

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

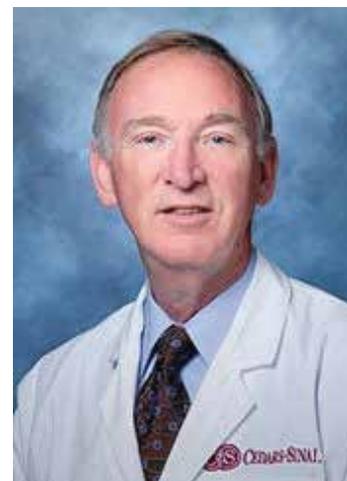
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Meet Our 2018 Symposium Keynote Speakers!

Please join us in welcoming our 2018 Symposium Keynote Speaker, **Richard A. Lewis, MD, Professor of Neurology at Cedars-Sinai Medical Center, Los Angeles, CA.**

Dr. Lewis's research interests include electrodiagnostic findings in demyelinating neuropathies both acquired and inherited. As a leader in the GBS|CIDP community, he has participated in numerous patient support meetings and conferences and is on the GBS|CIDP Foundation's International Global Medical Advisory Board, Peripheral Nerve Society and Board of Directors of the Inflammatory Neuropathy Consortium.



We are delighted to announce our keynote speaker for the 2018 Patient Symposium is actor (Happy on ABC's "Once Upon a Time" TV show), patient activist and GBS survivor, **Michael Coleman.**



Michael shared his inspiring patient journey from overwhelming fear to a declaration of lifelong happiness, with the GBS|CIDP community in 2017. Today we share his story to remind you of this incredible journey, and ask that you join us in welcoming Michael to the 2018 Patient Symposium team!

"My name is Dr. Gupta, and I am a neurologist. You have a rare condition called Guillain-Barré Syndrome. I am going to be honest with you: there is a very real chance you will not survive the week. I am admitting you to ICU, we need to act fast."

This was March 26th, 2016, the third time in my life I was in a hospital emergency room being told I may not survive the week. A few weeks prior to the statement above, I began experiencing some incredibly unique symptoms that were nearly impossible to explain. It was somewhat confusing as I was literally in the best shape of my life. I had committed to a strict program and was feeling incredible! Then, I started feeling strange sensations. I left a TV interview one day and tripped a few times to the ground on nothing. It was bizarre to say the least. I assumed I was just getting clumsy due to my busy schedule. Then I had a weird feeling of cold, short, minty breathing all of the time where my normal breath used to live. It was as though I'd just climbed a cold mountain and swallowed a pack of mints—all the time. And then my shoulders began to hurt like they've never hurt before.

I went to the walk-in clinic to get checked out. The doctor chalked up the sensations to a new

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GBS|CIDP Foundation Advocates on the Hill for Medicare IVIG Access Enhancement Act (H.R.4724)

As we have seen from communities that currently have access to home infusion, such as primary immunodeficiency diseases, the cost to choose the home as the preferred site of care has tremendous benefit in terms of health outcomes and overall convenience for patients. Individuals with CIDP and MMN often face mobility issues as limbs suffer nerve damage. Traveling to receive an infusion presents a tremendous hardship to many patients and their families. This hardship greatly affects rural patients who have to travel hundreds of miles and long hours to cities in order to receive treatment and are often forced to choose between paying a bill and incurring the cost to travel for their infusion. Through our work, the Foundation has seen that when there are obstacles to receiving regular infusions, medical management becomes complicated, and patients tend to skip scheduled infusions, which leads to progressive disability.

Many CIDP and MMN patients have access to IVIG home infusion through private insurance which allows them to lead productive and active lives. However, according to the current legislation, when these individuals age on to Medicare they can face disruption in their routine and suboptimal circumstances when seeking to manage their condition. Further, when the body's immune system is depressed at the end of an infusion cycle, CIDP and MMN patients face an elevated risk of contracting illness from visiting well-traveled sites of care for their next infusion. Most importantly patients and physicians should be able to choose their preferred site of care.

