

# The Communicator

GBS|CIDP FOUNDATION INTERNATIONAL

PROVIDING STRENGTH THROUGH SUPPORT



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

## IN THIS ISSUE

- 1 Puja Shankar
- 2 Welcome from Executive Director
- 3 Announcing the Foundation's First Program on Clinical Trial Education!
- 4 2020 Virtual Summit
- 4 First FDA Patient Listening Session GBS
- 4 2021 Symposium
- 5 An Update from 2016 GBS|CIDP Foundation Grant Recipient
- 6 GBS|CIDP Foundation International Dedicates October to Advocacy "Month of Action"
- 6 Announcing four new Centers of Excellence, including First Pediatric Center
- 7 APLUS Statement on the State of Plasma
- 8 100 Raise Well in August
- 8 First Regional Virtual Walk
- 9 New Online Patient Portal
- 10 Benson Volunteer Awards
- 11 Ask the Experts

## Puja Shankar

*Anesthesiology Resident,  
Beth Israel Hospital*

[www.gbs-cidp.org/patient-stories/puja-shankar/](http://www.gbs-cidp.org/patient-stories/puja-shankar/)



**"I need to be admitted,** I think I have Guillain Barre Syndrome" I stated confidently and somewhat shakily to the receptionist in front of the Emergency Department; this was ironically the same department I rotated in a month prior to my current presentation. She looked at me quizzically and I showed her my employee badge. The bold 'MD' letters next to my name changed her expression from confusion to concern.

I was seated in a wheelchair, clutching the bag I had packed that morning in anticipation of a hospital admission, and wheeled into the emergency room. Within minutes I was on a stretcher, drowning in a much too large, starched, sterile gown. I winced as an intravenous line pierced into the soft skin of my forearm, filling a myriad of colorful tubes with my blood. The pale pink EKG sheet demonstrated a heart rate most people have with strenuous exercise.

Attendings, residents, and nurses crowded as my high heart rate triggered the patient priority system. Amidst the growing fear and panic, I attempted to narrow my focus on the flustered intern

who repeated his questions twice before diligently writing down my answers. I empathized, trying to remember that I too had been in the same overwhelming position just a few days ago.

My own words sounded foreign, clumsily reiterating a story that even I was having trouble believing. For days I was woken by a racing heart rate, so fast that its beats were indistinguishable. An inappropriate, disturbing fatigue followed, leaving me breathless after menial tasks, causing me to rest after a few steps. But the most sinister symptom, which forced my arrival to the emergency room, was the development of persistent, pervasive tingling and numbness; it crawled from my toes, up my legs, wrapped around my chest and finally rose to my neck. My entire body was shaking, vibrating, even though outward appearances showed that my arms and legs were steady. These symptoms were bizarre, unnatural, and fit no mold I had ever known. As physicians are guilty of, I attempted to self-diagnose and treat my symptoms at home. But my attempts at rationalizing began to grow thin.

Shankar continued ►

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



## Thank You for Your Support During these Uncertain Times...

### Dear Friends,

Who could have predicted the year of pivots, first-times, and transformation, that has occurred in 2020? As the months unfolded it became clear that the Foundation would find its pathway, and begin to thrive once more, for our staff is strong in our commitment to the cause. But what became more evident, is that we had the great fortune of not only teaching but learning from the membership we serve, who are not strangers to sudden and unexpected circumstances. You are our role models for change, you are our guiding lights for facing the unknown with abounding resilience.

As we are all still grappling to gain more of our footing and traction for the months and year ahead, we dedicate this issue to our patients, our “role models for change” and share with you what I hope is also an inspiring model for adapting to uncertainty. You’ll note there are firsts in every program, such our first Virtual Summit, our first Regional Virtual walk, our first FDA virtual listening session, our first Coffee Chats including our first session for our new Youth, Teen and Young Adult (YTA) group, and our first Month of Action. Like many of you we have not only dipped our toes into a new normal, but have embraced the new opportunities for global inclusivity and connection, offered by new and innovative ways to communicate. We hope you have had the opportunity to join us in our “first-times” and will continue to journey with us as we explore even more new and innovative ways to support and educate our community.

We welcome your stories, questions, and suggestions as we continually strive to respond to your needs. We hope 2021 brings us together but in the meantime, please be vigilant; wear a mask and practice social distancing.

