeted muscle building, when performed carefully and in moderation, can increase strength, while balance disorders can be improved with Nordic walking or golfing.

Much remains to be learned about this relationship, although it is clear that non-drug therapies, such as regular physical activity, show great

promise in helping patients effectively (and inexpensively) cope with the effects of CIMN.



## Join us in welcoming Anna Yankelev!

Anna Yankelev joined the Foundation in February 2015. She graduated from Brandeis University with a BS in Public Health and an BA in Anthropology. After graduating, Anna lived in Israel for a year, developing and running programming for high-risk Arab and Israeli youth. Anna brings her experiences with community organizing and individual empowerment to the Foundation by providing support for liaisons and working on advocacy.

## Using Plasma Protein Therapies (IVIg)? Make Sure You Are Registered with the Patient Notification System (PNS)!

Over a decade ago, the Plasma Protein Therapeutics Association (PPTA) and its members, working in collaboration with consumer organizations, developed a first-of-its-kind Patient Notification System (PNS). This model notification system is a rapid, web-based tool that empowers patients with information about their medicines and is also available to physicians, nurses, and pharmacists. All you need to do is sign up! Register at [www.patientnotificationsystem.org](http://www.patientnotificationsystem.org). The PNS is a great source of trustworthy information; it provides confidential notification of therapy withdrawals and recalls. There is no charge to register.

We would like to make you aware of the many great features about the PNS. It's easily accessible and is the one place on the web that you can visit and log in to receive comprehensive information about immune globulins, blood clotting factors, alpha-1 proteinase inhibitors, and other lifesaving plasma protein therapies. Another important feature is that the PNS is confidential. Registrants, whether patients, physicians, family members, nurses, or pharmacists, are guaranteed that their information is never shared or accessible by anyone other than the third-party company that houses the computers to run the system. The PNS was created to provide consumers, healthcare providers, and others with a single, convenient source for up-to-date information about the plasma protein therapies they use and depend on.

### Register Online or Toll-Free

Anyone interested in registering with the PNS can go online at [www.patientnotificationsystem.org](http://www.patientnotificationsystem.org) or call the toll-free number, 1-888-UPDATE-U (1-888-873-2838). When you sign up some basic contact information will be required, such as your name, address, email and phone number. You'll set up your own login and receive a password.

### PNS in Action

Here's how the PNS works. If a therapy is withdrawn or recalled, the company involved immediately contacts Stericycle, Inc., which then notifies the registrant. Every effort is made to notify registrants within 24 hours. Registrants are notified twice. First, you will receive an email, phone call, or fax from Stericycle depending on your designated "primary" notification. Second, you will receive a letter via U.S. mail containing the same information. The reason you will receive two notifications is that you need to know before you infuse or inject your therapy that there has not been an event, which is the term that is used for a recall or a withdrawal. The redundancy of two types of notification is intended to ensure that you have received this important information.

Consumers also can go online to [www.patientnotificationsystem.org](http://www.patientnotificationsystem.org) or call a 24-hour, toll-free number 1-888-UPDATE-U (1-888-873-2838) for current information on product recalls or withdrawals. To maximize the usefulness of the system, it is important for consumers to keep accurate infusion logs and record the lot number, therapy, and manufacturer for all therapies they use. Infusion logs are available by calling the toll-free number.



*To make accessing the PNS site easier for users, the Association has developed a QR code which is a machine-readable code and will allow users to scan a barcode with a smart phone and immediately be taken to the PNS website.*

# Ned the Nerve explains Guillain-Barré Syndrome (GBS)

*(Say Ghee-yan Baa- ray Sin-drome!)*

**Created by Dr. Fiona Blyth**

Pediatric Registrar within the School of Pediatrics, Yorkshire and Humber Deanery, UK

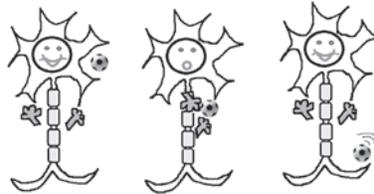
## Meet Ned!