The Medicare IVIG Access Enhancement Act (H.R.4724) will ensure that home infusion is still accessible and affordable to those patients who are receiving Medicare benefits. Thus far, 21 bipartisan Members of Congress have co-signed this bill, thanks to the efforts of GBS|CIDP Foundation International and the Health & Medicine Counsel of DC. But it doesn't end there. The more letters, the more signatures, the better the chances of the bill being signed into law. And we need your help to raise awareness and encourage support from your state representatives. Please share your patient story and let your state representative know why this bill is important to you and the GBS|CIDP community. **Send your letter to Dane Christiansen at the Health and Medicine Counsel of Washington DC at: christiansen@hmcw.org. Need assistance getting started? Find a "Please Support H.R. 4724" sample letter at www.gbs-cidp.org/advocacy.**



Disclaimer Information Questions presented in The Communicator 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 GBS|CIDP Foundation International. The organization 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 such as MMN. We respect your privacy.

Dear Friends,

We are located in Conshohocken, Pennsylvania which is located just outside the city of Philadelphia where we just celebrated our football team (EAGLES) winning the Super Bowl! The unique culture of this team is not unlike the attitude of so many of our patients. NEVER GIVE UP! We lived to see what folks said couldn't be done. Their persistence and faith soared them to victory!

This organization was started with the purpose of never losing sight of the patients. Every day we provide life-altering connections for those who need them most. When we can, former patients will even visit those still paralyzed and encourage them to never give up. You will get better. So let's enjoy our personal victories in life! We are here to cheer you on and help you get to the goal line. As we begin in 2018, we invite you to be present with us and to join our inspired community. In this issue you will learn of many opportunities to engage in the path of light, hope and recovery. Where will we meet you along the journey?

Warm Wishes,

Lisa Butler

Executive Director



GBS|CIDP Rare Disease Day Campaign! Teach One. Be One. Be a Champion for Rare Disease.



February 28, 2018 was the eleventh international Rare Disease Day. On and around this day hundreds of patient organizations from countries and regions all over the world held online and in-person awareness-raising activities.

This year the GBS|CIDP Foundation encouraged members around the world to **TEACH** someone about GBS, CIDP or a variant of the condition, and **BE** a champion for rare disease! The results were nothing less than inspiring.

Two Rare Disease Day Videos featured members of the Foundation were emailed to over 20,000 members. Many supporters joined our social media campaign using hashtags **#ShowYourRare** **#RareDiseaseDay** and **#gbscidp** and our social media presence during the campaign was undeniable! Awareness was officially raised! Thank you to all who shared their story and participated in this very important day of advocacy and community support.



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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.

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Dealing With Fatigue: What You Can Do

Editors Note: Fatigue is a common complaint among GBS and CIDP patients. We hope you will find these tips helpful in coping with fatigue.

People with primary immunodeficiency diseases (PI) can experience fatigue, which is the feeling of tiredness, lack of energy and/or general weariness that does not seem to go away. Although some degree of fatigue may be common among people with PI and other chronic illnesses, it's important to never assume that fatigue "goes with the disease" and that there is nothing that can be done about it.

First, you should try to figure out why you are fatigued. Obviously, when you don't feel well or have an active infection you are tired. It is a normal body response. But if you don't have an infection and are tired, then other causes of fatigue need to be considered.



You should consult your healthcare provider, as there may be another medical reason for your fatigue. For example, your provider might want to check to see if you are anemic. Anemia is a decreased number of red blood

cells or a decreased amount of hemoglobin. This can lead to a reduced amount of oxygen able to be carried by the blood to the tissues and organs, which need oxygen to function. Your healthcare provider can determine if you are anemic and what the specific cause of your anemia is.

Treatment options may be relatively simple. If your anemia is caused by a lack of iron, adding a daily iron supplement might be the recommended treatment.

Depression can also be a source of fatigue. The relatively high incidence of depression in people with chronic illness is well documented in scientific literature. Your clinician can help to determine if you are depressed and suggest ways of treating it.

Another source of fatigue can be stress. The importance of a healthy lifestyle which includes a balanced diet, adequate rest and exercise cannot be underestimated as a stress reducer. You should attempt to identify your stressors and seek ways to eliminate them or reduce their effect on you.

5 Tips for Fighting Fatigue

Here are some overall tips on how to improve your energy levels and combat fatigue. As always, consult your healthcare provider to determine what is best for you.

• Adjust Your Diet

Try to eat smaller meals spread out through your day to boost metabolism, blood sugar and keep energy up. Also,

avoid overeating as this, in itself, can cause fatigue and can drain your energy. Just think how tired everyone is after Thanksgiving dinner! A healthy diet can provide the nutrients essential for normal growth and development, body repair and maintenance. Your primary healthcare provider is an excellent resource for direction and advice regarding a healthy diet.