Sincerely,

*Lisa*

Lisa Butler, *Executive Director*

#### EXECUTIVE DIRECTOR

Lisa Butler

#### FOUNDER

Estelle L. Benson

#### OFFICERS

James Crone

*President*

Patricia H. Blomkwist-Markens

*Vice-President*

Jim Yadlon

*Treasurer*

Russell Walter

*Secretary*

#### BOARD OF DIRECTORS

Jeffrey Allen, MD

Joshua Baer

Peter Donofrio, MD

Nancy Di Salvo

Brenda Perales

David Rosner

Shane Sumlin

Corbin Whittington

*Nonprofit 501 (c)(3)*

#### MEDICAL ADVISORY BOARD

Peter Donofrio, MD

*Chairman*

Bart C. Jacobs, MD, PhD

*Vice-Chairman*

Jeffrey Allen, MD

Diana Castro, MD

Kenneth Gorson, MD

Sami Khella, MD

Richard A. Lewis, MD

Robert P. Lisak, MD

Eduardo Nobile-Orazio

MD, PhD

Gareth J Parry, ONZM,

MB, ChB, FRACP

Mamatha Pasnoor, MD

David S. Saperstein, MD

Kazim A. Sheikh, MD

Betty Soliven, MD

Maureen Su, MD

Peter Van den Bergh, FEAN

Pieter A. van Doorn, MD

Hugh J. Willison, MMBS,

PhD, FRCP

Eroboghene E. Ubogu, MD

#### HONORARY MEDICAL ADVISORY BOARD

These physicians have served on our board and we will always be grateful for their dedication to our cause:

Arthur K. Asbury, MD

Barry G.W. Arnason, MD

Richard J. Barohn, MD

Vera Bril, MD

Mark J. Brown, MD

David Cornblath, MD

Marinos C. Dalakas, MD

John D. England, MD

Clifton Gooch, MD

Jonathan Goldstein, MD

Michael C. Graves, MD

John W. Griffin, MD

Angelika F. Hahn, MD

Hans-Peter Hartung, MD

Thomas L. Hedge, MD

Richard A.C. Hughes, MD

Susan T. Iannacone, MD

Jonathan S. Katz, MD

Carol Lee Koski, MD

Robert G. Miller, MD

Allan H. Ropper, MD

John T. Sladky, MD

Joel S. Steinberg, MD

Gil I. Wolfe, MD

**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.

Shankar continued from page 1

The irony was not lost on me; all those years of allopathic medical schooling had ultimately led to frenetically practicing breathing exercises and yoga in order to avoid a hospital visit. The team listened attentively even as they cautiously congregated towards the foot end of my bed, stepping away from me as if to distance themselves from this strange illness. Wringing my fingers, I began to feel an uneasiness rising, collecting in my throat. Imagined fears loomed, and began to overtake real dangers. In an attempt to sway the physicians in front of me away from a somber diagnosis, I reiterated my otherwise negative medical history – I didn't take any medications and hadn't stepped foot into a doctor's office in over a decade. But they had heard enough from me. They conversed in hushed tones now amongst themselves, words hidden behind the masks. Given the complex reverse hierarchy when doctor becomes patient, information was presented to me gently and respectfully. A list of differential diagnosis was relayed to me, as I mentally prepared for a hospital admission. Words I had only known in textbooks were now a possible reality; multiple sclerosis, pulmonary embolism, neuromyelitis optica, Guillain-Barre syndrome and coronavirus.

Distinctions between days blurred as I experienced the breadths of modern medicine. I lay for hours in an ominously loud MRI scanner while my brain and spinal cord were sliced into hundreds of frames. Contrast dye injected during a CT scan of my lungs, warmed me until I was burning from the inside out. Spinal fluid was collected and tested. Innumerable blood draws were done twice a day from my plump, violet veins. Continuous cardiac monitoring meant that I was never alone; a small monitor made its home in the pocket of my hospital gown, nestled close to my chest. Its humming kept me company throughout the day since visitors

were restricted due to the pandemic. Eventually the laboratory testing and imaging began to coalesce and show results. I was diagnosed with a rare variant of Guillain-Barre Syndrome known as Acute Inflammatory Demyelinating Neuropathy and was started on intravenous immunoglobulins. Following the diagnosis, I couldn't shake the sense of profound betrayal; my body was producing antibodies against my own nervous system.

