

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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NEW!
October 3, 2020
 10am-2pm (EST)

2020 VIRTUAL SUMMIT

2020 Symposium News & Updates

Changing times requires changing minds, (and changing plans). In addition to providing support and education to patients and caregivers around the world, the safety and welfare of our communities is one of our top priorities. Therefore, due to the COVID-19 pandemic, we are announcing the postponement of the 2020 DC Symposium. Currently, a new date is still to be determined. If you are registered for the 2020 DC Symposium, and plan to attend in 2021, consider yourself registered for the new event date. If you can't make it, we can offer a refund of your registration fee. For more information, please contact Events and Outreach Manager, Kelly McCoy, kelly.mccoy@gbs-cidp.org.

Although our in-person event has been postponed, our plan to offer extraordinary presentations, programs, and opportunities to connect has not! Please join us for our NEW virtual Summit on October 3rd, 2020. Mark your calendars for an inspiring LIVE and FREE online event featuring the very same medical & wellness experts that host our in-person symposia and regional events. Featuring sessions like What's New in Research, Treatments and Clinical Trials, to Commonly Asked Questions for GBS, CIDP and Variants to Tools for Managing Stress, Youth & Teens with GBS|CIDP and Yoga from Your Chair, we will be offering live virtual programming throughout the entire Virtual Summit from 10am-2pm (EST). Registration will open July 25th, 2020 — stay tuned at gbs-cidp.org for more details. **We hope to “see” you in October!**



I'M STILL DANCING by Isabella Herman, page 9

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,

In the uncertain times of a global health crisis, two things have remained certain — our dedication to the needs of the GBS|CIDP patient community and the generosity of our supporters who remain steadfast in their belief in our mission. We want to send our sincere gratitude to those who donated to help offset the cost of increasing COVID-19 resources, like our special edition newsletter and our technology infrastructure, in order for us to operate and excel in this new virtual world.

Thanks to your support, we have hosted seven virtual “Ask the Experts” webinars covering topics from the role of plasma in the COVID-19 response to ways to naturally increase your immune system. Each episode has averaged nearly 750 views! We have also developed an online portal for COVID-19 news and updates, hosted our first few virtual Chapter Meetings, and even our first virtual Walk & Roll for New Jersey, raising over \$10,000.

Like many, we have all been trying to see the silver lining of this unique time. For us, we’ve been able to connect with a larger percentage of our patient community thanks to this virtual education programming. That would not be possible without our donors – so thank you!

Sincerely,

Lisa

Lisa Butler, *Executive Director*



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 or by emailing info@gbs-cidp.org.

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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.

October is Advocacy Month

Like so many other plans and programs, our 2020 Hill Day has taken on a whole new look and will now be a virtual Month of Action! This October, we encourage you to raise your voice on Capitol Hill for the GBS|CIDP community, right from your own home. Our Virtual "Month of Action" kicks off October 5th when we will outline the 3 easy steps you can do from home, including online virtual "Hill Day" training (at your convenience), speaking with representatives and their staff, key advocacy collateral, and incentives to encourage you every "step" of the way. Join the list of over 200 GBS|CIDP advocates who have turned the spotlight on legislation and policy issues that impact access to therapy and the quality of healthcare for our patient community. Find out more at: www.gbs-cidp.org/advocacy/



First NJ Virtual Walk & Roll!

June 7, 2020 celebrated the 7th year for the NJ Walk & Roll, chaired by volunteer Sue Salzmänn. And this year, NJ also kicked off our very first Regional Virtual Walk & Roll, raising over \$10k! There were nearly 30 virtual walkers who participated in a live Zoom Walk, including industry representatives, Global Medical Advisor, Dr. Maureen Su, members of the local community, and Foundation staff. For more information on hosting or attending a virtual Walk & Roll, please contact Walk Coordinator, Pam Franks at pamela.franks@gbs-cidp.org.



Monthly Virtual Coffee Chats Continue

Coffee Chats continue on Thursday, September 17, when we will be inviting parents of youth & teens with GBS/CIDP or a variant of the condition, to join us for a casual & supportive Zoom Coffee Chat (coffee optional!). The GBS|CIDP Foundation Coffee Chats are a "no pressure" way to meet others in a similar situation, connect with staff and volunteers from the Foundation, ask questions, share tips, and have some fun too. Check your email and/or stay tuned on our social media channels or website <https://www.gbs-cidp.org/support/news/>, for registration details. Seating is limited.



