The Ommunication 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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A SPECIAL GBS|CIDP AWARENESS MONTH EDITION

COVID-19 RESOURCES & RELIEF

Today. Tomorrow. Always.

#GBSCIDPawareness #todaytomorrowalways

Although we may be facing a period of uncertainty, you

can take comfort in knowing that you are not alone and that the GBS|CIDP Foundation International, as always, is here for you. Please know we are here through the challenges of the COVID-19 pandemic to answer questions, provide guidance, and serve, as always, the GBS|CIDP community through our support, education research, and advocacy programming. Your needs and concerns remain a top priority and we have taken great strides to keep you connected and informed as you cope with a GBS, CIDP

or variant diagnosis while finding your "new normal." **During GBS|CIDP Awareness Month (May)**, we encourage you to visit our social media channels as often as possible and to check for updates on our website as we expand our COVID-19 resources and find new, innovative ways to learn from top medical experts. You can also join our community conversations and take part in advocating for issues that directly affect you and your loved ones.

You are not alone. We are in this together, we are resilient, and we are here for you today, tomorrow, and always.



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



We are with you today, tomorrow, always.

Dear Friends,

Welcome to this special edition on the Communicator focused on COVID-19 resources for our community.

We are with you today, tomorrow, always. What do we mean? When there is confusion, stress, and anxiety at every turn for all of us, we are all challenged. When we look at our forty years of serving the GBS, CIDP and variant communities, we have never wavered from our mission; it is strong, meaningful, and impactful. At this time, we take comfort in our strong mission and remain committed to providing you with support, education, fund research and to advocate. I hope this consistency provides assurance now and always.

As I write this, I struggle to find a unique message, a new offering of comfort. But, I realize that this is not a time for the unique, or for individuals to stand out. No, in fact, this is a time for solidarity and supporting each other in our community.

As Forbes writers so appropriately say, "Even if resources feel limited in the coming weeks and months, let us not hold back from sharing and supporting each other...we may emerge as a driving force to invite others across the country to collaborate more effectively and more creatively for overall societal well-being."

We have many resources for information, support, and ways to engage with this community that we share in the special issue. If you can't find it here, please reach out, we are working, albeit remotely and remain committed to you.

"Despite the coronavirus challenges we currently face, this Foundation still has a mission to carry out. Coronavirus does not mean that there is a temporary halt on new GBS diagnoses or that CIDP and MMN patients have a reprieve from suffering and no longer need maintenance therapy. Essentially, we still have a full plate and must push forward with the Foundation's initiatives while the world is simultaneously grappling with a pandemic." Jim Crone, President of GBS|CIDP Foundation International, Board of Directors

As we face today and tomorrow because of yesterday, we need you now more than ever. Our community knows firsthand how a world can change overnight where we have shifted from fully functioning daily life to complete devastation of isolation by paralysis. We have faced gut-wrenching fear and found courage, strength. This is the time to remember that; we are stronger together!

Please take a minute to read our last page and consider a donation to our COVID-19 support and to continue to power our Foundation to serve you!

More grateful than ever,

Lisa Butler, Executive Director



You are not alone.

This special edition is being sent to all of our readers who are isolated at home. We are reaching out to you and connecting with you to let you know we are here for you. Those of us who have had GBS, CIDP, or variants know firsthand what isolation can be like – ICU stays and being trapped in your body. But we also know that someday it will pass! We must believe the amazing medical professionals who are on the front line, just the way we had to believe the doctors who took care of us. As they say "hang in there" we are here, and you are not alone.

*In good health,*Estelle



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COVID-19 FAQ from GBS|CIDP & Variant Community



Informing our GBS CIDP Foundation community is a top priority.

We have gathered the most pressing questions regarding COVID-19 through email, phone calls, and our social media channels and addressed them below. The answers are provided by the GBS|CIDP Foundation International Global Medical Advisory Board. As we continue to navigate through the COVID-19 outbreak, the Foundation is committed to providing information, answers to your questions, and updates at they are made available. More information can be found at: https://www.gbs-cidp.org/covid19/

Are you more at-risk for COVID-19 if you have previously had GBS?

Having GBS in the past does not put you at an increased risk for COVID-19 unless you have other underlying issues. As with all people, you should practice strict social distancing and abide by the current CDC guidelines.