My stay was racked with sleepless nights, characterized by the constant vibrations in my limbs and pervasive sense that the bed was moving under me. I developed a strange sort of seasickness, holding on to the rails of my bed and having to catch my breath often. It was always a relief when the phlebotomist greeted me at dawn and I could sit up with some purpose after dark, formless hours. As sun began to pour into my room, friendly cafeteria workers made their way inside, bringing in variations of the same meal. Friends and colleagues flitted in and out, perching themselves on the ledge by the large window, echoing kind, sympathetic sentiments. They were welcome, but fleeting distractions. The day truly began when my providers entered. I found the transformation of my role from physician to patient disorienting. For so long I had been the one standing over patients, my hands crossed compassionately, nodding and speaking with calm, reassured, confidence, always with an answer. But now suddenly I was looking up, it was my eyes flickering between the faces that loomed around me...

FOR PUJA'S FULL JOURNEY FROM PHYSICIAN TO PATIENT, AND ALL THE VALUABLE LESSONS LEARNED ALONG THE WAY GO TO...[WWW.GBS-CIDP.ORG/PATIENT-STORIES/PUJA-SHANKAR](https://www.gbs-cidp.org/patient-stories/puja-shankar)



## ANNOUNCING THE FOUNDATION'S FIRST PROGRAM ON CLINICAL TRIAL EDUCATION!

Held live on October 29 at 12:00pm EST, this multi-component patient/caregiver education initiative, entitled *How Can Participating in a Clinical Trial Help Me?* focused on CIDP, yet is available for all to learn.

The online program featured a multidisciplinary panel comprised of Foundation Executive Director, Lisa Butler, Global Medical Advisory Board member, Dr. Jeff Allen, and patient and clinical trial participant, Beth Thirtyacre. Panelists informed patients with CIDP and their caregivers about the role of clinical trials in improving individual and community health care, as well as when a clinical trial is a viable option for patients with CIDP.

Content was presented through a lively discussion between the members of the panel. Following this general education, a few currently active trials were presented and discussed. All content will endure on the Foundation's website following the program. Program will be available on demand for 6 months, registration required: <https://www.gbs-cidp.org/participating-in-a-clinical-trial/>



## 2020 VIRTUAL SUMMIT

### OVER 1300 ATTENDEES AT FIRST VIRTUAL SUMMIT!

On October 3rd, 2020, over 1,400 attendees from 25 countries logged on for an inspiring LIVE and FREE online event featuring the very same medical & wellness experts that host our in-person symposia and regional events. Viewers navigated through our new Virtual Summit Platform and listened to presentations from Foundation experts on topics such as *What's New in Research, Treatments and Clinical Trials, Commonly Asked Questions for GBS, CIDP, and Variants, Tools for Managing Stress, Youth & Teens with GBS/CIDP* and *Yoga from Your Chair*. An active live chat feature enabled participants to ask questions and connect with Foundation staff in real time. The day ended with a special "Registration Now Open" Announcement for the 2021 Biennial Symposium, (in-person), Washington DC. The Virtual Summit is available on demand at: <https://www.gbs-cidp.org/2020summit>

"The Foundation's summits and symposia are a really terrific resource for both clinicians and patients. At both a national and international level, it is really worth tuning in and being part of these events." –Dr. Jeff Allen

## First FDA Patient Listening Session, GBS

On September 29th, Foundation staff, patients, and caregivers from our community including, Jeremy Cugle, Tonya Charleston, Lee Anne Gooseman, Elsa Oliver, and Jonathan Gould joined together, online, with 30+ representatives from the US Food & Drug Administration (FDA) for our first "FDA Listening Session" on GBS. Lisa Butler introduced the mission and history of the Foundation, and offered a summary of unmet needs of patients, at the close of the session. This type of meeting offers FDA staff, who oversee drug approvals and research for our disease area, an opportunity to listen to patients tell their stories, from diagnosis to treatment to the day-to-day struggle of their "new normal." Listening Sessions are considered closed, non-public, non-recorded meetings designed for the purpose to help FDA understand what is important to patients, caregivers, and patient advocates when medical products are being developed as well as specific challenges faced while coping with their conditions. You can learn about listening sessions at: <https://www.fda.gov/patients/learn-about-fda-patient-engagement/patient-listening-sessions>

## Registration Now Open!

16th Biennial Symposium, Washington DC  
October 7-9, 2021

We are delighted to announce the new date for our 16th Symposium, Washington DC. Join us on October 7-9, 2021. Registration is now open. Please note, we will adhere to all CDC & WHO recommendations at the time of this event. Your health & safety is of utmost importance.

- Although symposium registration is now open, reservations at the Hilton are not yet available. We will send out the link to book your accommodations as soon as it is available.
- If you have previously registered for the 2020 Symposium and did not request a refund, you are registered for the 2021 event! You will need to rebook your hotel.
- If you have any questions please email [Kelly.McCoy@gbs-cidp.org](mailto:Kelly.McCoy@gbs-cidp.org).