• Get Some Sleep

Setting a pattern for your sleeping habits can improve the quality of your sleep, especially if you are getting to bed early enough. Most scientists recommend a consistent number of hours of sleep per night, and consistent bed times and waking times, as well. Try to go to sleep and wake up at roughly the same time each day, even on weekends or when you are on vacation.

• Get Moving

Studies have shown that physical activity, such as exercise or yoga, can jump start your energy levels. Each morning, try to fight off the early morning fatigue by doing some type of exercise and getting your body warmed up. Physical activity should be a part of everyone's life whether they are immunocompetent or immunodeficient. Not only is physical exercise good for the body, it is good for the mind, as well. Your primary healthcare provider can recommend an exercise program for you.

• Give Yourself a Break

Take a few minutes during the middle of your day to unwind. Sometimes, a few deep breaths or a short walk is all it takes to de-stress. Some people find that their productivity and energy levels increase after they take a break. Others feel a sense of accomplishment if they have made a "To Do" list and can cross off the tasks they have completed.

• Power Down

Sleep time should be No Power Hours. Melatonin is one of the body chemicals that needs to rise in order for you to fall and stay asleep. Light can keep your melatonin levels from rising. Similarly, gaming or other electronic activities can "rev" you up rather than calm you down. Your sleep routine should always include a period of time to calm down and relax. Each night, turn off all electronics an hour before you go to bed; this may help you to get the restorative sleep your body needs.

The bottom line is to discuss your fatigue with your healthcare provider. Together see if you can determine what is causing it and make a plan for how to prevent it or reduce the effect that it has on your life.

[First published, Fall, 2016, IDF Advocate. National Newsletter of The Immune Deficiency Foundation. Republished with permission.]

Will We See You In San Diego, November 1-3, 2018?

GBS | CIDP

Cheers to 30 Years!



Our very first International Symposium was held in Philadelphia on October 2, 1988. Nearly 30 years to the date we are excited to celebrate our 15th Biennial event! And with less than one year to go, our symposium registrations are rolling in.

For 30 years we have consistently received an outpouring of appreciation from attendees for offering such a unique experience for our patients, caregivers, families, and medical professionals. And this year will not disappoint as there is more excitement in store than ever before! Join us for this unique chance to get together with “old friends meeting for the first time!” Our sessions will be presented by our prestigious Global Medical Advisory Board Doctors & other experts from GBS|CIDP community. Help us celebrate three decades of making connections...that make a difference.

SESSIONS TO INCLUDE:

- Pain Management
- Research Updates
- Managing Residuals
- Insurance Updates
- Mindfulness
- Adaptive Equipment
- & More!

(schedule subject to change)

FEATURES TO INCLUDE:

- Global Medical Advisory Board One-On-Ones
- Interactive Industry Exhibit Space
- Welcome Reception (Kicked off by a Walk & Roll along Mission Bay)
- Raffles
- Closing Celebration & Announcement for the 2020 Symposium Location & More!

Our 2018 Symposium will be held at the beautiful Hilton San Diego Resort & Spa; Located on scenic Mission Bay, the San Diego resort is situated on an 18-acre park with lush gardens and rolling lawns, just steps from the beach. Hilton San Diego Resort & Spa is an ideal destination for exploration! Find out how to reserve at <https://www.gbs-cidp.org/symposium>



➔ **Don't miss EARLY BIRD SPECIAL!**

Our \$150 Full Registration Rate will only be available until April 15, 2018. Don't miss out!

Fee for Full Conference - Price: \$150.00

Includes all sessions, workshops, conference materials, box lunches, snacks, Thursday night Welcome Reception and Saturday evening reception. Does not include Friday dinner.

NEW! Couples Registration Rate - \$275

\$25 off when you register for a couple! Select '1' quantity at checkout!

Friday ONLY Attendee - Price: \$65.00

Includes all sessions, continental breakfast and boxed lunch. Does not include Thursday Welcome Reception or any Saturday Events. Does not include dinner Friday.

Saturday Attendee - Price: \$85.00

Includes all sessions, continental breakfast, boxed lunch and Saturday night closing celebration ONLY. Does not include Thursday Welcome Reception or Friday Sessions.

