

# 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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(left to right) Grifols Talecris Plasma Resources Operational Supervisor, Brency Vaught and donor, Victoria Picone

## 10 Years and 1,000 Donations Later

### Meet Victoria Picone

### We are continuously thankful

for the wonderful plasma donors in our community and their generosity to help save lives. One great example of this is Victoria Picone, a retired educator and longtime plasma donor in Bloomington, Illinois who recently hit her 1,000-plasma donation!

For the last 10 years, Victoria went to her local Talecris Plasma Resources Center two days a week, every week, come rain, snow, or shine. "It all started when a friend of a friend's granddaughter, was born with a rare condition. She needed a treatment that was made from blood plasma. *How can I help I wondered.*" Soon after Victoria found out she could donate blood plasma and that there was a center close by. "Yes! I can do that," she thought.

## Meet Alex Biagi

*"When you love something you do it until you can no longer do it."*

After enduring a young adulthood (1996-2001) of spinal stenosis, back surgeries (including a laminectomy and spinal fusion), and multiple knee surgeries, alongside many painful periods of recovery, Alex Biagi was back in shape and back to his old normal — a life of basketball and regular high school activities.

"I did lots of physical therapy and I tried to get my knees back in shape. It was very difficult, but I was able to get to a point where I could get my first job and I was also able to play basketball again." But as his challenging health issues continued, eventually his love of playing sports would transform into love of other passions such as art and music.

"So after high school (2000) I went to college to learn 3D animation, multimedia production and design. I also took several music production courses as well. I was really enjoying them so I was thinking about a double major with music as my second. I was really



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



*Our experiences are the thread  
that weaves us all together.*

## Dear Friends,

In this issue of *The Communicator* I share with you our response to a recent *NY Times* article *What is the Blood of a Poor Person Worth*, published on February 1, 2019, whose subject matter deeply affects our community. I feel it greatly represents our patients, caregivers, loved ones and friends — our collective and resounding voice and, my hope, is that you are comforted in knowing that the GBS|CIDP Foundation International will raise that voice, each and every time it is called forth.

In Response to *NY Times* article, ***What is the Blood of a Poor Person Worth?***, Feb. 1, 2019

(February 1, 2018) Imagine the shock and helplessness of seeing your child's body suddenly growing weak, clumsy, and unable to walk, or even stand; the fear that they may never live a normal life, or even survive this terrifying, disabling disorder. Imagine being greeted with the puzzlement of healthcare professionals, a battery of tests, misdiagnosis, needles, uncertainty and inconclusions — all the while the condition worsening before your eyes, and this person, this child, slipping right through your fingers. How will this all end? I truly hope for you, for the sake of your family, community and loved ones, that this feeling, this picture I have painted, stays only in your imagination. And that you never spiral down to the level of desperation brought on by a very rare and disabling condition, like I did.

On January 28th, 2001, my son was diagnosed with Guillain Barre Syndrome after ten days of rapid physical decline and mobility. He was admitted to ICU, diagnosed and was treated with Immune Globulin, a plasma product. My entire family was given a gift; the life-saving gift of plasma donation. And although he left the hospital strapped to a wheel chair, lacking the strength to even sit upright, he began a recovery that would progress and regress with a second stay in ICU and a second round of immune globulin. Source plasma is used to manufacture life-saving bio-medications for people living with rare, serious, and chronic diseases and will allow those individuals to live normal, healthy lives. In fact, Source plasma donors have safely donated — at a conservative estimate — more than 500 million times over the past few decades, saving countless lives. Thanks to these dedicated plasma donors, our son did recover, he is now part of the 5% of patients in the rare disease community of 7,000 that has a therapy.

When I read the article *What is the Blood of a Poor Person Worth?*, on February 1, published in *The New York Times*, I was struck by reference to the plasma donors, as “desperate people”, and the lack of information regarding how these people actually have given a much better quality of life back to so many. To me, there is no price too high for the value of my son's life, his well-being, his chance to go on, and to go far. And although, the debate continues, how much to pay? Why, to whom and how often? ... I feel the article lacked balance in its portrayal of Source plasma donors, who come from all walks of life, cultures, places and stories. These people are heroes to many, and should know that their choices have made a monumental difference in the lives of others. As the mother of child stricken with GBS, and the Executive Director of the GBS|CIDP Foundation International, an organization whose 44,000 members depend on the Foundation to fight for access to these life-saving treatments, I offer an infinite thank you to all donors, from all corners of the world.

Gratefully,

*Lisa*

Lisa Butler, Executive Director

## From the desk of Jim Crone, President of the GBS|CIDP Foundation International Board of Directors

As a patient and tireless advocate in the rare disease community, I am deeply troubled by pieces such as the *New York Times* article on plasma donation. These sensationalized reports in the media attempt to characterize compensated plasma donation as a practice that preys on individuals of a lower socioeconomic status at the expense of corporate greed. If the media would fully research the topic they might tell a very different story.