GBS|CIDP SYMPOSIUM

2021  
OCTOBER 7-9, 2021



Online registration, symposium updates and more information at:  
[www.gbs-cidp.org/2021symposium](http://www.gbs-cidp.org/2021symposium)

# An Update from 2016 GBS|CIDP Foundation Grant Recipient

*Dr. Eduardo Nobile-Orazio*

Member of Global Medical  
Advisory Board (GMAB)

## In 2016 The GBS|CIDP

**Foundation** awarded a research grant to Eduardo Nobile-Orazio, MD, PhD, FAAN, Professor of Neurology Neuromuscular and Neuroimmunology Service at Milan University. Dr. Nobile-Orazio's 2016 study titled: An Italian Multicenter Network for the diagnosis and therapy of chronic inflammatory demyelinating polyradiculoneuropathy (CIDP) and of its variants, contributed to the 2019 article: Risk factors for chronic inflammatory demyelinating polyradiculoneuropathy (CIDP): antecedent events, lifestyle and dietary habits. Data was from the Italian CIDP Database and article was published by the EAN (European Academy of Neurology). Again in 2019, and in 2020, Dr. Nobile-Orazio, and research team, were again published for their research supported by the Italian Multicenter database. A summary of the published findings are described in these three publications on the right. ►



### WILEY ONLINE LIBRARY

Relevance of Diagnostic Investigations in Chronic Inflammatory Demyelinating Poliradiculoneuropathy: Data from the Italian CIDP Database

A number of diagnostic tests are currently used to confirm the diagnosis of CIDP in patients who have a clinical history compatible with this diagnosis. Some of them are invasive, or at least disturbing, for the patients, such as lumbar puncture or nerve biopsy, or expensive, such as magnetic resonance of affected nerve. When we reviewed the data from our series of 437 patients included in the Italian database on CIDP, we found that in 80% of the patients motor nerve conduction studies were sufficient to make a definite diagnosis of CIDP while 20% of them required the use of supportive tests. These included lumbar puncture, sensory nerve conduction studies and occasionally nerve biopsy or nerve ultrasound or Magnetic Resonance. A response to therapy contributed to support the diagnosis in 40 patients. This study shows that in most patients with CIDP, the diagnosis is possible solely with motor nerve conduction studies while other investigations may help improving the diagnosis in a minority of patients and are therefore not necessary in the majority of patients.



### JOURNAL OF NEUROIMMUNOLOGY

Sensitivity and Specificity of a Commercial ELISA Test for Anti-Mag Antibodies in Patients with Neuropathy

The diagnosis of neuropathy associated with high titers of anti-MAG antibodies is mostly made using a commercial assay that permit a diffuse testing for these antibodies. These antibodies lead to the identification of a specific neuropathy that is different from CIDP and that have a different response to therapy. The main problem with this procedure is that the manufacturer currently recommends a cut-off of 1000 BTU. These value are however frequently found also in patients with other diagnosis leading to an over diagnosis of this neuropathy and to the inappropriate use of more invasive therapies. We analyzed the discriminating threshold analyzing the sera from 80 patients with the typical clinical and electrophysiological features of anti-MAG neuropathy and 383 controls with CIDP and other neuropathies or healthy controls and found that the best specificity for anti-MAG neuropathy was obtained with titers above 7000 BTU. Patients with titers between 1500-7000 BTU needed to be carefully evaluated, clinically and electrophysiologically, to differentiate anti-MAG neuropathy from other neuropathies and particularly from CIDP.



### JOURNAL OF NEUROLOGY

Impact of Environment Factors and Physical Activity on Disability and Quality of Life for CIDP

A few observational studies and randomized trials suggest that exercise and rehabilitation may improve activity limitation and quality of life in patients with chronic inflammatory demyelinating while in patients with chronic inflammatory demyelinating polyradiculoneuropathy (CIDP). While the impact of other modifiable factors on the severity of the disease is not clear. We used a structured questionnaire to investigate the possible influence of modifiable lifestyle and dietary habits on disability and quality of life in 323 patients with CIDP included in the Italian database. We found that physical activity was associated with lower sensory impairment and disability and a better quality of life independently from the severity of CIDP while none of the other environmental factors had an impact on the severity and health perception of CIDP. This study supports the role of physical activity in improving symptoms severity, disability, and quality of life in patients with CIDP.





