

# 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.*

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## Meet New Volunteer

*Rosa Valera of the Dominican Republic*

I am Rosa Valera from the Dominican Republic and I am 41 years old. I have been a teacher at all educational levels, preschool, elementary, high school, undergraduate, graduate. I have specialized in school management. I know American Sign Language in addition to Spanish. I am hard-working, loving and with a lot of empathy. I know this condition of GBS can hurt a lot and I know that people are afraid and sometimes ashamed for needing so much help from others. Why? Because I lived it.

I am a GBS patient. In December 2018 I had a gastric balloon surgery to lose weight. For days after, I kept vomiting and then the neurological symptoms started. I couldn't keep my eyes open, that was the first, followed by leg weakness, then pain and a burning sensation. Four months later, nine neurologists, blind, immobile and feeling crazy...we found the correct diagnosis. Currently I walk like a little duck and feel fatigued very quickly, but I came back to life! I have no complaints!

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## 2018 GBS|CIDP Foundation Research Grant Recipient, Dr. Lucilla Nobbio, Publishes Update in *Journal of Neurology, Neurosurgery & Psychology*

***CSF sphingomyelin: a new biomarker of demyelination in the diagnosis and management of CIDP and GBS***

### PRINCIPAL INVESTIGATORS:

**Luana Benedetti, MD, PhD and Lucilla Nobbio, PhD, University of Genova, Italy**

CIDP and GBS are immune-mediated neuropathies characterized by strong heterogeneity in terms of clinical manifestations, prognosis and response to treatment. They are treatable diseases and early recognition is essential but, besides clinical and neurophysiological

Grant Recipient continued on page 3 ►

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



*Please join us in celebrating  
our 40th year!*

## Dear Friends,

I'd like to take a moment to share my view. Today, I sit and look at the Foundation staff (via zoom), bursting with energy, smiling, enthused, and overflowing with ideas and plans for the year ahead. I stop and think, *"Is it still 2020? Are we still battling a global pandemic?"* You would never know by this view. How proud it makes me feel of our staff, our volunteers, and our community, as we have all stood up, and continue to stand up, in the face of bottomless uncertainty and unraveling plans; how we didn't turn away, we joined together and we pivoted. We prevailed.

Although 2020 will be a year that many will choose to forget or happily leave behind, I will always remember it as the year that the fabric of our community withstood its harshest and most challenging season of all. How we are in fact stronger, more connected, and more durable in its final days. Many of you have been riding alongside our pivoting plans as we quickly transformed to a remote and virtual reality. Many of you have even connected in a greater way with the community due to the digital ease of accessibility. And many of you have graciously expressed your appreciation for the continued support throughout the year. I speak for the entire Foundation and say, *you are so very welcome.*

As we now stand surefootedly at the entranceway to 2021, I am confident we will blend the now familiar virtual programming, with our tried and true, in-person events and face-to-face support, world-wide. We will of course follow the guidance of our medical advisors, but we are excited to be planning for a "hybrid" of services, including both online and in-person connections.

I hope you take a moment today, tomorrow, all season long and breathe in the view. I hope you see the strength and feel the connectedness of those around you, a community of which you are a very much a part of.

With warm wishes  
for you and yours,

*Lisa*

Lisa Butler, *Executive Director*



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

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## Why I am Volunteering for the GBS|CIDP Foundation International?

I am interested in volunteering to offer patient and caregiver support. Thus far, I left my contact information with my local neurologist to give it to families who wish to speak with me. I have spoken with the mother of a patient and with a patient from a town in the north of the island. I feel neurologists need more knowledge of this disease. They must have protocols that allow them early detection. No one should see 9 neurologists as was my case, the first neurologist must have the ability to make the correct diagnosis. Physical therapists, here, didn't know anything about my illness either. At least the ones I went to. My rehabilitation has been with YouTube videos that my doctor looked for and sent me.

This is an island! Only 8 universities in the country have medical schools, I have excellent relationships with at least 3 of those universities, so an annual event can be held for medical students in which they learn about diagnosis and treatment. I do not have the information on how many hospitals have a neurology area but it is not difficult to investigate it.

My younger brother is an "influencer" and now he is also a legislator for Santo Domingo. We have discussed ideas on how to raise awareness about this disease. We have not done anything concrete, yet. However, by working with the Foundation I will have more access to its media and social networks.