I had the privilege of working on an interdisciplinary team composed of physicians, ethicists, safety regulators, economists and patients that examined the topic of compensated plasma donation for use in the manufacture of plasma-derived medicinal products (PDMPs) such as Immunoglobulin (IG). We spent two years conducting in-depth research, discussion, writing and revising. Our final product was a comprehensive article published in the peer reviewed journal *Transfusion*. Members of the media should read “Risk-based decision making and ethical considerations in donor compensation for plasma-derived medicinal products” (<https://onlinelibrary.wiley.com/doi/10.1111/trf.13764>) before publishing any additional sensationalized and inaccurate pieces on compensated plasma donation.

These excerpts from our article summarize my thoughts:

*“Given advances in PDMPs and donor safety, one of the remaining threats to safety is a policy that undermines an adequate and sustainable supply of PDMPs.”*

*“Actions that limit patient access to treatment without considering supply issues raise the possibility that global patient needs will be eclipsed in pursuit of ethical ideals that are both impractical and unnecessary.”*

*“Failing to recognize unmet need ultimately limits patients’ access to PDMPs and effectively denies access to adequate health care. The safest drug that no one can afford or that arrives too late is of no benefit to a patient.”*

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getting into producing electronic music and I started to invest in some music gear. I bought an expensive piano, computer and a beginner digital music program. I was on my way! I figured since I wasn't going to pursue sports this would be the next best thing and things were going great! And I was starting to feel really good!" Never did he imagine that his physical health would present challenges in these areas too.

Everything took a turn in 2004. Alex's left hand started to hurt. At first, he was diagnosed with Carpal Tunnel Syndrome, and endured even more surgeries to resolve this painful condition.

"In addition to carpal tunnel surgery on both hands I also had ulnar nerve relocation surgery on both elbows." But, on Thanksgiving eve in 2004, something occurred that was far from his carpal tunnel symptoms — Alex fell down his stairs.

"My ankle gave way," Alex explained. "That's when we knew something else was going on." Alex started losing the use of his arms, hands and legs. From there forward, it took three years for doctors to diagnose Alex with Chronic Inflammatory Demyelinating Polyneuropathy (CIDP).

"It affects approximately one to two people in 100,000 per year," said Alex's doctor. "Alex has had a severe case of CIDP," he said.

When Alex was first diagnosed, he gave up on art because his hands simply wouldn't allow it. "But when you love something, you find a way." Three years ago he saw someone on the internet painting with their mouth. "I never even thought about doing it that way," he said. "I finally decided to give it a try."

For the past four years, Alex has been practicing this unique craft and his paintings continue to get better and better. His latest piece of art is making the rounds on the internet. A picture of him touching up his painted portrait of superstar athlete LeBron James exploded on Reddit.

"A good friend of mine decided to post the picture and it went viral," Alex explained.



Each piece of art takes time. Alex says it takes more than a month before there is a finished product. His work is more than just paint on a canvass, it's a symbol to never giving up.

"You gotta keep pursuing what you love. Otherwise you'll let the disease win," he said.

Alex's disease has tamed after going through a very high dose immunosuppression as part of a protocol that removes a patient's stem cells before the immunosuppression, and then reintroduces them once the immune system is severely weakened\*. Alex stated, "I was in a power chair off and on for four years prior to the stem cell transplant, now I'm occasionally walking close to 2 miles without stopping, with braces. And I'm getting full range of motion back in my arms."

**\*A statement from the GBS|CIDP  
Medical Advisory Board**

"Although Stem Cell Transplant in CIDP may be helpful in some patients it is unproven and comes with significant risk. Patients need to find a neurologist who can educate them on proper escalation of immunotherapy proportional to the severity of their disease - which almost never means SCT."

Find more information on Alex and his journey:  
[www.alexbiaggi.com](http://www.alexbiaggi.com)

**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.



Picone continued from page 1

Now ten years and 1000 plasma donations later Victoria says, “I’ve really gotten to know everyone at the center, and some of the other donors too. They have truly become like a big extended family to me. They actually treat me like a VIP when I walk through the door!”

With an original goal of donating 500, Victoria’s aspirations soon grew after time spent with the very lives of patients she has touched.

“I told myself I would try and give 500 times, that was my goal.” But after a visit to the Grifols plasma manufacturing plant, alongside CIDP patients, her goal soon changed. “Now I wanted to keep going.” The time spent at the center ranges from 2-3 hour per week, but to Victoria she wouldn’t spend her time any other way. “Giving to the community, gives back to you tenfold. It feels great! You just think about all the people you can help, and it really makes it all worth it.”

Thank you to Victoria and the amazing team at Talecris Plasma Resources in Bloomington, IL.