## GBS|CIDP Foundation International Dedicates October to Advocacy “Month of Action”

**This October**, the GBS|CIDP Foundation International encouraged patients and caregivers affected by Guillain-Barre Syndrome (GBS), Chronic Inflammatory Demyelinating Polyneuropathy (CIDP), or variants of the condition such as Multifocal Motor Neuropathy (MMN), to join a virtual “Month of Action” advocacy campaign. Opportunities for participating in “Month of Action” included: Online advocacy training videos; Speaking with Members of Congress and their staff; Sharing key advocacy collateral. Currently, there are 250 GBS|CIDP advocates who have supported legislation and policy issues that impact access to therapy and the quality of healthcare for our patient community. Interested in advocating for a great cause? A step-by-step guide to get started, including a summary of current legislative agenda, can be found at: [gbs-cidp.org/october-month-of-action](https://www.gbs-cidp.org/october-month-of-action).

“

*“The GBS|CIDP Foundation International is dedicated to advancing policy and legislation that improves, protects, and preserves access to timely care and appropriate treatment in the appropriate setting for GBS, CIDP, and variants patients.”*

—CHELSEY FIX, Advocacy Manager GBS|CIDP Foundation International



### ANNOUNCING Four New Centers of Excellence, Including First in Pediatric Care

Our Global Medical Advisory Board has set standards for what they consider to be excellent medical centers for the diagnosis and treatment of GBS, CIDP, MMN, and related neuropathies. Based on levels of expertise, available treatments, facilities, and research capabilities, these are the medical centers that we can unequivocally recommend as a “Centers of Excellence.” We have currently deemed 56 medical facilities, worldwide, as Center of Excellence for GBS|CIDP and variant conditions. Today, please join us in welcoming:

- Our first division of pediatric care, Buergeer Center for Advanced Pediatric Care of Children’s Hospital of Philadelphia
- University of Michigan Department of Neurology
- Penn Presbyterian Medical Center of the University of Pennsylvania Health System
- Department of Neurology University of Miami Miller School of Medicine

Contact information for COE’s can be found at <https://www.gbs-cidp.org/support/centers-of-excellence/>

## GRIFOLS LAUNCHES NATIONWIDE PLASMA DONOR RECRUITMENT CAMPAIGN

As part of Grifols long-standing commitment to help ensure the plasma supply is there for those who rely on plasma-derived medicines, the Company is pleased to announce that it has officially launched its multi-channel, nationwide plasma donor recruitment campaign to raise awareness about the importance of plasma donation and to recruit more plasma donors into its network of plasma donor centers. The objective is to make as many people as possible aware that their plasma is a “light” inside of them, which can be shared to potentially make many lives brighter. The campaign will provide education on the important role of plasma in producing life-saving medicines and motivating individuals to become donors.

The “Give Your Light” campaign is a highly targeted campaign being featured across multiple channels including radio, broadcast and streaming TV, social media, printed materials and paid digital advertising. Additionally, Grifols is proud to partner with the 2020 virtual “iHeartRadio Music Festival,” widely acknowledged as the most social music event in the world. Through these various channels, Grifols will educate on the important role of plasma in producing life-saving medicines and motivating individuals to be the difference in countless patient lives.

To learn more visit <https://www.grifolspasma.com/en/giveyourlight>.

# GRIFOLS



## APLUS Statement on the State of Plasma

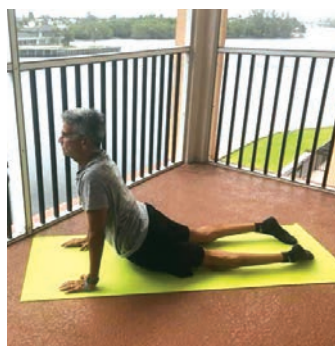
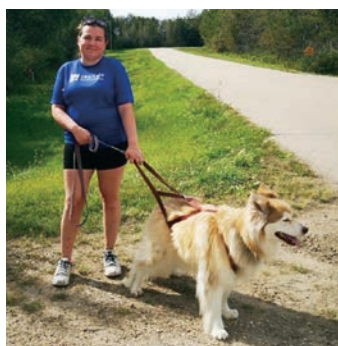
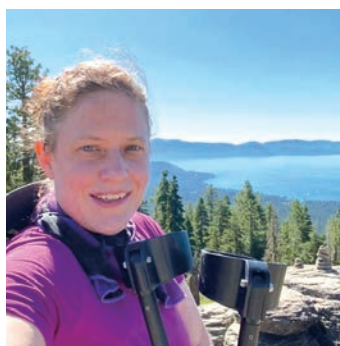
The American Plasma Users Coalition (APLUS) recognizes and applauds the recent statements from the White House that emphasize the importance of plasma and how essential plasma donors are to the healthcare system. This statement rings true for convalescent plasma that may help countless patients battling COVID-19 and is especially true for people all over the world who depend on plasma-derived therapies created from source plasma donations to live.