BRAVO!

In total, the NJ Walk has raised over \$100,000 for GBS|CIDP research since 2013. We are deeply grateful for the continued commitment, enthusiasm, and kindness of the entire Salzmänn Family and their community. Thank You!



Merrilyn Macurak of South Carolina holds first Virtual Chapter Meeting



On May 7, Regional Director Merrilyn Macurak along with Events & Outreach Manager, Kelly McCoy, co-hosted our first Virtual Chapter Meeting, with special guest and social worker, Chrissie Jenkins. Twenty-three people from the Southeast region signed onto to Zoom for a lively, supportive and informative virtual meeting. "The Foundation looks forward to our in-person meetings one day hopefully soon, however our virtual chapter meetings really help patients to stay connected and supported in these very challenging times. They are free, and all are invited," said McCoy. Please also see our calendar of events for virtual chapter meetings that are currently scheduled.

INTERESTED IN HOSTING OR ATTENDING A VIRTUAL CHAPTER MEETING?

Chapter meetings are an ideal way to learn more about coping with your condition as well as meet other patients and caregivers in similar situations right in your own region. If you are interested in hosting a virtual chapter meeting, please contact Events & Outreach Manager, Kelly McCoy, kelly.mccoy@gbs-cidp.org, as she is happy to assist and provide step-by-guidance on setting up a successful virtual support event.



GBS|CIDP Foundation Announces New Chair of GMAB

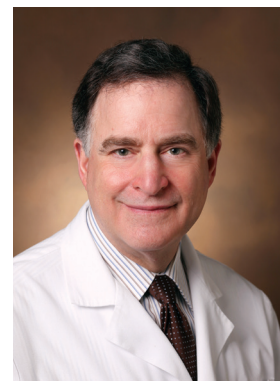
Peter Donofrio, M.D.

Neurology Vanderbilt University Medical Center

Photo by Anne Rayner; VU

On June 1, 2020, Dr.

Ken Gorson officially passed the chairmanship to Dr. Peter Donofrio as Chairman of our esteemed Global Medical Advisory Board (GMAB). We thank Dr. Gorson for his guidance and many contributions in the past three years including the leadership of the US International



Dr. Peter Donofrio

Guillain-Barre Syndrome Outcome (IGOS) program, the Zika Virus Outbreak and its effect on the GBS|CIDP community, and now our COVID-19 response. Dr. Gorson has led the current reconfiguration of the GMAB, and recently participated in the three-year strategic plan for the Foundation which included a new vision for our research funding. Dr. Gorson was the first recipient of the Benson volunteer award for our pillar of education and always inspires our patients with presentations at Foundation events. We are honored by Dr. Gorson's commitment and vision and are thankful that he will still hold a seat on our GMAB.

We are now honored to announce our new chair, Dr. Peter Donofrio, Professor of Neurology at Vanderbilt University Medical Center, who has graciously accepted this new role with intent and enthusiasm. Dr. Donofrio has been an active and influential member of the GMAB for the past four years. He is a frequent presenter at Foundation conferences and symposia, as well as a featured guest in our virtual educational series.

Please join us in thanking Dr. Gorson for his leadership and commitment for the past three years, and welcoming Dr. Donofrio to the role of Chairman of the GBS|CIDP Foundation Global Medical Advisory Board (GMAB).

GBS | CIDP
Foundation International

This August, challenge yourself to 30 days of wellness activities while raising Funds for Research, too! Whether you're a sportster, yogi, or a professional curler (curler = someone who is proficient of curling up with a good beach read), there are so many ways to stay positive and healthy while supporting the GBS|CIDP community too. **Our goal is to reach 100 participants and raise \$50,000 for research.** We are encouraging fundraisers from around the globe to raise money for research, learn and share wellness tips, all while raising awareness for GBS and CIDP. We'll even provide a 30-day calendar of fun activities to keep you motivated, happy and healthy... all month long. It's as easy as 1-2-3...

Register at <https://www.gbs-cidp.org/30daychallenge/> for your own personal fundraising page. Upon registration, participants will be provided with step-by-step instructions on how to personalize their fundraising page with wellness pictures, personal stories and a fundraising goal.