As an MMN or CIDP patient, am I at a greater risk for developing COVID-19?

No, however, if you take any immunosuppressive drugs, you would be at greater risk. This could include but is not limited to drugs such as; Imuran or asithyropan, Rituxin or rituximab, Celcept or microphenalate or cyclosporin. Patients taking corticosteroids are particularly at risk. Taking IVIG alone will not predispose patients to higher risk.

The Global Medical Advisory Board emphasizes strict adherence to the CDC quidelines and those of local or state governments.

"During the COVID-19 pandemic, the GBS|CIDP Foundation is here full time for your questions. We encourage patients or families of patients with GBS or CIDP to contact us with concerns about disease diagnosis and management as we together meet and conquer the challenges brought on by the COVID-19 virus."

Peter Donofrio, MD, GBS|CIDP Foundation International Global Medical Advisory Board "President Elect"



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 qbs-cidp.org or by emailing info@gbs-cidp.org.

CONTACT US

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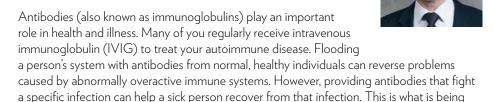
Disclaimer Information: Questions presented in The Communicator are intended for general educational purposes only and should not be construed as advising on diagnosis or treatment of Guillain-Barré syndrome or any other medical condition.

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.

studied now for COVID-19.

What is Convalescent Plasma?

By David Saperstein, MD Member of GBS|CIDP Foundation Global Medical Advisory Board



After someone recovers from a virus, our bodies produce antibodies that recognize the virus so our immune system can attack it if we are exposed to it again in the future. While not a perfect defense, such antibodies can prevent subsequent infections or at least make our reaction to the virus less severe. These are called "protective antibodies." Most people who have recovered from COVID-19 infection should have protective antibodies in their blood stream. Portions of blood taken from recovered patients contains so-called "convalescent plasma." Manufacturers who already make IVIG are equipped to process convalescent plasma so that it can purified into a product that can be given to patients.

It is hoped that this hyperimmune plasma, when given to a patient sick with COVID-19, will help that patient recover. We do not know if this will work, but it has worked for other viral infections and is an exciting area of research.

The plasma contains antibodies but not the virus itself, so there is no risk of transmitting COVID-19 infection via convalescent or hyperimmune plasma. This plasma will come from blood donated by people who have recovered from COVID-19 infection. This will not prevent the processing of IVIG, derived from source plasma, used routinely to treat GBS, CIDP and other autoimmune diseases. Also, there is no risk to these patients if they receive IVIG that contains antibodies derived from patients who were infected with COVID-19. (Source plasma is plasma that is collected from healthy, voluntary donors through a process called plasmapheresis and is used exclusively for further manufacturing into final therapies [fractionation]).

While these are challenging times, it is good to know that the science of immunology can not only continue to help those of you with GBS/CIDP but also those suffering from COVID-19 infection.







"Even during hard times, we are here to support our families and patients. Our kids and teens are the future and we will continue taking care of them."

Diana Castro, MD, member of GBS|CIDP Foundation International Global Medical Advisory Board



Global Plasma Leaders Collaborate to Accelerate Development of Potential COVID-19 Hyperimmune Therapy

Partnership brings together worldleading plasma companies to focus on developing and delivering a hyperimmune immunoglobulin in the global fight against COVID-19. Pharmaceutical companies from Japan and the USA including, Osaka, Biotest, BPL Group, LFB, Octapharma, CSL Behring and Takeda Pharmaceutical Company Limited have joined forced to develop a potential plasma-derived therapy for treating COVID-19. The alliance will begin immediately with the investigational development of one, unbranded anti-SARS-CoV-2 polyclonal hyperimmune immunoglobulin medicine with the potential to treat individuals with serious complications from COVID-19. "Unprecedented times call for bold moves," said Julie Kim. President of Plasma-Derived Therapies Business Unit, Takeda. Read full press release at: https://www.gbs-cidp.org/globalplasma-leaders-collaborate/

Grifols Announces Formal Collaboration with US Government to Produce the First Treatment Specifically Targeting COVID-19