Families suffer a lot. I would like to imagine a network of volunteers like my mother, enthusiastic and committed, helping families to be creative in adapting the bathroom, food, and patient hygiene. Something like "the heart of one mother to that of another." Family support is vital in recovery.

And I want to remind others to celebrate! We have to celebrate that we are alive! My neurologist and I danced when I was discharged!

Grant Recipient continued from page 1

criteria, there are not clinically acceptable biological markers to diagnose and classify GBS, CIDP and their variants. Treasuring the needs of GBS|CIDP community, we have been engaged for a few years in identifying and validating up to the clinical implementation a biomarker of demyelination for these patients. In this Italian multicenter prospective study, we demonstrate that sphingomyelin (SM) dosage in the CSF of patients with CIDP and GBS may effectively improve their management and thereby the quality of life of affected individuals and their families.

In fact, CSF SM dosage has shown to be:

- a good diagnostic biomarker enabling, at the same time, a correct diagnosis in more than 80% of patients and the identification of misdiagnosed patients with a 100% specificity;
- a good staging biomarker enabling the proper identification of the vast majority of patients with CIDP in the active stage of the disease, fundamental to select the most appropriate timing for therapeutic intervention;
- a reliable, accurate and clinically acceptable biomarker because it is simple, inexpensive and easily amenable to routine use without the need for sophisticated equipment or operator skill.

### FULL ARTICLE CAN BE FOUND AT:

[HTTPS://JNNP.BMJ.COM/CONTENT/  
EARLY/2020/10/22/JNNP-2020-324445.FULL](https://jnnp.bmj.com/content/early/2020/10/22/jnnp-2020-324445.full)



## CONTACT US

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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 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).

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**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.

## A STATEMENT FROM THE DESK OF OUR GLOBAL MEDICAL ADVISORY BOARD

NOVEMBER 19, 2020

Please see our website for updated information. [www.gbs-cidp.org](http://www.gbs-cidp.org).



## COVID-19 AND GBS|CIDP

The GBS|CIDP Foundation has received many questions about COVID-19 and its relationship to Guillain-Barré syndrome and CIDP. It is important to emphasize that presently we have no information on potential cause and effect. One must keep in mind that COVID-19 became known to most of us in March of this year and it is now November. We have limited data to draw a relationship between the virus and neurologic illness based on 8 months of observation. So far, there does not appear to be a high increase in GBS or CIDP following COVID-19 infections. Even if there were a higher incidence, management would be preventative using frequent handwashing, physical distancing, and quarantining in the appropriate situation. If a patient developed GBS or CIDP after a COVID infection, the treatment would be the same as a patient who was not infected by the COVID vaccine.

## THERE IS NO DATA SO FAR TO SUPPORT THAT PATIENTS WITH PRIOR GBS OR CIDP ARE MORE PRONE TO DEVELOP AN INFECTION WITH COVID-19.

In the past week, two pharmaceutical companies have announced preliminary data on the protective effect of COVID vaccines. One reported 90% protection and the other 94.5%. The data is preliminary. It has not been reviewed by experts in the field of vaccine epidemiology or the FDA. The vaccines, if protective, will not be available for widespread use until late spring 2021.

The GBS|CIDP Foundation has also received questions about the safety of these COVID vaccines but this needs to be further investigated. It would be appropriate at this time to summarize the stance of the GBS|CIDP Foundation regarding the seasonal flu vaccination:

Studies on the safety of flu vaccinations showed that for every 1,000,000 people who get a flu vaccine, there is 1 (one) additional case of GBS. Normally in 1,000,000 people, there would be 20 cases of GBS (2/100,000) but if they all got the flu vaccine, there would be 21. Who is the one person who got their GBS from the vaccine versus the 20 who would have gotten GBS anyway is not known. Thus, we advocate for receiving the yearly seasonal flu vaccination in the fall of each year. We can easily quantitate the benefits of 1,000,000 people getting the flu vaccine in terms of deaths/hospitalizations/days off work. Those benefits far outweigh the very small risk of GBS in patients who receive the flu vaccine (again 1 extra case for every 1,000,000 people vaccinated).