Share your page, starting August 1st, with family, friends, neighbors and coworkers! We'll provide templates for social media posts and emails and all you will have to do is add your personal page link. Voila! You'll be fundraising in minutes!

Share some more! Throughout the 30-Day Challenge, fundraisers will be given various incentives based on their fundraising activity:

- All fundraisers will receive a GBS|CIDP car magnet upon registration and a GBS|CIDP car cup holder coaster during the campaign.
- When you reach the \$50 milestone, you will receive a GBS|CIDP face mask.
- When you reach the \$250 milestone, you will receive a RAISEWELL tee shirt.
- When you reach the \$500 milestone, you will receive a GBS|CIDP 24 oz. water bottle.
- **Grand prize will be a FitBit Inspire, awarded to the Top Fundraiser and to the Team Captain with most members!**

www.gbs-cidp.org/30daychallenge/



LAST NOTE

And again, all funds raised will be used to support the GBS|CIDP research grant program. Are you ready to Raise Well? Go to <https://www.gbs-cidp.org/30daychallenge/> for more details, or if you have questions, contact Development Director Madeline Miller at madeline.miller@gbs-cidp.org.



2020 GBS|CIDP FOUNDATION INTERNATIONAL RESEARCH GRANTS ANNOUNCED!

Research grants are made possible through the benevolence of many sources, including the Helen S. Manheimer Research Fund, contributions from individuals or variants, our national Walk & Roll fundraising program, and who have been personally touched by GBS, CIDP, or variants, and by several commercial sources. Through the generosity of these contributors, to whom the Foundation is most grateful, we are able continue our Research Grant Program for the 14th consecutive year.

2020 RESEARCH GRANT RECIPIENTS INCLUDE:

NUMBER ONE



PRINCIPAL INVESTIGATORS

Frank Baas, MD, PhD, Prof
*Leiden University Medical Center Leiden,
The Netherlands*

TITLE OF PROJECT

Inhibition of the terminal complement pathway in EAN with a novel monoclonal antibody targeting C6

SYNOPSIS

In this project, we will show whether blockade of C6 is an attractive target, as generation of MAC is prevented, but in contrast to C5-inhibition, the C5a-induced pathways remain unaffected.

NUMBER TWO



PRINCIPAL INVESTIGATORS

Natalia Gonzalez, MD and
Lisa Hobson-Webb, MD
Duke University Medical Center

TITLE OF PROJECT

Nerve Ultrasound for Diagnosis and Prognosis of GBS

SYNOPSIS

Delay in Guillain-Barré syndrome (GBS) diagnosis and treatment is associated with higher frequency of intubation and residual weakness. We have two main objectives for this pilot study:

(1) to define peripheral nerve ultrasound (US) measures diagnostic of GBS in the acute setting and (2) to identify peripheral nerve US biomarkers of GBS prognosis.

NUMBER THREE



PRINCIPAL INVESTIGATORS

Luis Querol MD PhD
Hospital de la Santa Creu i Sant Pau

TITLE OF PROJECT

Precision medicine in chronic inflammatory neuropathy assessment

SYNOPSIS

The aim of this project is to find precise tools that help optimize patient monitoring in daily clinical practice by using two objective measures of disease activity: a wearable system to monitor gait parameters, and serum neurofilament levels, a novel blood biomarker of neuronal damage used in other neurological diseases. If successful, this project will provide better tools to assess disease status and treatment effect and, ultimately, more precision in neurological assessment that help improve patient care and clinical trial outcomes. Continued...

NUMBERFOUR



PRINCIPAL INVESTIGATORS

Professor Michael Lunn
Institute of Neurology, University College London (UCL)

TITLE OF PROJECT

Validation of novel biomarkers in acquired inflammatory neuropathies

SYNOPSIS

Inflammatory neuropathies are a heterogeneous group of acquired nerve-damaging disorders, which commonly have life-changing implications for sufferers. The most common chronic immune-mediated form, CIDP, has an estimated prevalence of 3 per 100,000 in the United Kingdom. To resolve these unmet needs, we will identify novel POEMS, GBS and CIDP biomarker.