Grifols announces that it has entered into a formal collaboration with the United States Biomedical Advanced Research Development Authority (BARDA), the Food and Drug Administration (FDA) and other Federal public health agencies to collect plasma from convalescent COVID-19 patients, process this specific plasma into a hyperimmune globulin and support the necessary preclinical and clinical studies to determine if anti-SARS-CoV-2 hyperimmune globulin therapy can successfully be used to treat COVID-19 disease. More at qbs-cidp.org/covid19

ADVOCACY Quantity of the second secon

It is no secret that the US government has been busy formulating meaningful responses to the current COVID-19 pandemic. Advocacy Manager Chelsey Fix held a virtual call with Dane Christiansen, Executive Vice President of the Health and Medicine Counsel of Washington, to answer important questions, like the one below, about the current state of Congress and how our community can be involved in shaping future policy. Watch the full interview: gbs-cidp.org/virtual-ask-the-expert-educational-series/

Q: Home infusion is big in our community, and is not always covered by Medicare. Home infusion also has many benefits during this current pandemic. What would future efforts by Congress look like, in terms of home infusion?

A: (Dane Christiansen) The Foundation has been working on home infusion for some time now through HR 2905, which is meant to facilitate access to home infusion for CIDP and MMN patients. If anything, the current situation helps explain why this legislation is so important. A patient and their doctor should have the power to decide what is the best healthcare for them. It shouldn't take a serious situation like this to highlight economic and health factors, but it does show why this is so timely and important. This could potentially be considered for any upcoming COVID-19 legislation and they could continue to make improvements. Congress likes to do things that are broad and "across the board", and they've done that now. They are going to continue to make further refinements moving forward.

From an advocacy perspective, we can continue to make the case that CIDP and MMN patients deserve additional accommodations beyond just expanded home health and telehealth, and their providers may be able to decide that they want to do a different arrangement. Having a benefit in place may not only solve this issue during the COVID-19 pandemic, but potentially solve home infusion issues moving forward. I do think that HR 2905 is a good solution and a framework for something we can accomplish in the future that is more a direct improvement for the CIDP and MMN community.



Although we are currently working apart, we are working together in new and innovative ways. As always it is a priority of The Foundation's to keep our programs running, research grants moving forward, and continuing to provide our members with the vital resources they need as they cope with a GBS|CIDP diagnosis for themselves or a loved one.

VIRTUAL ASK THE EXPERTS

Join us! As we have postponed spring chapter meetings, fundraising walks and activities, and in the theme of "working together in new and innovative ways," we have developed a virtual "Ask the Expert" educational series featuring medical experts from the Foundation's Global Medical Advisory Board. Our educational series will be prerecorded, and hosted by members of the GBS|CIDP Foundation staff, who will be asking questions that have come straight from our members via social media, phone calls, and emails. The series will be presented on our website and YouTube channel, and will remain there so you can view them at a time that is convenient for you!

SCHEDULE OF PRESENTATION TO BE POSTED AS FOLLOWS:

April 16: Advocacy Updates, Home Infusion, Insurance & Beyond with Dane Christiansen, Health & Medical Counsel of Washington DC

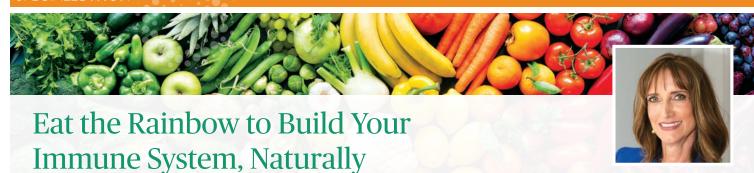
April 23: COVID-19, Ask the Expert with Dr. Ken Gorson

May 4: Building Your Immune System, Naturally with Dr. Julie Rowin

May 11: Life after GBS|CIDP Diagnosis for Youth & Teens with Dr. Diana Castro

Remember, you can review the "Ask the Expert" session at any time that is convenient for you at: gbs-cidp.org/virtual-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/* for the most recent updates.



By Julie Rowin, MD

When my patients ask me what they can do to naturally optimize their immune health, this is what I tell them:

Eat the Rainbow! Eat 9-12 servings of plant foods daily of all colors (purple, red, green, yellow, white, and ORANGE!) The phytonutrients/vitamins and minerals in these colors are each essential to your immune health. Particularly important for immune health are the orange colored vegetables and fruits, such as carrots, whole oranges (not juice as it has too much sugar), bell peppers, and sweet potatoes, yams and turmeric root. Make it your goal to get the full seven colors every day with a variety of foods.