“

*“Giving to the community, gives back to you tenfold. It feels great! You just think about all the people you can help, and it really makes it all worth it.”*

–VICTORIA PICONE

## Dr. Bart Jacobs, Vice Chairman of GMAB, and coauthors, nominated for “Editor’s Choice,” *Brain Journal*

### *Regional variation of Guillain-Barré syndrome*

*Brain*, Volume 141, Issue 10, 1 October 2018, Pages 2866–2877



An article published in *Brain Journal*, September 25, 2018, regarding research findings of the International Guillain Barre Outcome Survey (IGOS), partially supported by GBS|CIDP Foundation International, received the “Editor’s Choice.” Findings of IGOS are significant to the GBS community as noted in the abstract summary of article below:

Guillain-Barré syndrome is a heterogeneous disorder regarding the clinical presentation, electrophysiological subtype and outcome. Previous single country reports indicate that Guillain-Barré syndrome may differ among regions, but no systematic comparative studies have been conducted. Comparative studies are required to identify factors determining disease susceptibility, variation and prognosis, and to improve diagnostic criteria. The International Guillain-Barré Syndrome Outcome Study is a prospective, observational cohort study including all patients within the diagnostic spectrum, aiming to describe the heterogeneity of Guillain-Barré syndrome worldwide. The current study was based on the first 1000 inclusions with a follow-up of at least 1 year and confirmed the variation in clinical presentation, course and outcome between patients. The full clinical spectrum of Guillain-Barré syndrome was observed in patients from all countries participating in the International Guillain-Barré Syndrome Outcome Study, but the frequency of variants strongly differed between regions. “This is significant findings for the IGOS team and for researchers in the field of GBS,” said Dr. Jacobs. “We now know that there is an important factor that determines the clinical variant and depends on the region. This could be environmental factors as infections, or endogenous factors as genetic variation, that we will need to investigate further. The BRAIN paper is the first in an extensive series of studies in IGOS on GBS causes, diagnostic criteria, subtypes, treatment responses, outcome measures, prognostic models and long-term effects.”

For full article: *Brain*, Volume 141, Issue 10, 1 October 2018, Pages 2866–2877, <https://doi.org/10.1093/brain/awy232>

## ATTENTION CIDP PATIENTS IN CANADA, UK, GERMANY, FRANCE, ITALY AND SPAIN

*Baxalta/ IQVIA CIDP Treatment Trial, Now Enrolling Patients Worldwide*

More information at [clinicaltrials.gov](http://clinicaltrials.gov).

<https://clinicaltrials.gov/ct2/show/NCT02955355?term=Baxalta&recrs=ab&cond=CIDP&rank=1>



## How has a GBS|CIDP diagnosis affected you?

*Tell us about it! New Patient Registry Launches on Rare Disease Day!*

**JOIN THE NEW GBS|CIDP PATIENT REGISTRY, SHARE YOUR EXPERIENCE, AND PLAY A CRITICAL ROLE IN A BETTER TOMORROW FOR THE GBS|CIDP PATIENT COMMUNITY.**

The GBS|CIDP Foundation invites you to join the online Patient Registry for patients with GBS|CIDP or variants of the condition. The GBS|CIDP Patient Registry, consisting of patient reported standardized questionnaires, will allow healthcare professionals access to critical, **de-identified** patient data and a more in-depth understanding of the patient experience. This unique collection of data can be critical for the pursuit of medical advancements and development of patient resources. The registry will be hosted in partnership with the National Organization for Rare Disorders (NORD); an independent non-profit patient advocacy organization dedicated to individuals with rare diseases and the organizations who serve them. **Studies of these conditions may take years to finish, but patient reported registries provide power in numbers!** The Foundation will provide periodic updates and results with the discoveries made possible with this impactful data.

If you are a patient, or the primary caretaker of a patient living with GBS, CIDP or a variant of the condition such as MMN or Anti-Mag, we encourage you share your experience, enroll in GBS|CIDP patient registry and play a role in a better tomorrow for GBS|CIDP patients everywhere.

Find out more: [gbs-cidp.org/new-gbscidp-patient-registry/](https://gbs-cidp.org/new-gbscidp-patient-registry/)



## THANK YOU PLASMA DONORS

Thank you for the LOVE this February to all of our patients, from our plasma donors! Plasma donors, from 220 Grifols plasma donor centers, had the opportunity to learn more about how their donations help save lives and signed giant Valentine cards for our patients, many of whom they've helped! Thank you to all for your compassion and generosity.



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

Contact us online at [gbs-cidp.org](https://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](https://gbs-cidp.org)  
**E** [info@gbs-cidp.org](mailto:info@gbs-cidp.org)



## GBS|CIDP Foundation Advocacy News

Philip Goglas II, Legislative Director, Health and Medicine Counsel of Washington, D.C.