APLUS is a coalition of national patient organizations, of which GBS|CIDP Foundation is a part of, created to address the unique needs of patients with rare diseases who use life-saving plasma protein therapies created from source plasma. APLUS member organizations share a common desire to ensure that the patient voice is heard when relevant public policies, regulations, directives, guidelines, and recommendations affecting access to safe and effective therapy and treatment are considered. Together, our coalition represents more than 125,000 Americans living with chronic disorders dependent upon plasma protein therapies for their daily living. Safety is of utmost concern to APLUS: we believe that plasma collection regulations should always prioritize the safety of the donor and the safety of the eventual plasma user.

Source plasma is plasma that is collected from healthy, voluntary donors through a process called plasmapheresis and is used exclusively for further manufacturing into final plasma protein therapies. It is vital that U.S. maintain a constant and robust flow of source plasma collection. It may take 450-500 plasma donations to make enough finished product to treat one adult CIDP patient for one year, and may take many more for other conditions. The U.S. collects the vast majority of plasma worldwide. Alternative sources for plasma collection on the scale needed are non-existent.

Plasma protein therapies are unique and non-interchangeable, and a lessening of plasma donations has the potential to create a significant strain on patients' treatment plans, many of which are life-sustaining. APLUS continues to acknowledge source plasma donors as everyday heroes who help people all over the world live with complicated, rare disorders.

If you are interested in learning more about source plasma donation, please visit a plasma donation center near you – <https://www.donatingplasma.org/donation/find-a-donor-center>



# 100 RAISE WELL IN AUGUST

## 30-DAY WELLNESS CHALLENGE



This August, the Foundation challenged over 100 participants to 30 days of wellness activities and to raise funds for our research grant program. Through the month of August, these participants helped us raise over \$47,000 dollars to support those living with the challenges of Guillain-Barre Syndrome (GBS), CIDP and their variants, such as MMN. Thank you to CSL Behring and Argenx for sponsoring the Raise Well Challenge. A special thanks to Accredo for sponsoring our Wellness Wednesday emails. Our top individual fundraiser was Michelle Delehanty, who raised a whopping \$1,490 for research! Our top team captain was Erica Agran, who recruited 7 amazing team members that helped Team Iron Lynn raise a grand total of \$2,697!

### The following fundraisers raised over \$500! A big thank you and congratulations to these participants!

MICHELLE DELEHANTY, PENNSYLVANIA • LYNN ROGERS, ILLINOIS • MARY MANIER, MICHIGAN • BRENDA PERALES, VIRGINIA • TONY GREEN, GEORGIA • GABRIEL ELKASLASSY, PANAMA • ANDREW SCHEICH, MICHIGAN • MORGAN FURLONG, CALIFORNIA • CRYSTAL SADA, NEW YORK • ERICA AGRAN, ILLINOIS

# #strongertogether

2020 VIRTUAL WALK DAYS



## FIRST REGIONAL VIRTUAL WALK

On September 12, 2020, The GBS|CIDP Foundation International hosted the first of its multi-city Virtual Walk Days! Cities that participated were Pittsburgh, Columbus, Conway/Myrtle Beach, Chicago, and Staten Island. We had some trivia "travel" fun with each city along the way, and there were 125 participants registered for the event, raising nearly \$23,000 for our research grant program. In 2020 we have raised over \$68,000.00 for research through our walk program to date! Please join us on November 14 for our next multi-city walk! All are welcome, no matter where you may reside. More information can be found at: [gbs-cidp.org/volunteer/walk-and-roll](https://gbs-cidp.org/volunteer/walk-and-roll)



## New Online Patient Story Portal



**Stories can be healing** for the both the listener and the storyteller. Whether it inspires, educates, offers support in knowing you are not alone, sharing your story is the most meaningful way to raise awareness and inspire GBS|CIDP patients around the world. We encourage you to check out our new Patient Story portal, with greater ease of navigation and more stories than ever before. And just as in life and with your journey with GBS|CIDP or variant conditions, some days are truly challenging, some days are triumphant. But all stories will connect with others on the same or similar journey. We look forward to reading your stories of courage, struggle, hope and healing.