NUMBERFIVE



PRINCIPAL INVESTIGATORS

Amro Stino, MD
University of Michigan Medical School

TITLE OF PROJECT

Lenalidomide in anti-MAG Neuropathy: Phase 1b Study

SYNOPSIS

We aim to assess the safety profile and maximum tolerated dose of Lenalidomide in anti-MAG neuropathy. Drug efficacy will serve as secondary outcome. Lenalidomide is current standard of care therapy in the treatment of paraproteinemic neuropathies, namely osteosclerotic myeloma (POEMS syndrome), amyloid, and multiple myeloma. Its safety and efficacy in anti-MAG IgM associated demyelinating neuropathy (DADS syndrome) has not been previously explored.

NUMBERSIX



PRINCIPAL INVESTIGATORS

Camiel Verhamme MD PhD
Amsterdam University Medical Centers, location AMC, Amsterdam, the Netherlands

TITLE OF PROJECT

Optimizing (electro) diagnosis in CIDP with machine learning

SYNOPSIS

Despite current diagnostic criteria sets for CIDP, the rate of misdiagnosis is high. In this project, our aim is to develop machine learning (ML) algorithms with improved (electro) diagnostic accuracy for CIDP as compared to current criteria sets.

NUMBERSEVEN



PRINCIPAL INVESTIGATORS

Luuk Wieske MD PhD
Amsterdam University Medical Centers, location AMC, Amsterdam, the Netherlands

TITLE OF PROJECT

Proteomics based discovery of disease activity biomarkers in chronic inflammatory demyelinating polyneuropathy

SYNOPSIS

Patients suffering from and clinicians treating chronic inflammatory demyelinating polyneuropathy (CIDP) are currently lacking disease activity biomarkers that can provide objective guidance on when to start and stop treatment. Serum proteins may serve as quantitative, responsive and easily obtainable disease activity biomarkers. In this project, our aim is to identify potential disease activity biomarkers by screening a focused blood proteome comprised of 184 proteins related to the nervous system and inflammation.

GMAB AT NIH STATE OF SCIENCE VIDEOCAST FOR AFM & GBS

GMAB members Dr. Maureen Su and Dr. Kazim Sheikh joined representatives from the NIH and the other leading researchers on May 7, 2020 for an NIH State of Science VideoCast. The purpose of the workshop was to bring together experts in research and treatment of two acute paralytic neurological conditions, acute flaccid myelitis (AFM) and Guillain-Barre Syndrome (GBS), to identify gaps in scientific knowledge that, if filled, could advance understanding of pathological mechanisms and accelerate the development of effective prevention and treatment strategies.

Full workshop can be viewed at <https://videocast.nih.gov/watch=37434>. Plans for an extended version of this session are underway. For questions contact chelsey.fix@gb-cidp.org.



Strategies for Building Resilience During Times of Change

By Dr. Julie Rowin

A publication from Dr. Julie Rowin's Blog Post found at: julierowinmd.com



While some people may have a difficult time accepting and adjusting to abrupt changes, others can not only adapt but, in fact, thrive. Resilient people are able to see what are perceived as “adverse” events as an opportunity to grow and branch out in new directions. How do you respond to change? If you are interested in embracing change and growth, then consider these strategies for helping you to build resilience.

1 Practice Gratitude and Optimism

Our brains naturally want to seek out problems. When all you see is negative, broaden your perspective by asking yourself, “What good has come about as a result of this adversity?” Practicing positive thinking does not mean ignoring the problem. It means understanding that setbacks are temporary and that you have the skills and abilities to combat the challenges you face. What you are dealing with may be difficult, but it’s important to remain hopeful and positive about a brighter future, so that you can move forward toward healing and ultimately growth. Need some help? Cognitive behavioral therapy (CBT) has been shown to be beneficial for coping and anxiety. Working with a therapist on relaxation techniques and to understand how negative thought patterns influence feelings and behaviors has been shown to be an effective way to build resilience. Many therapists are utilizing telehealth.

2 Cultivate Relationships

Remember that social distancing does not mean emotional distancing. Social support is one of the greatest alleviators of stress. Get creative about ways to stay connected

with friends and family during difficult times. Connectedness is fundamental to well-being. We are supposed to exist in community. The need for social connection is biologically hard-wired and it is necessary for health, both mental and physical. Keep connected with those who value you, with whom you can share information and have fun. It is important to surround yourself with people who support your ideas and give you a sense of peace, well-being, and resilience.