### We are currently working

with our Congressional champions on reintroducing the **Medicare IVIG Access Enhancement Act (H.R. 4724)** which would create a three-year demonstration project extending Medicare coverage of IVIG therapy in the home for the treatment of CIDP and MMN. The establishment of a home infusion option for patients with CIDP and MMN will help promote therapy adherence, enhance quality of life, and promote positive health outcomes for beneficiaries with CIDP and MMN.

There has been an important shift on Congress' view of the *Affordable Care Act* (ACA) recently. Over the past year we have seen a change from attempts to dismantle the ACA to both Republicans and Democrats focusing on protecting basic patient protections such as

- prohibiting insurer discrimination against pre-existing conditions
- allowing young adults to stay on their parents' insurance until the age of 26

- establishing out-of-pocket maximums for covered services
- prohibiting annual and lifetime caps on insurance coverage.

The one challenge to this is a federal judge in Texas ruled that the ACA is unconstitutional and the entire law should be struck down. The ruling has not had an immediate effect and we anticipate it will be quite some time before there is any effect.

For the first time in over 20 years, Congress approved funding for the Department of Health and Human Services and the Department of Defense prior to the beginning of the fiscal year on October 1st. Continuing with their commitment to robust funding, NIH received another \$2 billion increase and increased funds to combat the opioid crisis.

Senators are currently working on the FY 2020 DoD appropriations bill and deciding which conditions will be included on the next PRMRP eligible conditions list. At this critical juncture, please reach out to the offices of

your Senators and ask that they "support the inclusion of Guillain-Barré Syndrome in the DoD PRMRP's eligible conditions list in FY 2020."

### TAKE ACTION

- E-mail the Foundation's Washington Representative, Philip Goglas II, at [Goglas@hmcw.org](mailto:Goglas@hmcw.org) and let him know that you would like to reach out to your Senator in this regard. Please include the state you live in in your e-mail as Phil will use this information to identify your Senator and their appropriate staffer.
- If you are well-acquainted with the staff in your Senator's office, please feel free to send them a personal e-mail or coordinated group message through Phil (we want to make sure they do not receive multiple or overwhelming e-mails on this issue)."
- For more information contact Advocacy Manager, Chelsey Fix at [Chelsey.fix@gb-cidp.org](mailto:Chelsey.fix@gb-cidp.org).

## IN APPRECIATION OF PLASMA DONORS

By **HONORABLE JOHN GARAMENDI** of California in the house of representatives | Tuesday, February 5, 2019

*From the Congressional Record Online through the Government Publishing Office [www.gpo.gov]*

**MR. GARAMENDI:** Madam Speaker, I rise today to recognize the importance of donating plasma and to applaud those individuals that make the commitment to be a plasma donor. Many Americans are impacted by rare, serious, and sometimes life-threatening medical conditions that are effectively managed by therapies derived from donated plasma. Patients affected by alpha-1 antitrypsin deficiency, chronic inflammatory demyelinating polyneuropathy, hemophilia, hereditary angioedema, platelet disorders, primary immunodeficiency diseases, as well as other communities rely on plasma-derived therapies. For many of these patients, plasma-derived therapies represent life-sustaining or life-improving medicine

that is only available and accessible as a result of plasma donors. Moreover, these therapies represent the cutting-edge of medicine and it often takes dozens of donations to prepare one course of treatment for a single patient.

These communities are collectively represented by the American Plasma Users Coalition, which works on policy issues to protect the safety of plasma donors and plasma products, and to ensure an adequate supply of plasma donations to meet the medical needs of patients. As science advances and we are better able to diagnose these conditions and treat additional conditions due to breakthroughs with plasma-derived therapies, we will need more Americans

to make the important choice to donate plasma to ensure all patients continue to have access to essential treatments. Many of us have already made the commitment to be either an occasional or regular plasma donor. Often times, this decision stems from knowing a patient who relies on plasma-derived therapies and understanding the tremendous impact a simple donation has on their health and the well-being of their family. Plasma donors come from all walks-of-life and all backgrounds, but to the patient community they are everyday heroes. Madam Speaker, let us recognize the contributions of plasma donors while calling attention to the importance of plasma donation.





## FIND A CHAPTER MEETING NEAR YOU!

Chapter meetings are a great opportunity to share your story with others, learn more about your condition, and build a local support network.

3.23.2019	Fort Myers, FL
3.30.2019	Asheville, NC
4.6.2019	Alexandria, VA
4.6.2019	Raleigh, NC
4.7.2019	Greenwich, CT
4.13.2019	Hackettstown, NJ
4.20.2019	Phoenix, AZ
4.20.2019	Roanoke, VA
4.27.2019	Twin Cities, MN
5.4.2019	Albuquerque, NM
6.1.2019	Conshohocken, PA
6.1.2019	Lebanon, NH
6.15.2019	Columbus, OH

**Announcing, new international GBS|CIDP Chapters:**  
Denmark and Hungary!



## Why Do I Volunteer?

There is not greater way to express the dedication and passion of our GBS|CIDP volunteers than to share their answer, in their own words, to a singular question: Why do you volunteer?