## Ask the Expert...

With Dr. Jeff Allen,  
Member GBS|CIDP Foundation  
Global Medical Advisory Board

“Although it’s the most prominent one, CIDP is NOT the only auto-immune disease with which I’ve been diagnosed. I also have Hashimoto and Lyme Disease. What correlation, if any, is there between these three autoimmune diseases? Or, for that matter, any combination of CIDP with others?”

PATIENT ATTENDEE,  
2020 VIRTUAL SUMMIT

A great question with a near impossible answer. It is well known that where there is one autoimmune disease there is not uncommonly another. Any one individual that has an autoimmune disease has an increased likelihood of having a second. There usually is no clear connection to the specific autoimmune diseases that come together, but more generally diseases of autoimmunity tend to cluster in individual patients and families. For these reasons it is suspected that some people and families have genetic susceptibility to autoimmune diseases. In some autoimmune diseases genetic susceptibility markers are known, but not CIDP. It is very questions like this that INCbase will be so important. By pooling together genetic material from 1000's of people with CIDP we may begin to better understand what makes some people more susceptible to CIDP.



On December 1, Giving Tuesday, kicked-off the ultimate season of kindness, hope and caring for our global community. Every dollar donated to the Foundation on Giving Tuesday and beyond is forever appreciated. In this year of unprecedented challenges, the GBS|CIDP community went above and beyond in how they gave. They gave from their heart, they gave joy. Taking the time to speak with patients in need via zoom or a telephone, sending a greeting card or simply telling their own story, has had lasting impact for so many. We want to thank every member of the community for the endless support and compassion! And we encourage everyone to participate in building up the spirit our community in any way they can.

## Ways to Give...

### GIFT OF LISTENING

- Join our international team of “Points of Contact” – if you are a patient or caregiver with experience in the conditions that affect our community, join our team of local supporters and be the voice of comfort and guidance for those in your area. Contact [Kelly.mccoy@gbs-cidp.org](mailto:Kelly.mccoy@gbs-cidp.org), for more information.

### GIFT OF TIME

- Volunteer to host a 2021 Walk & Roll for Research, or attend a Walk & Roll in your area (or one of our Virtual Walk & Rolls!) Contact [Pamela.franks@gbs-cidp.org](mailto:Pamela.franks@gbs-cidp.org) for more details.
- Greeting Card Alert Program! Volunteer to send a greeting card of encouragement to those who are newly diagnosed. <https://www.gbs-cidp.org/greeting-card-alert-program/>

### GIFT OF AWARENESS

- Start an email or social media campaign and ask friends to share your messages and posts that raise awareness for GBS|CIDP or variants. You can use #gbscidp to help track the posts, or use one of our educational videos from Youtube!
- **Facebook Watch Party!** Share one or more of our Virtual “Ask the Experts” Programs with your friends, family, or community. <https://www.gbs-cidp.org/ask-the-expert-educational-series/>. Topics include: Coping with GBS|CIDP for Youth & Teens, Ways to Advocate, Stress Management, Clinical Research...there’s something of interest for everyone.
- **Whether you’re a patient, caregiver, medical professional or friend, your story matters.** Send us your story for our new patient story portal; your words will be healing to so many. Check out the stories from our community here: [www.gbs-cidp.org/support/connect-with-gbs-cidp-community/patient-stories/](http://www.gbs-cidp.org/support/connect-with-gbs-cidp-community/patient-stories/). Send your story to [Maureen.neville@gbs-cidp.org](mailto:Maureen.neville@gbs-cidp.org).

### GIFT OF PLASMA

- Did you know our plasma industry partners are reporting a decrease in plasma donations for 2020? Find out more about our PLASMA PLEASE campaign, consider donating plasma, and/or encourage your friends and family to do the same. Source plasma provides life-giving treatment to the GBS, CIDP and variant communities. <https://www.gbs-cidp.org/plasma-please/>
- **Plasma Possibilities Program** – Grifols’ Plasma Possibilities Program partners with local, pre-approved charities within a donor’s center to raise money by allowing donors to donate a portion of their plasma compensation. Donors have the option of donating part or all of their rewards for that day’s donation. That’s two ways to GIVE! <https://www.grifolsplasma.com/en/plasmapossibilities>
- **CSL** – Adopt a Patient Program. Contact [Meg.francescangeli@gbs-cidp.org](mailto:Meg.francescangeli@gbs-cidp.org) for more information about this exciting new way to get involved.