3 Practice Mindfulness in a Way That Speaks to You

During times of stress, it helps to pause and bring our attention to the present. In doing so, we often find that things are not as bad as they seem. Below are two activities that will help to practice mindfulness.

- Connect with nature. For many individuals connecting with nature can almost replace missed social connections. Get outside, walk in the park, start a garden. When you cannot get outdoors, bring nature indoors by making a small indoor green space. Even a plant or flowers can help! Taking more time to connect with nature will boost your mood and reduce stress.
- Deep breathing exercises and yoga poses are particularly helpful during stressful times. By practicing the slow forms of yoga such as yoga nidra, yin yoga or restorative yoga

2-3 times per week, you will notice improved anxiety levels and better resilience. You can find on-line yoga classes to do in your home, for example, The Yoga/Down Dog app is great and has free beginning, chair, nidra and restorative classes. Yoga Studio: Mind & Body has an extensive library of yoga poses, meditation and classes. In addition, many local yoga studios are doing on-line live classes and would love to have your business.

4 Exercise

Regular physical exercise protects against the emotional consequences of stress. Set a timer for 15 minutes a few times a day and move. Washing your windows counts, as does walking the dog or dancing to music! Utilize the resources offered online. The internet is filled with live stream workouts right now. Or try a work-out app like Johnson and Johnson 7-minute workout – you just need a wall and a chair!

Full article found at <https://www.gbs-cidp.org/6-strategies-for-building-resilience-during-times-of-change/>



Julie Rowin, MD
Integrative Neurology

I'm Still Dancing

By Isabella Herman

In March of 2013, I was a normal kid. Having just turned 10 years old, I was a ball of energy: always dancing and running around. My dreams of being a principal dancer were in full swing, and I was sure nothing could take that away from me. In April of that same year, this changed drastically. I began to experience loss of sensation and random collapses, not sure the cause or reason. By April 7th, the symptoms were severe enough to make my parents take me to the ER.

I remember waiting for what felt like forever in a room with uncomfortable plastic chairs and looking around to see all the other kids who were sick or hurt. There were crying babies and intimidating teenagers, but what I remember most was that none of them looked like me. I looked fine, like I was a perfectly healthy kid. After being taken to a room and asked a series of questions that my mom gracefully answered, the doctors did a standard neurological exam on me and admitted me to the hospital.

The next morning, I woke up early and was taken downstairs in a wheelchair to have a MRI and spinal tap that confirmed my initial diagnosis: Guillain-Barre Syndrome. None of my family had ever heard of this condition, but after some intense research, we were petrified.

After five rounds of IVIG and nine days in the hospital, I was transferred to an inpatient rehab facility where I spent five days before finally going home. Only days later, though, I started to decline, eventually becoming paralyzed from the waist down with weakness in my upper extremities and difficulty breathing. I was then sent back to the hospital for Plasmapheresis.

This whole process was tough on me — both physically and mentally. As a string-bean of a kid, my body took some time to recover from the initial placement of the catheter, and I had adverse reactions to the blood constantly going in and out of my body. For 16 days, I experienced the fear and pain of

treatment days, and the relief and temporary comfort of rest days. I vividly remember the doctors telling me that there was little chance that I'd walk again, much less dance. I was determined to prove them wrong.

After about a month in the hospital and some time again in inpatient rehab, I was released to go home, but the battle was far from over. I remained in a wheelchair for about 3 months, and continued physical therapy for a while after that. Other than a minor relapse in October 2013 (double vision only), I recovered pretty well, returning to what seemed like normal life.

The next few years I spent dancing and exploring different sports as I went through middle school. At one point, I was running cross country, playing basketball, competing in high jump at track meets, on the cheer squad, and dancing for fun. We thought that GBS was just a thing of the past, something that changed my life drastically, but that I was now free of.

We were wrong.

This time, the symptoms progressed much quicker, and it wasn't long before I was in a hospital bed, unable to move my lower body at all. The recovery was miraculous — thanks to the power of prayer and medicine, but it was that same month (October 2016) that I was diagnosed with Chronic Inflammatory Demyelinating Polyneuropathy. I was devastated.

I was put on prednisone and continued a mostly normal life for a few months, — still dancing, cheering, and playing basketball — but with the new year came some scary surprises. 2017 was filled with countless rounds of IVIG, long hospital stays, learning to walk (yet again), and many more hardships. However, I was still able to audition for my high school dance team — becoming one of the two freshmen who made the team. Though not as frequent as the struggles, the times when I was able to dance were worth every minute of pain.