Registration does not include airfare, travel, or hotel accommodations.

Register and reserve your hotel online at <https://www.gbs-cidp.org/symposium/> or call the Foundation office at 610-667-0131.

**EARLY BIRD
DISCOUNT**
Deadline: April 15, 2018

Meet Our 2018 Symposium Keynote Speakers!

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antidepressant I was taking. He recommended I stop taking it and come back a few weeks later. I did as directed, but a few days later things got worse. Everything was being intensified to extreme levels. Once again I went to the doctor's office and was sent home and told to return in a few weeks.

On March 25th, 2016 around midnight, I found myself freezing uncontrollably. I laid in front of my fireplace with my arms at my sides. My shoulders now felt as though they were being ripped aggressively out of my sockets and I lay there in uncontrollable tears. My wife was upstairs asleep. Not being one to over-dramatize anything, I gave her a gentle nudge and told her I was going to go to emergency "...just to be safe. It's probably nothing, but I'm out of ideas." I spent eight hours in the hospital and went through nearly every test available, but the doctors couldn't find anything. That morning, a new doctor on shift came to release me. She was kind and empathetic and told me, "We've looked at almost everything and can't really see anything. We're going to send you home, but if these problems persist, come back and see us in a few weeks."

Now in helpless tears, I begged her, "Please don't make me go home. I am probably being dramatic here, but I think I'm dying. I am so scared. Please try everything/anything else before I have to go. If I go, I'm not sure I'll be able to come back." After a few moments, she decided to explore one more test but told me it was a long shot; very painful and not likely to find anything. Desperate, I said I would do anything to not go home. She scheduled a lumbar puncture for me. A few hours later, my wife and I waited for the results. As we were talking the entire left side of my face dropped. I felt strange but didn't know what was happening. My wife looked like she was seeing a ghost. She panicked and rushed to get the nurse. She came back with the nurse and as they were checking me out, the right side of my face dropped too. Five minutes later Dr. Gupta entered my room and delivered the sentence I started this story with above.

I was rushed to ICU where the rest of my body quickly followed suit on the "dropping" sensation. I couldn't blink, swallow, and fought to breathe. I lay there in near complete paralysis as I heard people discussing my odds of survival and recovery.

I should note that at this time I had a 6 month old daughter and 4 year old daughter. My thoughts were on nothing but, "I can't die. This would be an incredibly cruel thing to do to my wife. I have to help her raise these babies." I was flooded with love and support from friends and family. My agents, cast-mates, everyone was so incredible during this time. You really find out a lot about people in times like this and I was overwhelmed with love.

A few days after my initial five days of IVIG treatment saw me getting progressively worse. The doctors came in and told me I'd need help breathing and they were going to give me a tracheotomy. Terrified, I begged them to let me use my CPAP machine for a night or two in the hopes my recovery was just delayed. Almost completely paralyzed and without nerve connection to most of my body, I lay there for another day and suddenly... a twitch. I got a feeling back. I stayed in that hospital for a few more weeks and eventually was able to get into a wheelchair and reclaim some mobility.

At this time, I was offered an opportunity to attend a Once Upon a Time convention in the UK in April. Aha!!! A target for recovery. I still had lots of "dental freezing" feelings throughout my body and this prohibited me from being able to walk or even talk. But now that I knew I wasn't going to die and would contribute to raising my two girls again, my new focus was London. I was released under the condition that I'd promise to come in every single day for intense rehab.

After London, the team at Creation Entertainment welcomed me with open arms. Even with my crooked face, they offered me opportunities to participate in "Once Upon a Time" conventions. I love these people like family. Sixteen months later, I'm still in multiple therapy sessions every week. I am still partially paralyzed in the left side of my face. That being said, I've never been busier.

I will beat this disease and I will continue to be a strong voice in creating awareness for this debilitating condition for the rest of my days. As you have all made me incredibly Happy with your love, I wish you all the same in return.

Please. Be Happy. Trust me on this one. I'm kind of an expert on the subject.



It Helps To Know The Experts

Announcing Three New Medical Centers of Excellence

Our Global Medical Advisory Board has set standards for what they consider to be excellent medical centers for the diagnosis and treatment of GBS and CIDP. Based on levels of expertise, available treatments, facilities, and research capabilities, our growing list includes some of the top medical facilities in the world.