### GIFT OF INSPIRATION

- Perhaps you’d like to give a gift that inspires others to give? How about a Matching Gift? You can choose a date and amount, and match donations dollar to dollar! Contact [Madeline.miller@gbs-cidp.org](mailto:Madeline.miller@gbs-cidp.org)
- Monthly Giving is an easy way to ensure that the inspired work of the Foundation continues for years to come. Find out more.

### GIFT OF SUPPORT

- We thank you for any donation, large or small. Your donation will directly impact the work of the Foundation and the community we serve.

# Plasma, Please!



The world needs plasma donations. Help us raise awareness of this important issue by sharing these pages with friends and family.

Source plasma is collected from healthy people and used to create very specialized medicines. People all over the world rely on medicine created from source plasma to live, including patients with CIDP, primary immunodeficiencies, alpha-1 antitrypsin deficiency, hemophilia, shock, severe burns, organ transplants, and other conditions.

Currently, companies that manufacture the therapies needed by our patient community – and hundreds of thousands of people across the world – are reporting a sharp decrease in the number of people who are donating plasma. This shortage creates a direct threat to the health and wellness of our patient population, who are treated with immunoglobulin (Ig).

We are asking for healthy adults to consider donating plasma. Chances are, you know someone who depends on source plasma donations to live. So what can you do for them?

## PLASMA, PLEASE!

This is your chance to make a difference in their life while also helping countless others across the world.

## Questions?

### DOES IT HURT?

Plasma donors often compare the feeling to a bee sting!

### WHAT IS PLASMA?

Plasma is a component of your blood. When removed from red blood cells, it looks like a strawcolored liquid and contains antibodies, proteins, water, etc.

### WHO CAN DONATE?

Healthy adults! Donors need to weigh at least 110 lbs (50kg) and pass a physical/health history exam.

### DO YOU GET PAID FOR DONATING PLASMA?

In the U.S., some plasma donation centers offer a fee for your time spent at the center. You will need to inquire with your local center for more detail.

# Here's What You Need to Know About Donating Plasma

## Ask the Plasma Expert...



*With Julie A. Birkofer and Mat Gulick of the Plasma Protein Therapeutics Association*

### CAN IVIG BE MADE FROM WHOLE BLOOD DONATION AS WELL OR JUST PLASMA?

Recovered plasma, obtained from a whole blood donation, is a suitable raw material for the manufacture of IVIGs. There just isn't enough of it! The world cannot depend on recovered plasma to meet patients' clinical needs.

### CAN YOU DONATE PLASMA IF YOU'VE HAD GBS, OR OTHER AUTOIMMUNE CONDITIONS?

If a U.S. source plasma center is EU certified, the deferral would be automatic. EU requires deferral of donors who have neurological conditions or a recurring or relapsing disease or condition. In the U.S., however, the regulations/guidances are not so black and white. However, many would be deferred either because of the condition itself or medications being taken for the condition or general physical condition at the time of the interview or physical examination. For the most part, individual company policies dictate.

### CAN I DONATE PLASMA OR BLOOD FOR COVID-19 RESEARCH IF I AM USING SCIG?

People receiving antibody therapies should not donate. There is not a concern for product safety, but rather for the health and well-being of the person wanting to donate. It would be impossible to monitor the effectiveness of a person's antibody treatments if they were also donating antibodies.

### WHAT TYPE OF SAFETY MEASURES ARE DONATION CENTERS TAKING DURING COVID-19?

Donation centers have implemented safety protocols that include sanitation of facilities and equipment, mask wearing and other PPE measures, and social distancing.

- 1 There are plasma collection centers all across the US, Canada, and Europe. Find the closest collection center to you at [donatingplasma.org](https://donatingplasma.org). You usually do not need an appointment, but you should confirm that now.
- 2 When you arrive to donate plasma, you will present your ID, and first time donors will undergo a physical examination. All plasma donors will give a quick blood sample (finger prick) to check protein levels.
- 3 A thorough health history will be taken.
- 4 Now, assuming everything checks out, you will be ready to donate plasma. The process is called plasmapheresis, and involves a technician placing a needle that connects to a machine that draws blood. The blood will be drawn, and the machine removes the plasma from your blood, and then your blood (without the plasma) is returned to you!
- 5 The whole process takes about 90 minutes (2 hours for new donors), and plasma donors in the US may be compensated for the time they spend donating source plasma. Compensation depends on the plasma center's policies.
- 6 **IMPORTANT STEP:** The first time you donate plasma, you must return to the center to give a second donation! Otherwise, your first plasma donation can't be used. The purpose of this 2nd donation policy is to verify your initial health screening test results and keep people who use medicine created from source plasma safe.