If you have a story to share please contact Maureen Neville  
maureen.neville@gbs-cidp.org.

### New story portal can be found at:

<https://www.gbs-cidp.org/support/connect-with-gbs-cidp-community/patient-stories/>



“

*“The destiny of the world is determined less by the battles that are lost and won than by the stories it loves and believes in.”*

—HAROLD GODDARD



## NEW Clinical Trial

### A Study to Assess the Long-term Safety and Efficacy of a Subcutaneous Formulation of Efgartigimod in Adults With Chronic Inflammatory Demyelinating Polyneuropathy (ADHERE+)

This is the open-label extension study of phase II ARGX-113-1802 to evaluate the long-term safety and efficacy of the subcutaneous formulation of efgartigimod in adults with CIDP. If you are interested in learning more or participating in this clinical trial, go to [www.gbs-cidp.org/support/resources/clinical-trials-additional-resources](http://www.gbs-cidp.org/support/resources/clinical-trials-additional-resources).



Please update your contact information to make sure we have your current email address. Your information will not be shared with anyone outside of the Foundation.

Contact us online at [gbs-cidp.org](http://gbs-cidp.org) or by emailing [info@gbs-cidp.org](mailto:info@gbs-cidp.org).

### CONTACT US

**GBS CIDP Foundation International**  
International Office  
375 East Elm Street, Suite 101  
Conshohocken, PA 19428

**T** 866-224-3301  
**T** 610-667-0131  
**F** 610-667-7036  
**W** [gbs-cidp.org](http://gbs-cidp.org)  
**E** [info@gbs-cidp.org](mailto:info@gbs-cidp.org)



# Benson Volunteer Awards

Presented at 2020 Virtual Summit

*Please join us in congratulating our 2020 Benson Award recipients for their outstanding compassion and commitment in the areas of Support, Education, Research, Advocacy and International Activities for the GBS|CIDP and variant community.*



**RICK FORNEY**

Virginia

*Awarded for Support*



**MERRILYN MACURAK**

South Carolina

*Awarded for Support*



**DR. JEFFREY ALLEN**

Minnesota

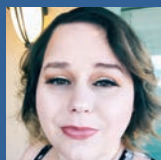
*Awarded for Education*



**PROFESSOR HUGH WILLISON**

United Kingdom

*Awarded for Research*



**MISTY HERNANDEZ**

Arizona

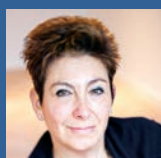
*Awarded for Advocacy*



**JON TOUMEY**

Indianapolis

*Awarded for Advocacy*



**PATRICIA BLOMKWIST-MARKENS**

The Netherlands

*Awarded for International Activities*

## WELCOME TO NEW INTERNATIONAL VOLUNTEER



Please join us in welcoming Alejandro Umaña from Costa Rica to our Foundation family. Alejandro is our newest international volunteer!

"I was diagnosed with GBS back in February 2020. It was the Miller Fisher Syndrome version, and in about a week I was not able to walk well and do my normal life. After 6 months of recovery and treatment (rehabilitation), I'm about 90% recovered with minimum residual effects, and starting to do my normal life. Since the time I discovered that I had GBS, it has been my main goal to reach people with the syndrome here in Costa Rica, to try to provide support and let them know that there are people out there who have been through their very same struggle, had the same condition. Also I am trying to raise awareness to all the population here in my country, since this is not a very common and known disease. I learned about the Foundation through my social network and I am excited to be a part of the volunteer team."

To connect with Alejandro, please reach out to Kelly McCoy, [kelly.mccoy@gbs-cidp.org](mailto:kelly.mccoy@gbs-cidp.org).



# Ask the Experts...

*The following questions, submitted by patients themselves, were answered by members of the Foundation's Global Medical Advisory Board, at the Virtual Summit on October 3rd.*

## I AM A GBS PATIENT. HOW LONG UNTIL I AM 'RECOVERED' AND HOW DO I KNOW WHAT IS A RESIDUAL AND WHAT IS A RELAPSE?

Every patient's recovery process is different. GBS has a typical course with an early short term active disease of usually around 4-8 weeks. After 8 weeks course, the nerve recovery process will begin and is different for every patient. Some patients will be left with residuals and some may not. It's important to know the difference between residuals and relapse. A residual is a complaint/symptom that has been apparent from the start of the GBS diagnosis. If a patient has new complaints or deficits after 8 weeks after the diagnosis, it's important to make an appointment with your doctor. This could be a relapse or a new diagnosis. This is especially important if these complaints are not part of the GBS spectrum.