Hugs & gratitude to Regional Director and 2018 Benson Volunteer Award Recipient, Jim Yadlon, for sharing the inspiring words in his "Why hold a chapter meeting" letter to the volunteers in his region.

## WHY HOLD A CHAPTER MEETING?

My name is Jim Yadlon and I am the Liaison for Central NJ in the Northeast US Region of the GBS|CIDP Foundation. I have hosted two meetings per year, every year since 2011.

In my role as a volunteer liaison, it is my belief that it is my responsibility to host one or two meetings per year for my Chapter members. I have approximately 500 members in my area who have suffered with the hardships of GBS or CIDP. But the main reason that I do two meetings per year is that during each meeting, thirty five to fifty attendees; patients, caregivers, pharmacy representatives and even a neuromuscular neurologist (*she amazingly attends every meeting*) receive critical knowledge for living and coping with GBS, CIDP and MMN as well as intangibles that cannot be measured. They receive the hugs of care and understanding from fellow patients and caregivers who comprehend exactly what they are going through, daily life occurrences that no one else can possibly understand and the difficulties of living with these devastating conditions. The only people who know what it is like to be in pain or to not be able to walk or to not be able to perform their jobs anymore; to suddenly be burdened with debilitating financial issues and to have to deal with cruel and uncaring insurance companies (who think they have the right to make decisions about your medical care!), are the people in the room – the patients and caregivers who sit shoulder to shoulder for two or three hours, twice per year. We have a cadre of regular attendees who like to come for every meeting but the majority of attendees are newcomers who have been recently struck down with GBS or CIDP and who are seeking answers to their life-changing new normal.

We all know that each case of GBS and CIDP is as unique in fruition as each snowflake is a one of a kind. Yet, each patient in a GBS|CIDP Foundation Meeting feels each other's pain and the struggles of each other's life. When the clock strikes noon and my meetings close out, another

## VOLUNTEERS NEEDED IN:

Coastal Georgia, West Virginia, Southeastern Florida, Miami, Alaska, Hawaii

continued ▶

hour passes before everyone has left the room, no one wants to leave anyone behind, and questions unasked. Stories of hardship and frustration are heard around the room, many questions fly in the air as each patient or caregiver wants to find new ways to live their lives just a little better. Many will pick up a tip or two about new ways to do their care and some will walk away still a bit frustrated by their situation but everyone feels the love in the room and hugs (lots of hugs!) and well wishes are exchanged. Despite the enormous struggles, everyone feels a weight lifted off of their shoulders as they now know that they are not alone.

I have a lot of help when I plan and execute meetings. Kelly McCoy, the Foundation's Outreach Manager coordinates all of the necessary details from her office and sends me all of the Foundation supplies that I need for the meeting. I will pick up a few cases of water and some cookies and pastries the day before.

I am blessed with a caring family and my wife-caregiver helps me at every meeting, even though it is still very difficult for her to listen to the stories after forty five years. She still has flashbacks of me in the ICU and she will have to step back from the room and take a deep breath. My daughters come to every meeting and help and listen and learn and give their perspectives on being supporters. My daughters were left speechless after their first meeting as they knew little of their parent's experiences with GBS. They learned something positive about their own family history and learned how their parents dealt with GBS. They now know how GBS or CIDP affects so many lives. They love attending the meetings and helping all of the patients and caregivers who come and look for guidance.

I admit that I am nervous for weeks ahead of my meetings as I want everyone who attends to benefit from the speakers and then sharing their experiences and learning as much as they can. I use the same room each time and as each meeting occurs I learn new ways to do future meetings more efficiently and effectively. Holding chapter meetings can be a nerve wracking and stressful experience, but the importance of regular meetings cannot be overstated. Our members rely on the GBS|CIDP Foundation Liaisons to guide them through their time with GBS or

CIDP and to be there regularly with new information and support. They benefit greatly from telling their stories to their peers and receiving feedback from their fellow patients. The internet provides a valuable service to our members as sites like Facebook and the GBS|CIDP Foundation website provide a huge service for sharing and learning how others cope. But, face to face encounters are by far the most effective way to get relief, knowledge and the opportunity to share your experiences and find comfort and understanding from your fellow patients and caregivers.