FIND THE CLOSEST COLLECTION CENTER TO YOU AT [DONATINGPLASMA.ORG](https://donatingplasma.org).

#### QUESTIONS, PLEASE CONTACT:

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# Building Muscle at Any Age

By Dr. Julie Rowin, A publication from Dr. Julie Rowin's Blog Post found at: [julierowinmd.com](http://julierowinmd.com)



The benefits of maintaining muscle mass at any age cannot be underestimated.

## HERE'S WHY:

- ▶ Muscle is involved in brain function in a big way. Muscle directly communicates with the brain through chemicals and messengers such as brain-derived neurotrophic factor (BDNF). These chemicals are released every time we exercise. So exercise not only makes your muscles bigger, it makes your brain bigger and improves cognitive performance, too. The loss of muscle mass that occurs with aging, known as sarcopenia, is highly correlated with loss of cognitive function, another reason to stay strong!
- ▶ More muscle burns more fat. Those little organelles in the muscle called "mitochondria" are your energy powerhouses and by exercising muscle (even one bout of exercise) you make more of them, leaving you with more energy and a healthy metabolism. Building muscle mass is essential for weight loss, longevity and prevention of metabolic disease like diabetes. It is becoming clear that the obesity epidemic is in large part due to an increasingly sedentary society.

## "Can I increase muscle at any age?" "Yes!"

The common reasons for low muscle mass include:

- ▶ a diet too low in protein
- ▶ lack of effective exercise regimens
- ▶ reduced ability to digest protein as we age

## How much protein do you need to build muscle?

Unless you are completely sedentary, the USDA's recommended daily allowance (RDA) of 0.36 grams of protein per pound of

body weight is likely not enough for optimal health and fitness.

Adults looking to build muscle and strength need at least 0.6 grams of protein per pound of body weight per day. This works out to at least 90 grams of protein daily for a 150-pound person.

## Here are some tips from Danka Lekovic, NASM certified nutrition coach, on how to get more protein into your diet:

- ▶ Consume leucine rich foods such as whole organic eggs, fish, organic poultry and grass-fed beef and dairy. Leucine, along with isoleucine and valine, is a main driver in muscle protein synthesis and recovery.
- ▶ Aim for 20-30 grams of protein per meal. Increase the protein content of your meal by adding legumes, nuts and seeds, greens, cruciferous vegetables, mushrooms or avocado to your main protein dish.
- ▶ Snack on:
  - hummus with vegetables
  - an ounce of cheese
  - unsweetened Greek yogurt or cottage cheese
  - a hard-boiled egg
  - a handful of nuts or seeds

If you are having difficulty fitting in the recommended amount of protein, consider using a protein powder supplement that uses either grass-fed whey (We like Levels whey protein powder) or an organic plant-based protein such as pea, hemp or rice protein powder such as Nutribiotic brand, made without fillers or sweeteners. See that it contains 1-3 grams of leucine.

Whey protein is a "fast" absorbing protein and is an excellent choice to consume in a post-

exercise shake combined with a carbohydrate such as fruit and a healthy fat like nuts or avocado. Most whey powdered supplements are low in lactose and generally well-tolerated. Casein, is a "slow" absorbing protein that is a good choice at bedtime to feed muscles overnight while we sleep and fast. If you can tolerate dairy, choose cottage cheese or unsweetened Greek yogurt for this reason as they are high in casein.

"Performing resistance type exercises is what actually builds muscle, but there must be enough available dietary protein to support the building and maintenance of new muscle."