In November of 2017, I received a cycle of plasmapheresis that would grant me almost an entire year in remission. I was able to



compete with my dance team, perform in our annual spring show, and dance to my full ability for almost the entirety of my sophomore football season. This period of freedom from treatments and relapses made it all the more difficult when I, inevitably, relapsed again in October of 2018.

Those 11 months of symptom-free bliss were the longest I have gone without experiencing symptoms. Since October of 2018, I've been on a rollercoaster of progression with this condition, and all I can do is be grateful for the time that I am at full strength and never take anything for granted.

I am now in my third year of high school drill team, preparing for officer tryouts later this spring or summer. Last May, I choreographed a dance called "Paralyzed" — telling my story and experiences with GBS/CIDP: <https://www.youtube.com/watch?v=Y8h8u1CQnWg>

Though this condition is easily the hardest thing I've ever had to go through - and I'm sure it will continue to be a battle for a long time, I am grateful for the lessons I've learned through my experiences. This has taught me that no one can take away my drive and determination, that nothing can take away who I am. Even when paralyzed in a hospital bed, I am still a passionate and dedicated dancer and athlete. I've also learned to be kind and compassionate to everyone I meet — you never know the battles they are fighting. Finally, I've learned to never take anything for granted. Whether it be walking, running a mile in athletics, or doing stamina kicks (the most painful part of any dance team practice), you never know when it could be taken away from you.

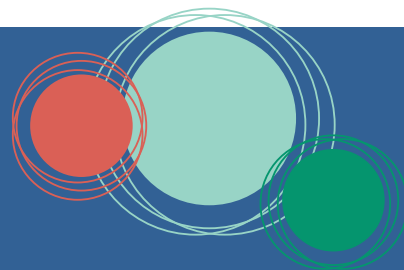
MORE ON ISABELLA'S STORY AT: WWW.BELLA226.BLOGSPOT.COM

Youth Teens and Young Adults (YTA)

The Sport of Staying Home

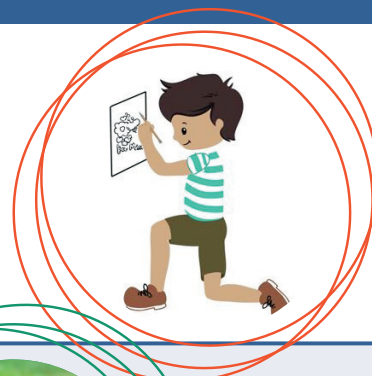
By Kaitlyn Lorant PT, DPT

For individuals with GBS or CIPD, rehabilitation is of the utmost importance. While in quarantine during the COVID-19 pandemic, it can be daunting to create new and engaging activities to maintain strength, flexibility, and aerobic endurance. This article compiles a list of some fun, yet feasible exercises and activities to do while at home. Before starting any new exercises, patients and families should always consult with their therapy and medical team to ensure the activity is safe to perform.



1 Let's target those legs! Parents — find a window or hang up some paper and place a step stool in front. Have your child perform step-ups onto the stool to reach for something stuck on the window or to color on the paper. My personal favorite is to use tape to stick balloons onto a window or a wall that are challenging to reach for. Encourage your child to perform 1 step up for every 1 minute of coloring or after grabbing each toy.

- This activity can also be performed in tall kneeling or half kneeling instead of standing.¹



2 Let's get outside (following social distancing guidelines)! Parents, if you have a kiddie pool, set it up in the backyard and put toys in the pool that will sink. Have your child stand in the pool and squat/bend down to grab the toys.

- Another idea in the pool is to have your child sit down and play “red light/green light” while kicking their legs in the water. Red light means stop, yellow light mean slow, green light means fast!



3 Let's move like an animal! Animal walks are one of the easiest exercises to implement and provide a high reward of working the whole body. These activities work best in an area with plenty of space and are something the whole family can participate in!



4 Let's get moving! This activity will require stickers, paper, and tape. Tape two pieces of paper to the floor about 6 feet apart. Start at one piece of paper and side shuffle to the other piece of paper and place a sticker on the paper. The side shuffle can be performed quickly or slowly. Make it a timed game and see how many stickers are on the pieces of paper after 3 minutes! For added difficulty, put a resistance band around the thighs or ankles!²



5 Let's do some yoga! Yoga is an activity for kids typically 8 years and older, and any skill level. It targets all muscles in the body and incorporates stretching! For younger kids, write different yoga poses on popsicle sticks and take turns picking sticks.