Holding regular meetings can cause some anxiety as you go about preparing all of the details - you want everything to come out perfectly and your room to be filled with patients and caregivers who want to listen and learn. Finding a speaker is one of the harder tasks but Kelly has quite a few options for you and make that job easier. Finding a suitable room and setting the date should be your first actions but once that is completed, it's downhill from there, as all of the pieces will begin to fall in line. How will you promote your meetings? You may not know that the GBS|CIDP Foundation office does all of the announcements and mailings.

But when the meetings are over, I call the feeling of accomplishment of a successful meeting (and all meetings are successful), "Meeting Euphoria". Whether you have five or fifty attendees, I guarantee you have that "feel good" feeling of knowing that you helped your member patients and caregivers, just a bit, and you know that you have opened doors for your attendees to go forward and help themselves live better lives. They now know that fellow patients and caregivers and the GBS|CIDP Foundation are with them and ready, willing and able to help them in any way possible.

*Go forth and do meetings! Patients are waiting for you!*

**THANK YOU KINDLY,  
JIM**

If you are interested in holding chapter meetings in your area or volunteering for the GBS|CIDP Foundation please contact Kelly McCoy at [kelly.mccoy@gbs-cidp.org](mailto:kelly.mccoy@gbs-cidp.org).

## You Made it Happen!

Thanks to your donations and participation in the GBS|CIDP Foundation Walk & Roll Program, the Foundation reached its 2018 goal of **\$150,000** and fully funded three grants for research! Will we reach our goal of funding \$200,000 (4 research grants) in 2019? Join us and see! **Volunteers needed in San Diego, Boston and Chicago!**



### 2019 WALK & ROLL SCHEDULE (to date)

<b>4.13.2019</b>	<b>Charleston, SC</b>
<b>4.27.2019</b>	<b>Washington, DC</b>
<b>6.1.2019</b>	<b>Twin Cities</b>
<b>6.1.2019</b>	<b>San Francisco, CA</b>
<b>6.2.2019</b>	<b>Philadelphia, PA</b>
<b>6.9.2019</b>	<b>New Jersey</b>
<b>6.22.2019</b>	<b>Houston, TX</b>
<b>9.7.2019</b>	<b>Myrtle Beach, SC</b>
<b>9.14.2019</b>	<b>Staten Island</b>
<b>9.21.2019</b>	<b>Pittsburgh, PA</b>

### More Fall Walk & Roll Dates Coming Soon!

If you are interested in hosting a walk or forming a walk team, contact Walk Program Manager, Jessica McManus at [Jessica.mcmanus@gbs-cidp.org](mailto:Jessica.mcmanus@gbs-cidp.org). More information at: <https://www.gbs-cidp.org/volunteer/walk-and-roll/>



# Meet CIDP Patient and New Orleans Iron Man, Trent Fielder

Recently we had the privilege to connect with Trent Fielder and learned why and how he continues to challenge himself both physically and mentally, and why he believes,

*“We all have the ability to inspire if we live our lives with our spirit first.”*

## WHEN WERE YOU DIAGNOSED?

December 16, 2011.

## WHEN & WHY WERE YOU INSPIRED TO TRAIN FOR IRON MAN?

I was part of a unique rehabilitation program called the Adaptive Training Foundation ([www.adaptivetrainingfoundation.org](http://www.adaptivetrainingfoundation.org)).

I was accepted into their Class 10 in the fall of 2017. The large majority of those who are in the program are wounded veterans. As I came to know them and their courage, one organization also became dear to my heart. #22Kill is an organization dedicated to ending veteran suicide. Every day 22 veterans kill themselves. They have been through so much. It became clear to me what I needed to do and how to bring attention to their suffering. I blurted out that I was going to do an Ironman.

It was a calling from the very beginning. It expanded to more than just 22Kill and became a calling for all who suffer. We, as a country and even beyond the borders, are suffering. We have lost sight of how important it is to help others and share the burden of suffering. We isolate ourselves, as is common, because we think no one can understand. The reality is suffering is universal and so is healing if we will just reach out to each other.

Every day I trained, I prayed for other people. I had an open dialogue with God for hours each day about other people. Veterans that had died, police officers and firemen that I had met whose eyes told a story. I never made a single day about me only others. As a result,

I became stronger every day. There was never any fear, only determination to give hope back to people.

## WHAT TYPE OF TRAINING DID YOU DO?

It consisted of swimming, hand bike and racing wheelchair. I could not afford any equipment so I was blessed with equipment to borrow and train with.

Swimming was always the hardest for me because, due to the complications I have experienced, I don't have full lung capacity and irregular breathing causes panic due to the embolisms I had in 2014. I had to find a way to control it so I found an underwater IPOD and headphones through Underwater Audio. This allowed me to use specific songs that gave me cadence to my breathing and motions. I knew when to breathe in or out based on the rhythm. As I became stronger, I could go longer distances, finally reaching and maintaining about 1.4-1.5 miles. The race distance is 1.2 but it is open water so much more difficult.