## Performing resistance exercise will significantly counter declines associated with the (un)natural aging process:

- ▶ Do resistance types of exercise utilizing bands, machines, dumbbells or using body weight at least three times per week. Here is a webinar on MG and exercise that I did with A.C.E. certified personal trainer, Julie Hossack.
- ▶ Engage the help of a personal trainer or physical therapist to establish a safe and effective program where you progress appropriately.
- ▶ Do gradual, progressive increases in resistance. If you can easily perform 10 reps of any exercise it will not build muscle. You must progress the weight to see results.
- ▶ Have your body fat percentage measured. This is a more valuable indicator of health than weight or BMI.

FULL ARTICLE CAN BE FOUND AT:  
[HTTPS://WWW.GBS-CIDP.ORG/  
 BUILDING-MUSCLE-AT-ANY-AGE/](https://www.gbs-cidp.org/building-muscle-at-any-age/)



## RUNNING TO RAISE AWARENESS AND FUNDRAISING FOR GBS|CIDP FOUNDATION INTERNATIONAL

On November 14th, João Mateus, a 33-year-old Portuguese fund manager and marathon runner, paid tribute to his grandmother, Maria Manuela Mateus – loved and cherished by all. Manuela Mateus was born in Grândola-Alentejo, in the South of Portugal and worked at António Inácio da Cruz Secondary School. Unfortunately, Manuela passed away in 2016 due to complications of GBS. With the main purpose of raising the highest amount of funds possible to support GBS | CIDP Foundation International's Research Grant Program, as well as raising awareness for this neurologic disease, Joao Mateus ran approximately 56 miles (90kms) from his home door in Amadora (Lisbon) to his grandmother's former home, a beautiful tribute to her memory. Congratulations Joao, and thank you for your support and dedication to the mission of GBS|CIDP Foundation International!



## Board of Directors Member, Russ Walters of California, Participates in Peer Reviewed Medical Research

Member Russ Walter served as a consumer reviewer for applications submitted for the Department of Defense's Peer Reviewed Medical Research Program (PRMRP) for fiscal year 2020. His dedication and hard work provided an important perspective as a panel member on the prestigious review team. His input will help Congressionally Directed Medical Research Programs (CDMRP) achieve its vision of transforming healthcare of Service members, Veterans, their families, and the American public. Thank you, Russ, for your dedication to the GBS|CIDP and variant community!



## CHAPTER MEETINGS UPDATE



We are so thankful to our team of volunteers who have made the pivot to virtual meetings in 2020.

We have hosted 20 successful Zoom to meetings, and more are on the horizon! Please visit our event's calendar to see what events are upcoming, and remember, all are welcome! Travel virtually all around the country & catch up with local membership!

In-Person meetings are currently on hold through June of 2021 to keep our community safe, but we will host more Zoom meetings, so stay tuned. Interested in hosting local meetings or providing patient support via telephone or email? Visit <https://www.gbs-cidp.org/volunteer/> or email Kelly.mccoy@gbs-cidp.org!

# #strongertogether

2020 VIRTUAL WALK DAYS

## 2020, THE YEAR OF VIRTUAL WALK & ROLL!

COVID-19 sent our Walk & Roll program for a loop this year, but the Foundation maintained its dedication to our community-funded research grant. At the end of February, we were able to hold our only in-person walk in Clovis, CA. Over 270 people registered for this event, and raised over \$9,500.00! After evaluating the situation in each of our walk locations, a decision was made to go virtual for the remaining 17 walks. Going virtual allowed our community to still come together and celebrate, raise awareness, fundraise and to walk and roll in the safety of your own neighborhood or local park.

We designated Virtual Walk Days in the months of September, October, and November. During these uncertain times, those living with the daily challenges of GBS, CIDP and variants, such as MMN, needed our support more than ever...and you delivered! To date, over 1,000 people have registered to participate in these virtual events, and have raised over \$83,684 for GBS|CIDP research.

A big thank you to all of our teams, donors, sponsors, walk chairs, and volunteers for their continued dedication to the Foundation. You are always by our side, even in these difficult times!

Planning is already underway for 2021! If you are interested in hosting a Walk & Roll in your area or volunteering with the program, please contact Pamela.franks@gsb-cidp.org.