We are pleased to announce that as of 2018, three new medical facilities have joined our Centers of Excellence list:



University Hospital Saint-Luc

University of Louvain, Belgium

Avenue Hippocrate 10

Brussels, 1200

Belgium

<https://www.saintluc.be/services/>

[medicaux/neuromusculaire/index.php](https://www.saintluc.be/services/medicaux/neuromusculaire/index.php)

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institutes/neurology/index.html

Dr. Shan Chen 732-235-7733

For more information on the GBS Centers of Excellence please go to:

<https://www.gbs-cidp.org/support/centers-of-excellence/> or contact Lori Basiege at lori.basiege@gbs-cidp.org

WELCOME Our New Director of Marketing and Communications, Maureen Neville

Maureen joined GBS|CIDP as the Director of Marketing and Communications in December of 2017. She has previously held the position of Director of Marketing and Communications for FIRST, the Foundation for Ichthyosis & Related Skin Types, where her primary role was to advance FIRST's brand as the leader in ichthyosis patient advocacy and broaden awareness of the Foundation's programs, research and advocacy initiatives. Her fifteen year career in marketing and communications includes the development of traditional and digital marketing content for the healthcare, retail and higher education sectors.



Maureen has a unique knack for creative writing and developing "patient stories" that educate, motivate, and inspire. She is delighted to join the GBS team and excited to advocate and raise awareness for the mission of the GBS|CIDP Foundation International. She lives in Skippack, PA with her 3 lovable dogs, and her husband Jerry. She enjoys fiction and playwriting and in 2011 & 2017 received public readings of her work at Playcrafters Theater, Skippack.

Coming This Spring!

Live-Online Patient Education Event

*Our upcoming live-online education event, **Understanding CIDP for Patients and Caregivers**, is the next best thing to in-person patient support and a great resource for your friends and families.* The program will be hosted by a panel of experts including Ken Gorson, MD and Executive Director, Lisa Butler of the GBS|CIDP Foundation International, in partnership with NeuroCareLive. You'll discover all the latest news, information and tips to cope and thrive with CIDP. The session will include an overview of CIDP, how to recognize symptoms, a list of latest treatments, self-care strategies, opportunities to advocate, online resources and more.

As an interactive session, live attendees will be able to ask questions of the experts and get answers in real time. Can't make it to the live date? Don't worry – it will also be available on demand from the GBS website afterwards.

Before the program, we'll be emailing you an invitation to the program's question board online, where you can ask the speakers your questions about CIDP anonymously. The most voted-on questions will be included as part of the program!

Stay tuned for all the details at gbs-cidp.org.

GBS|CIDP Stories from Around the World



Meet GBS member Nancy DiSalvo, a tireless international advocate for the GBS|CIDP community, and learn why she feels “each small accomplishment is a major victory.”

We sat down with Nancy at our 2017 International Liaison Meeting in Amsterdam. Here’s what she shared about her experience with both GBS, and CIDP.

The morning of November 8 1990 and as I went to get out of bed I fell down and thought, “I must be really sleepy today”; afterwards I had difficulty holding the toothbrush, comb, etc. What I had managed to do naturally the day before had become impossible. The fear was overwhelming. ER, hospital, diagnosis: Guillain-Barré Syndrome. I was 20 years old and I cried for two whole days, completely paralyzed. However, I could talk, feel, and understand. When I was told that I would heal, I started to fight. The ventilator was always at hand in the corner of my room looking at me in the darkness of the night. Fortunately, it was never needed. After three months in the hospital with nerve pain, fear and hope - that is when I found myself. I discovered the unconditional love of family and true friends. I could not have overcome such suffering without their constant support and continuous presence. I rediscovered God. I found an inner strength that was unknown to me, which gave me the courage to accept as well as the strength to go on. I had to learn to move my thumb, to sit, how to walk, breathe ... each breath was intense and full of hope. Every movement, a conquest. Every step a journey. The “first steps” without a walker took place in April 1991, five months after the advent of this stranger in my life. I still remember the excitement and happiness, like a toddler giving his first steps.

Later on there were several new “conquests”: the stairs, the writing, the keyboard of a computer and every moment was a victory. On May 14 1992, I had a GBS “recurrence”. I remember being in that same hospital, that same room, and not being able to fall asleep fearing I would wake up tetraplegic like two years earlier. Luckily, it was not as devastating. I regained control of my life and made some accomplishments. I traveled; I danced and took some falls. I matured with the awareness of being lucky knowing my limit and enjoying life.