- For teens and young adults, many yoga studios and fitness apps offer free online classes! Remember when searching for a yoga class, look for the yoga instructor's credentials. Yoga Ed is a great online resource to start your search! (<https://academy.yogaed.com>)



¹ <https://images.app.goo.gl/vMn7MEvpK6beJRDR7> ² <https://www.pinkoatmeal.com/lower-body-strengthening-exercises-for-kids/>

Ask the Expert...

Featuring Dr. Peter Donofrio



WHAT IS THE LINK BETWEEN GUILLAIN-BARRÉ SYNDROME AND COVID-19?

As of Today (June 19, 2020), there are only about 15 reported cases in the world of people developing GBS after testing positive for COVID-19. Experts are still unsure if there will be a higher or lower incidence of GBS after COVID-19 infection; however, in a case report published this month in the *Journal of Clinical Neuroscience*, researchers concluded that GBS should be considered as a possible “neurological complication of infection with COVID-19.” We will need much more information in the future to determine how likely a person might develop GBS after a Covid-19 infection.

VIRTUAL “ASK THE EXPERTS” CONTINUES THROUGHOUT THE SUMMER, 2020!

Episode 6

COVID-19 Research Collaboration, as well as the role of plasma in the COVID-19 response, aired on June 19 and featured special guests Patrick Collins, Director of Healthcare Policy and External Affairs at CSL Behring, and Mittie Doyle, Vice President of Research & Development Immunology & Neurology at CSL Behring.

Episode 7

COVID-19 Research, as well as the role of plasma in the COVID-19 response – Part 2, aired on June 26, also was hosted by Lisa Butler, special guests from Grifols, including, Joe Zuraw, Sr. Director, Corporate Affairs, Vlasta Hakes, Director of Corporate Affairs and Nick Uzl, Associate Director, Corporate Affairs.

Episode 8

The Clinical Trial Process, from clinical development to market shelves. This episode, scheduled to air in late July, explores the unique relationship between research & advocacy, with Advocacy Manager, Chelsey Fix, and Foundation member and researcher, Lynn Rogers.

VIEW ALL VIRTUAL ASK THE EPISODES HERE:

<https://www.gbs-cidp.org/ask-the-expert-educational-series/>

As news of the global pandemic is still evolving, please note that details are subject to change with regard to COVID-19 legislation and research. Please continue to check [gbs-cidp.org/covid19/](https://www.gbs-cidp.org/covid19/) for the most recent updates.



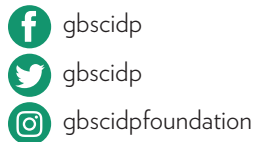
Estelle Benson Awarded 2020 Public Recognition Award for AANEM and special Tribute from the PNS

The AANEM's Public Recognition Award honors public figures, celebrities, or entities that have made extraordinary contributions toward increasing public awareness of muscle and nerve disorders. This year, because of her achievements in creating awareness and an avenue for support for those suffering from neuromuscular diseases, the AANEM Awards Committee has nominated Estelle Benson for the 2020 *Public Recognition Award*. Congratulations Estelle!

Additionally, on June 28th, the Peripheral Nerve Society (PNS) held their annual meeting (virtually), where Dr. David Cornblath honored Estelle with a very special tribute for her “extraordinary vision and energy” in building the GBS|CIDP Foundation International to over 35,000 members worldwide with 160 chapters in 47 countries. During Dr. Cornblath's heartfelt tribute to Estelle he said, “It is a great pleasure to give this PNS Award to Estelle Benson, Founder of the GBS|CIDP Foundation International,” he continued, “Since Estelle and I go way back, giving her this PNS Award is really special for me. And for those of us with long memories, Estelle has always been part of the PNS and INC. She has been to almost every meeting of both since forever. Her organization generously supported us before we were able to support ourselves. They have continued to support our research and many of us have attended her meetings as well. Her enthusiasm for GBS and now CIDP and MMN are infectious.”

Please join us in congratulating Estelle for her amazing accomplishments!

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. Thank you!

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.**