## TEENS & YOUNG ADULTS CONNECT

Our Youth, Teen & Young Adult program (YTA) has officially kicked off **"Teens & YA Connect."** Teens & YA (Young Adults) Connect is a casual Zoom hangout session for younger patients (16 – 26) to meet one another and share your experiences with GBS, CIDP, or variant conditions. A big part of what the YTA Program is designed to do is provide a safe and open place where younger patients can meet (virtually) with other peers who understand the challenges they are facing in their everyday lives. We encourage all younger patients to join us on these casual zoom gatherings to share their experiences and use this as an outlet to listen to one another and build lasting friendships. Every Zoom gathering will be moderated by a Foundation staff leader, who will guide conversations as needed throughout the session.

Questions, please contact Meg.francescangeli@gsb-cidp.org. Visit our YTA page on the website for our calendar of **"Teens & YA Connect"** with Meg Francescangeli & YTA committee member, Michael Coleman. <https://www.gbs-cidp.org/support/yta/>




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Forty years later, what started as eight people in the Benson dining room turned into hundreds of patients around the world gathering in their towns and cities to educate, learn, and support each other.

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## HAPPY 40TH!

The idea that a promise that she made in 1979 to her husband, Bob, as he laid in the ICU, paralyzed from GBS would not only last 40 years but become what the GBS|CIDP Foundation International is today never even crossed Estelle Benson's mind. A woman, passionate about the recovery of her husband and making sure that others had the resources and support that they didn't have, became dedicated to creating a support group for GBS patients. Forty years later, what started as eight people in the Benson dining room turned into hundreds of patients around the world gathering in their towns and cities to educate, learn, and support each other. One chapter meeting for GBS patients in Pennsylvania turned into 155 chapters for GBS, CIDP, and variant patients in over 40 countries around the world.

This year, the GBS|CIDP Foundation International is proud to celebrate 40 years of dedication to GBS and CIDP patients around the world. This continued dedication to patients has allowed us to provide constant support to patients, their caregivers, and medical professionals, fund research that will better the lives of patients, and advocate for legislation that benefits thousands of patients across the country. Our 60,000 members, hundreds of volunteers, Board of Directors, and Global Medical Advisory Board have proved to our community what we as a Foundation have known all along: no one is alone.

You may have received a 40th Anniversary sticker in the mail. Join us in celebrating four decades of the GBS|CIDP Foundation International by sending us a picture of you wearing your sticker to [Madeline.miller@gsb-cidp.org](mailto:Madeline.miller@gsb-cidp.org) or posting a picture online with [#gbscidpturns40](https://twitter.com/gbscidpturns40).

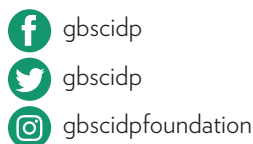


## NEW! FOUNDATION MEMBER SERVICES MANAGER

In 2020 our members reached out for support, resources and connections more than ever before. As serving each and every one of members is a top priority, even at the most challenging of times, we soon realized the need to have someone on staff that was both knowledgeable in the conditions of GBS|CIDP as well as highly skillful at managing and responding to the many daily inquiries. Lori Basiege, a former GBS patient, has been with the Foundation as Special Projects Manager for over 4 years, and will now also manage the Foundation's member services center by supporting members in a wide range of inquiries and requests. Lori will remain our key contact for communications with our GMAB when necessary, and manage the application process for both our Research Grant and Center of Excellence Programs. We are delighted to continue to serve our membership effectively and efficiently with the most current resources and information available. And please join us in congratulating Lori! Contact her at [Lori.basiege@gsb-cidp.org](mailto:Lori.basiege@gsb-cidp.org).



CHANGE SERVICE REQUESTED



SUPPORT EDUCATION RESEARCH ADVOCACY SUPPORT EDUCATION RESEARCH ADVOCACY



## NEW! COMMUNITY CHATS

If you attended the Virtual Summit in October, you may have participated in our active chat! You asked & we listened! We will host 'Community Catch Up Chats' throughout the end of 2020 & early 2021.

**JOIN US FROM JANUARY – MARCH** for *GBS, CIDP & Emotional Health "Virtual Summit Rewind" Chats*. Space will be limited. Check your email inboxes for invites & to register.

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

### DIAGNOSED WITH MMN?

Brenda Perales  
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  
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. For more information on our youth, teen, and young adult (YTA) programming contact Meg.francescangeli@gbs-cidp.org.

### LOOKING FOR A 20-SOMETHING 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 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.

### 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.**