## IS THERE A CHECKLIST OR REGULATION THAT I CAN USE AS A REFERENCE TO IDENTIFY MMN SYMPTOMS AND CHALLENGES TO OTHERS THAT ARE NOT FAMILIAR WITH THE SYMPTOMS?

MMN is asymmetrical, very slow to progress, and it is not predictable what parts of your body will be affected and when. A patient will have a loss or reduced reflexes in affected limbs.

Patients frequently develop weakness in their hand(s), resulting in dropping of objects or sometimes inability to turn a key in a lock. The weakness associated with MMN can be recognized as fitting a specific nerve territory. There is essentially no numbness, tingling, or pain. Patients with MMN can have other symptoms, including twitching, or small random dimpling of the muscle under the skin which neurologists call fasciculations.

## HOW CAN I BE SURE I HAVE CIDP?

Although CIDP can affect different people in different ways there are certain features that are distinctly unusual for the disease. It's important to discuss these "red flags" with your doctor as they may suggest a completely different diagnosis. Some "red flags" include:

### Is it CIDP? These "red flags" might suggest something else.

#### SYMPTOMS

- Prominent pain
- Symptoms all in the feet or legs
- Symptoms different on one side of your body than the other
- Prominent light headedness, dizziness, passing out, bowel or bladder changes
- Prominent fatigue without other CIDP hallmarks

#### NERVE CONDUCTION STUDIES

- Absence of clear evidence of demyelination. Ask your doctor to review the guidelines to see if benchmarks for demyelination are met.

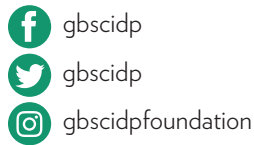
#### OTHER FEATURES

- Family history of neuropathy
- Treated with steroids or IVIG and did not have a clear and unquestionable positive response
- Is there a better explanation for the neuropathy, such as diabetes, toxin exposure, vitamin deficiency, or something else
- Your doctor finds that your reflexes are present or even "brisk"

- Full article on this topic can be found at: <https://www.gbs-cidp.org/hey-doc-are-you-sure-this-is-cidp/>

For more expert guidance see our online "Ask the Expert" series: <https://www.gbs-cidp.org/ecom/ask-the-experts/>

CHANGE SERVICE REQUESTED



SUPPORT EDUCATION RESEARCH ADVOCACY SUPPORT EDUCATION RESEARCH ADVOCACY



## DO YOU HAVE A NEW ADDRESS, EMAIL, LAST NAME, OR PLACE OF EMPLOYMENT?

Be sure and update your contact record with the Foundation. We'd love to stay in touch and we want to be sure you are receiving all news, updates and communications. Send new information to [info@gbs-cidp.org](mailto:info@gbs-cidp.org). Thank you!

## CONTACTS AND RESOURCES FOR ALL STAGES OF LIFE WITH GBS|CIDP & VARIANTS

### DIAGNOSED WITH MMN?

Brenda Perales  
[brendajp62@icloud.com](mailto:brendajp62@icloud.com)

### MILLER FISHER VARIANT GROUP

Please call us to connect with others.

### CHILDREN WITH GBS

Lisa Butler, 610-667-0131  
GBS|CIDP Foundation International  
[lisa.butler@gbs-cidp.org](mailto: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](mailto:holly.cannon@gbs-cidp.org). For more information on our youth, teen, and young adult (YTA) programming contact [meg.francescangeli@gbs-cidp.org](mailto:meg.francescangeli@gbs-cidp.org).

### LOOKING FOR A 20-SOMETHING CONTACT?

Kyle Van Mouwerik  
[kyle.vanmouwerik@gbs-cidp.org](mailto: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 [meg.francescangeli@gbs-cidp.org](mailto:meg.francescangeli@gbs-cidp.org) 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 Advocacy Manager Chelsey Fix, [chelsey.fix@gbs-cidp.org](mailto:chelsey.fix@gbs-cidp.org).

### INTERNATIONAL OFFICE

610-667-0131

### DO YOU HAVE A VARIANT

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
- GBS X2
- Miller Fisher
- MMN

**WE ARE A  
SUPPORTIVE ALLY  
ON AN UNPLANNED  
JOURNEY...**



**ENSURING NO  
ONE IS  
TRAVELING  
ALONE...**



**BUILDING A  
PATIENT-CENTERED  
COMMUNITY OF  
HEALING...**



**TO HELP  
YOU ON YOUR  
WAY TO A NEW  
NORMAL.**