The handbike was a harder transition because the bike was meant for someone else and I used a device called a Compu-trainer. This device utilized a computer and equipment attached to the bike to simulate different types of races and conditions. Once I was able to do it, I practiced about 3 days a week on it, eventually getting up to 40 miles. Hydration was so crucial and a diet for during the race. I dropped about 25 lbs. and adjusted patterns to keep strength in my shoulders. The racing chair was also borrowed but I was able to make it work much easier.

## WHEN, WHERE WAS THE COMPETITION?

October 21 in New Orleans, LA

## WHAT WAS IT LIKE TO CROSS THE FINISH LINE?

I was so focused on trying to make the correct pattern work (since I can't feel my legs, I had to generate enough vibration so I would have the proprioception. I had practiced



this for months but I had more trouble than I expected because I couldn't fully feel my hips. When I tore my rotator cuffs early on, it became a matter of will but the calling was clear. I heard God's voice to stand at .2 miles. My team and many others helped me. A police officer who had followed me had driven ahead letting people know I was going to walk so there were a large amount of people.

As I turned the corner, I could hear my kid's voices so it gave me the courage to do it. The slower I move the less feeling I have in my hips because the vibration is diminished. My handler and new friend who drove down from OK after hearing my story, Adam Bailey, is the one who caught me. The powerful thing I will never forget is I could have gone longer. More miles on the bike, more on the chair which I still believe is due to the focus being on others. My 7 year old twins were right there. My son looked right at me and asked, "Daddy, does this mean you can play soccer with me?"

## WHAT ARE YOUR PLANS FOR FUTURE COMPETITIONS?

Many people who have been suffering, even some with GBS, those fighting depression and suicidal thoughts, want to train and race. Some want to race with me but others just want to experience a new perspective on life. The calling is the same but with momentum. The plan is to race in Galveston in April and then again in July for the NYC Paratriathlon Championships. We all have the ability to inspire if we live our lives with our spirit first.



## Self-Care for the Care Giver

### *Nicety or Necessity?*

Jane Meier Hamilton MSN, RN

**How are you doing?** During the years when my husband and parents needed care, I was often depressed and worn down by juggling sad situations and endless responsibilities. There was never enough energy or time. I'd fall into bed each night, exhausted by all I'd done and worried about all that was yet to do. Overloaded with so many demands, my needs often fell to the bottom of the priority list.

If you're a caregiver, you know caring for others isn't easy. Yes, it's a meaningful and important, kind and generous thing to do. But many times it's demanding, difficult and downright dreadful. Has it taken a toll on your physical or mental health, on your personal finances, family relationships or work-life? If so, you're not alone.

Here are some facts: There are over 65 million family caregivers in America, nearly 40% of all adults. More than 70% of caregivers are employed, at least part time. On top of time at work, caregivers spend an average 20 hours/week for 4.6 years giving care. It's not hard to see why over half report moderate to high levels of caregiver stress, which erodes the immune system and increases the likelihood of disease, depression or hospitalization. 20 to 30% of family caregivers use prescription drugs for depression, anxiety, and insomnia. That's 2-3 times as often as the general population. These facts tell us one important thing: All of us who give care need to take care.

As a nurse, I know this is true. Although I teach people about self-care, sometimes I don't practice what I preach. Why? There are several reasons. My quick answer: I have no time! 21st century life runs at a fast pace: 24/7/365. There are too many things to do and too little time. Something has to give, and usually it's my self-care.

Guilt is another reason why I don't take care. Others' concerns seem more important than mine, or they have more needs and fewer resources. They're sick, vulnerable and needy; I'm healthy, strong and capable. How can I not help?

Finally, sometimes I start to think self-care doesn't matter. I deny the consequences of chronic stress and tell myself I can absorb the pressure, live without a break, or a walk or some time to be with friends. I minimize and deny being overloaded, and overlook the cost of over-functioning. I turn a blind eye to the health risks, and the price I pay in my relationships and work-life.

Thoughts, feelings and choices like these push my needs down and off my priority list. Self-care becomes an unattainable nicety instead of an undeniable necessity. This is not healthy.

How about for you; is self-care a nicety or a necessity? No matter how small, whatever action you take to care for yourself in a healthy way will be good for both you and your loved ones. As you do so much for others, remember to take good care of yourself, too...Jane

### ARE YOU A CARE GIVER FOR A PATIENT WITH GBS|CIDP OR A VARIANT OF THE CONDITION?

Stay tuned in 2019 as we rollout our new resource Guide for Care Givers. Interested in participating in a Care Giver Focus Group? Contact Director of Marketing and Communications, Maureen Neville – [Maureen.neville@gbs-cidp.org](mailto:Maureen.neville@gbs-cidp.org).