Brief flashback: I lived in the U.S. from age 4 to 13, growing up in New Castle, Pennsylvania. My father went to the U.S. as an immigrant in 1974; when my parents decided to return to Italy in 1983, me and my younger sister were obliged as minors, while our older brother and sister (both American citizens), decided to stay. It was a devastating separation, both from my siblings and from a country I thought was my home.



In September 1997, I finally went back “home” to visit my family in the U.S., after my recovery from GBS - another goal conquered. During my visit, my brother contacted the Cleveland Clinic asking about GBS. After a couple of days, I received an envelope full of brochures and contacts directly from the Foundation. From that moment on I would receive my Foundation envelope directly in Italy. I felt that I wasn’t alone and all the stories, the pictures, the Symposium information, enriched me and gave me the will to go on. Robert and Estelle Benson are my heroes. I started to read about CIDP through these newsletters, as it became GBS|CIDP FOUNDATION.

Then in my life along came CIDP (2006), which answered many questions regarding my weakness and continuous falls. All along, it was not a total surprise. I started to receive IVIg and corticosteroids. I took many medical exams: MRI, EMG, EP, and Sural Nerve Biopsy. After 10 days I received the final diagnosis: CIDP. It took me years to understand that I was not having GBS residuals. I have been on IVIg for 12 years and just this January 2018 I decided to make a change and started Hizentra SCIg. I can’t run, I can’t dance and I can’t jump, I can walk but for no longer than ½ km. But I can do many other things and my goal is to continue to work as I have always done, since 1990. I have only stopped when my body would not respond. My motto is that I will never stop as long as these legs keep on walking and this heart keeps on beating. Our perspective of life is different compared to those who are “healthy”, each small accomplishment is a major victory. Being a part of the Foundation as a patient is fundamental and enriching; as an International Liaison is encouraging and inspiring. I am forever grateful.

You can also view Nancy’s video story at: <https://youtube/Bz6GEAieU10>

Find a GBS|CIDP chapter meeting near you at <https://www.gbs-cidp.org/events-calendar/>.
Interested in planning one of your own? Contact Kelly McCoy, kelly.mccoy@gbs-cidp.org.

GBS|CIDP Stories from Around the World



First Chapter Meeting in Nigeria a Big Success!

The Foundation had the pleasure of meeting Nigerian Liaison Sosanya Babafemi Adeoluwa at our International Liaison Meeting in Amsterdam last fall. After learning more about the process of planning a chapter meeting from GBS staff, and inspired by the power of connecting with other patients, Babafemi decided it was time to plan his own chapter meeting and encourage local patients to experience these very same benefits. And just two months later, voila, the very first chapter meeting in Nigeria was on the calendar!

The meeting, which took place in a church hall, was attended by nearly 15 adults, a GBS survivor, a Neurosurgeon (Guest Speaker) and a Consultant Physiotherapist. "The attendance was quite encouraging. In all, I feel it was a great outing," said Babafemi during a recent discussion. Additionally we asked Babafemi if he could share his experience of planning the meeting, the outcome of the day, and his future plans for building and maintaining a local GBS support network. Here's what he had to say:

1) When and why did you connect with the GBS|CIDP Foundation?

I connected with the GBS|CIDP Foundation in 2012 before I made full recovery. There was limited information about what I was passing through. Despite the fact that I was like a centre of attraction for Student Doctors and Nurses at the ICU where I was admitted, no one could really tell me what to expect or how to deal with my predicaments. I took my search for help to the internet and there I discovered this great organization. My inquiries were promptly responded to and they kept in touch. My connection with the Foundation exposed me to a community of committed caregivers and I was availed every information I needed to continue fighting till I came out fully recovered. Thereafter, I was appointed the Liaison for Nigeria and it has all been memorable, pleasant experiences thus far.



2) What inspired you to hold a chapter meeting in your area?

After surviving GBS the way I did, I never desire for anyone to pass through the ordeal alone, like I did. I wanted to be there for anyone passing challenged with inflammatory neuropathy (GBS and its variants); starting at my own little corner. When I consider the daunting challenges of pulling it off, it seemed impossible. Then at the International Liaison's Meeting in Amsterdam, the Foundation representatives had a session on Organizing Chapter Meetings and at the end of that session, I committed myself that I was going to organise a chapter meeting, whatever the cost. Kelly and Patricia were my willing partners in progress. The entire expenses were footed by me but I'm glad it was a success.