*Hi! I'm Ned the Nerve!*

## What do nerves do?

*Nerves send messages from your brain to the rest of your body. I send messages by catching them with my head, passing them down my body and then kicking them off with my tail to other nerves; just like this:*



## What is GBS?



*GBS is rare but can occur in people of all ages. Nerves wear special jackets which help us pass messages down our bodies. In GBS, our jackets fall off and we can't send messages down to our tails and pass them on. We drop the messages and cannot tell your muscles to move.*

## What causes GBS?



*Doctors don't know the answer to this. Sometimes GBS can occur after a tummy bug or a sore throat. This may be because the body system that fights illnesses is working so hard that it fights nerves by mistake.*

## What does it feel like?



*First you may notice weakness or tingling in your legs. This may spread to your arms and upper body. You may feel tired and weak and have difficulty breathing. But don't worry, doctors will give you special medicine to help you feel better soon.*

## Getting Better

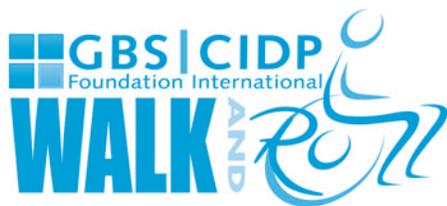


*Different people recover at different speeds. You may still feel tired several months after being in hospital. Don't worry though! Most people with GBS make a full recovery and live normal healthy lives.*



I am deployed with the Defense Logistics Agency, stationed at Bagram Air Field in the Parwan Province of Afghanistan located at the western foothills of the Himalayan Mountains. Life here is busy but I always find time at the end of the day to read emails from home, including ones sent to my GBS-CIDP Foundation account. I try to respond to all inquiries, including requests from new people that visited the website. So please keep the emails coming. Reading emails from home is a great escape from the rigors of life in this battlefield environment. To my Central Ohio Chapter Peeps - SEE YOU WHEN I GET BACK THIS SUMMER!

— Bill Ainsley: Ohio Liaison



2015 marks the third year of our signature Walk and Roll program. Our Walk and Roll for GBS|CIDP inspires local communities to join together to support GBS, CIDP and related syndromes such as MMN.

This year, thousands of individuals, teams, and caring sponsors will participate at one of our sites or virtual program! In just three years, we have been able to grow from 3 inaugural walks to a program hosting at least 10 walks in major cities all over the United States.

**With at least 5 more walk sites still in the works, our Walk Schedule for 2015 so far includes:**

**Dallas, TX** - May 3rd at Frisco Commons Park

**Oklahoma City, OK** - May 16th at Earlywine Park

**New York City, NY** - May 17th at Alley Pond Park

**Chicago, IL** - May 30th at Busse Woods Forest Preserves

**Bernardsville, NJ** - May 31st at Harry Dunham Park

**Philadelphia, PA** - June 14th at Wilson Farm Park

**Seattle, WA** - June 14th

**San Diego, CA** - June 20th at Rancho Bernardo Community Park

**Myrtle Beach, SC** - September 19th at Riverfront Park

**Pittsburgh, PA** - September 19th at South Park

**Huntington, WV** - September 26th at Barboursville Park

**Virtual Walk** - Available year-round for anyone unable to attend

To register for any of our walks, simply visit our Walk and Roll page at: [gbs-cidpwalk.org](http://gbs-cidpwalk.org) or click the Walk and Roll logo on any of the pages on our website.

Funds raised through our walks will help us to achieve our vision of a future when no one with GBS, CIDP or related syndromes such as MMN suffers alone, and that everyone has access to the right diagnosis and the right treatment, right away!

It is never too late to start planning a walk. If you are interested, please contact the Foundation at 610-667-0131 or by email at [allison.dadouris@gbs-cidp.org](mailto:allison.dadouris@gbs-cidp.org).

## REGISTER TO WIN!

All Walk and Roll donors and participants, stay tuned for details on entering our raffle to win a brand new

### Huffy Mountain Bike!

*Thank you to SoleoHealth for donating three bikes to our Walk and Roll Program!*



International Office  
The Holly Building  
104 ½ Forrest Avenue  
Narberth, PA 19072-2215



CHANGE SERVICE REQUESTED

Non-Profit  
U.S. Postage  
**PAID**  
Permit No. 215  
West Chester, PA 19382

## 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  
kylevanmouwerik@hotmail.com

### **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 National office.  
Anna.Yankelev@gbs-cidp.org

**Make sure to inform the National Office if you have been diagnosed with one of the following. This will insure that you will be added to condition-specific communication.**

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