Jane Meier Hamilton MSN, RN, is the author of *The Caregiver's Guide to Self-Care* and a 35-year nursing veteran who has also been a family caregiver for 20 years. In addition to a range of clinical and teaching experiences, she has published numerous journal articles and co-authored *Survival Skills for the New Nurse* (JB Lippincott, 1986).

Jane will be joining the GBS|CIDP Foundation's roster of professional presenters at the Princeton Regional Conference on March 9, 2019. Her session topic is: "This is our New Normal...Now What?!" – a supportive and informative presentation for both patients and caregivers.

## GBS|CIDP Foundation International Earns Coveted 4-Star Rating from Charity Navigator

GBS|CIDP Foundation International's strong financial health and commitment to accountability and transparency have earned it a 4-star rating from Charity Navigator, America's largest independent charity evaluator. This is the 7th consecutive time that GBS|CIDP Foundation International has earned this top distinction.



Since 2002, using objective analysis, Charity Navigator has awarded only the most fiscally responsible organizations a 4-star rating. In 2011, Charity Navigator added 17 metrics, focused on governance and ethical practices as well as measures of openness, to its ratings methodology. These Accountability & Transparency metrics, which account for 50 percent of a charity's overall rating, reveal which charities operate in accordance with industry best practices and whether they are open with their donors and stakeholders. On June 1, 2016, Charity Navigator upgraded their methodology for rating each charity's financial health with CN 2.1. These enhancements further substantiates the financial health of their four star charities.

GBS|CIDP Foundation International's exceptional 4-star rating sets it apart from its peers and demonstrates its trustworthiness to the public," according to Michael Thatcher, President & CEO of Charity Navigator. "Only a quarter of charities rated by Charity Navigator receive the distinction of our 4-star rating. This adds GBS|CIDP Foundation International to a preeminent group of charities working to overcome our world's most pressing challenges. Based on its 4-star rating, people can trust that their donations are going to a financially responsible and ethical charity when they decide to support GBS|CIDP Foundation International."

"It's important our donors trust that we're using their donations wisely to accomplish our mission of supporting, educating, funding research, and advocating for patients coping with Guillain-Barre Syndrome (GBS), CIDP, or variants of the condition," said Lisa Butler, Executive Director. "Our 4-star Charity Navigator rating demonstrates to our supporters our good governance and financial accountability."

GBS|CIDP Foundation International's rating and other information about charitable giving are available free of charge on [www.charitynavigator.org](http://www.charitynavigator.org). More-detailed information about GBS|CIDP Foundation International's rating is available to Charity Navigator site visitors who become registered users, another free service.

## HAPPY SPRING! THE GRASS IS GROWING AND SO ARE WE!

*Please join us in welcoming two new members to the GBS|CIDP home office staff in Conshohocken, PA!*

### Advocacy Manager CHELSEY FIX

Chelsey comes to GBS-CIDP Foundation International as the Advocacy Manager. She previously held the title of Associate Director, Industry and Government Relations at another rare disease patient advocacy organization. Chelsey brings 4 1/2 years of experience in working with rare disease patient communities to advocate to the federal and state government for research funding and fair healthcare regulations. Chelsey holds an MPH degree from Temple University, and is passionate about the relationship between research, policy/laws, and the community. In her spare time, Chelsey loves reading mystery/thriller novels and walking her American Bulldog, Moose. Drop a note to say hello at [Chelsey.fix@gsb-cidp.org](mailto:Chelsey.fix@gsb-cidp.org).



### Event and Programs Associate MEG FRANCESCANGELI

Meg started with the foundation in January 2019 as the Event and Programs Associate. She has a BA in Communications with a concentration in Public Relations and Advertising from Alvernia University. She will be bringing her knowledge of communications and event management to her role at the GBS-CIDP Foundation. In joining the Foundation, Meg looks forward to connecting with patients and families who have been affected by GBS-CIDP. She enjoys the beach, sports, and spending time with her family, friends, and her dog Boomer. Drop a note to say hello at [Meg.francescangeli@gsb-cidp.org](mailto:Meg.francescangeli@gsb-cidp.org).



welcome



CHANGE SERVICE REQUESTED

SUPPORT EDUCATION RESEARCH ADVOCACY SUPPORT EDUCATION RESEARCH ADVOCACY

**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.**

## MARK YOUR 2020 CALENDARS!

We are delighted to announce that the 16th GBS|CIDP International Patient Symposium will be held **October 1-3, 2020** at the Hilton Mark Alexandria, Virginia!

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

### DIAGNOSED WITH MMN?

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  
lisa.butler@gb-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@gb-cidp.org

### LOOKING FOR A 20-SOMETHING CONTACT?

Kyle Van Mouwerik  
kyle.vanmouwerik@gb-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, local level,  
contact Advocacy Manager Chelsey Fix,  
Chelsey.fix@gb-cidp.org to sign up.

### 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