3) What did you learn from the chapter meeting?

At first, it looked impossible, undoable. Being the first, there was anxiety and many challenges. In the end however, I learnt that organising a chapter meeting is not really as difficult as it seemed. With support from Kelly and Patricia and others at the GBS|CIDP Foundation, at some point, I was feeling why haven't I been doing this all along? All it took was proper planning. Testimonies and recommendations I got after the meeting also confirmed that this should not just be a one time thing.

4) Will you continue to hold chapter meetings?

Now I'm planning on holding these meetings at least once in a quarter in every region of Nigeria. So definitely, YES! Plans are already underway for the next meeting/outreach. The guest speaker is already informed. As a means of creating awareness, we intend to donate wheelchairs and crutches to handicapped patients and survivors. We also intend to translate some of GBS|CIDP Foundation's materials to the 3 major languages in Nigeria. We are looking for partners/sponsors in this regard.

Success in Salt Lake City!

On February 3, 2018, GBS volunteer Oliver Smith held a unique chapter meeting for local patients. Here's what Oli had to say about the event...

"We had a great Utah Chapter meeting on Feb 3rd, 2018. We were hosted by Grifols Biomat USA, in their location in Salt Lake City, Utah. We were given a tour of the facility and learned about the collection, storage & transport of plasma. We learned that plasma has a life of 10 years, as long as it is frozen in the proper amount of time before proteins start breaking down. There were a few other who weren't in this picture, but it was the perfect sized group based on the amount of room we had.

After the tour, our group met in an office and shared our stories and experiences as survivors and it was a nice gathering. It is always amazing to get together with people who understand and who have empathy. The plasma center staff was very inspired and so proud of the work they are involved in. I was able to speak at a staff meeting earlier in the week and the employees were amazed to hear a story of someone recovering from paralysis thanks to plasma. Seeing people who's lives had been saved with plasma was a real eye opener for the staff. They were inspired to see us all together, and many thanks were given to the workers, and donors, involved in such important work".



CHAPTER MEETING CALENDAR

Partial listing (more dates to come).

DATE	CHAPTER LIAISON	LOCATION	CITY, STATE	SPEAKER
3-Feb	Oli Smith	BioMat USA	Salt Lake City, UT	Plasma Awareness Meeting
10-Feb	Dave Mayer	Kaiser-Point West Medical Offices	Sacramento, CA	Dr. James Mally
10-Feb	Russ Walter	Palo Alto Medical Foundation	Palo Alto, CA	Group Meeting
3-Mar	Gary Ruppel	HealthSouth Rehabilitation Hospital	Franklin, TN	Sheila Davis OTR
10-Mar	Tonya Charleston	Inova Mount Vernon Hospital	Alexandria, VA	Linda Wentz
18-Mar	Sibylle Derosa	Greenwich Hospital	Greenwich, CT	Virginia Kraus/Grifols
20-Mar	Lizz Russell	Sharps Hospital	San Diego, CA	Group Meeting
27-Mar	Bob Burton	Elk Lodge	Newburgh, NY	Group Meeting
31-Mar	Bruce Throckmorton	Sunnyslope Mennonite Church	Phoenix, AZ	Dr. Todd Levine
14-Apr	Megan Kaump	Bethesda Hospital	St. Paul, MN	Dr. Jeff Allen/GMAB
14-Apr	Rick Forney	Roanoke Biomat	Roanoke, VA	Plasma Awareness Meeting
21-Apr	Gail Buckingham	Owatonna Hospital	Owatonna, MN	David Levy
28-Apr	Anita Joy	Immanuel United Methodists Church	Syracuse, NY	Brian Amidon
28-Apr	Pat Schardt	Madonna Rehabilitation Hospital	Lincoln, NE	Christina Kennett
21-Apr	Sheila Blaine	Hackettstown Medical Center	Hackettstown, NJ	Group Meeting
5-May	Jack Sena	Isleta Resort and Casino	Albuquerque, NM	Dr. Carol Lee Koski/GMAB
5-May	Diana Christian	Care Partners	Asheville, NC	Jennifer Jones, DO
5-May	Bob Fuerstenau	Centre Pointe Health and Rehabilitation	Tallahassee, FL	PT/OT
12-May	Lee Ann Gooseman	King County Library Service Center	Issaquah, WA	Group Meeting
15-May	Wes Henrikson	Ginopolis Restaurant	Oakland County, MI	PT/OT
18-May	Jon Toumey	Marion County Public Library	Indianapolis, IN	Virginia Kraus/Grifols
19-May	Kristen Spaunhorst	The Center of Clayton	Clayton, MO	Dr. Roula al-Dahhak, MD
20-May	Glenn Miller	Baton Rouge Marriott	Baton Rouge, LA	Steve Rees MD

To find a meeting near you visit gbs-cidp.org/events-calendar.

Why Walk for GBS|CIDP?

2018 Walk Roll Update

Walk & Roll for GBS|CIDP is a great way to raise awareness, show your support, make friends and build a local network. And this year we've taken it one step further. We are walking for scientific innovation, a quicker diagnosis and better treatments. **We are walking for RESEARCH!** And each walk is one mile closer to overcoming the challenges of living with GBS, CIDP and its variants, such as MMN. Invite your friends, family, neighbors and community to join our mission, walk or roll one mile, and have fun too!

Funds raised through our walk program will help to support our research initiatives including:

- Diagnosis** Developing methods to more rapidly diagnose GBS, CIDP and its variants, such as MMN.
- Treatments** Developing more effective treatments to limit the disease progression, prevent complications and reduce long-term adversities.
- Genetics** Identifying mechanisms involved in the pathogenesis of family disorders.



2018 Walk & Roll Calendar:

- Fresno CA • 3/10/2018
- Charleston, SC • 4/21/2018
- Houston • 5/19/2018
- Minneapolis • 5/19/2018
- Philadelphia • 6/3/2018
- San Francisco • 6/9/2018
- New Jersey • 6/10/2018
- Myrtle Beach • 9/8/2018
- Pittsburgh, PA • 9/15/2018
- Staten Island, NY • 9/15/2018
- Partial listing (more dates to come).

Visit gbs-cidp.org
and sign up today!!

Want to plan one
of your own?

Contact Walk & Roll Manager
Jessica McManus
jmcmamus@gbs-cidp.org.



2018 Benson Fellow Announcement

The GBS|CIDP Foundation International has established the Benson Fellowship to fund Peripheral Neuropathy Fellowships in honor of Robert Benson, a survivor of Guillain-Barré Syndrome, and his wife Estelle Benson. The purpose of the Benson Fellowship is to encourage professional training in the peripheral inflammatory neuropathy area for medical doctors, and to encourage philanthropic support to help address this significant challenge within the medical community.

The GBS|CIDP Foundation International is pleased to announce the 2018 Benson Fellowship will be awarded to Dr. Janev Fehmi of the Nuffield Department of Clinical Neuroscience (NDCN) for her study in **characterising the pathogenic mechanisms of nodal auto-antibodies in the inflammatory neuropathies**. Dr. Janev Fehmi is currently enrolled in the UK National Training Programme in Neurology, Bristol, England. "I feel passionate about specializing in the field of peripheral nerve disorders, and this would allow me to develop the core skills required to embark on a career as an academic Neurologist," said Dr. Fehmi. Of note, Dr. Fehmi contributed to the ongoing development of the first neurology training program in Cambodia, has presented at national neurology conferences, and has participated in research published in peer-reviewed journals.





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SAVE THE DATE!
Join us for our
15th Biennial Symposium
in San Diego, CA
NOVEMBER 1-3, 2018

MAY is
GBS|CIDP Foundation
Awareness Month.
HEROES WANTED!
Get involved this year by honoring your hero with a personal story about your GBS or CIDP hero, and/or donation to support the mission of the GBS|CIDP Foundation.
More information at:
<https://www.gbs-cidp.org/may-gbscidp-awareness-month-honor-hero/>

Refer to the enclosed chapter directory to 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 us 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

Teenagers with GBS and CIDP
For teens ages 12 to 18 with GBS or CIDP to connect with one another, share stories, and support each other. This group is also open to teenage children of patients. Contact us to find out how to join!

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.

Advocacy
If you are interested in advocacy activities on a federal, state, or local level, contact us to sign up!

International Office:
610-667-0131

Be sure to inform us if you have been diagnosed with one of the following. This will add your name to condition-specific communications.

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