- More Rainbow Recipes can be found at Dr. Rowin's website: julierowinmd.com
- See full interview with Dr. Rowin,
 "8 Ways to Build Your Immune System" at: gbs-cidp.org/ask-the-expert-educational-series

RAINBOW SMOOTHIE RECIPE

Makes 2 servings (1 serving ≈ 8–10 ounces)

INGREDIENTS

- ½ cup (cold) green tea
- 1 cup hemp or almond milk (unsweetened)
- 1–2 tablespoons chia seeds, whole or ground
- ¼ teaspoon cinnamon
- 1/2 teaspoon ginger (dried) or 1/2 teaspoon fresh ginger, minced
- 1 tablespoon fresh lemon juice n 1 teaspoon maple syrup or 1 teaspoon stevia
- ½ cup (no sugar added) frozen blueberries
- ½ cup (no sugar added) frozen strawberries
- ½ cup (no sugar added) frozen mangoes
- 1 cup packed baby spinach
- *Add ¼ to ½ cup ice to increase thickness if desired

DIRECTIONS

Add prepared green tea, hemp or almond milk to blender. Then add the rest of the ingredients in the order listed ending with baby spinach. Blend at very low speed until ingredients are mixed then gradually increase speed to high and blend well for 1 minute. Serve immediately. (If unable to serve immediately, please omit chia or other seeds as gelling will occur and it will be less palatable.)

OPTIONS

Add 1–2 scoops protein powder, 1–2 tablespoons nut butters or ground flax or hemp seeds or a combination of these options to add quality protein, healthy fats and fiber to this smoothie. If using fresh fruit be sure to add $\frac{1}{2}$ –1 cup ice to mixture to desired thickness.

(ref. The Institute for Functional Medicine. IFM.org)

How to Prepare for Getting an Infusion at an Infusion Center During COVID-19

The following are best practices when preparing for your *Infusion Center Appointment*:

- 1 Wear a mask or available cloth face protection (scarf, bandana) to the infusion center, and keep it on for the duration of your visit.
- **2** Bring only one caregiver, if necessary, to the infusion center.
- 3 The caregiver, if present, should wear a mask or available cloth face protection (scarf, bandana) for the duration of the visit.
- 4 Please wait in your car until your scheduled visit time.
- 5 Bring limited personal items into the infusion center.
 - Clean and disinfect any personal items you brought (i.e., cell phone, keys, etc.) immediately after your visit.



Advancing Ig Therapy Practice

What to Expect at the Infusion Center:

- 1 All personnel should wear personal protective equipment that will <u>always</u> include a mask, and may also include gloves, gown, face protection, protective eyewear, shoe coverings, etc.
- **2** Expect that the infusion center will have fewer patients at one time, with infusion chairs positioned at least 6 feet apart.

(additional resources: IgNS Ig Therapy Standards of Practice. Edition 2.1, 2019. www.ig-ns.org; IgNS COVID-19 Resource Guide and FAQ. www.ig-ns.org)



PLEASE HELP US TO SERVE THE GBS|CIDP AND VARIANT COMMUNITY WITH CONTINUAL COVID-19 RESOURCES AND RELIEF

DEAR FRIENDS.

Our Foundation is strong in our ability to adapt in uncertain times, as so many of our new patients face a similar feeling in the early stages of their diagnosis. And during this COVID-19 crisis, as inquiries have increased by nearly 30%, we have responded to each patient or caregiver with the very same compassion and accuracy. We hope you have benefitted from our new and innovative communications, including this special edition newsletter, and the news and updates on our COVID-19 website portal, which has attracted over 27,000 views. We strive to keep you more informed, more supported, more educated, more inspired by the reach of advocacy. Our resilient, world-wide team has been in constant communication, including our staff, Board of Directors and Global Medial Advisory Board (GMAB). We share this message of support from Dr. Ken Gorson, the President of our GMAB:

"During these enormously challenging times, it remains so important that we as a community, our GBS|CIDP community of patients, caregivers, physicians, and supporters, have perspective: we will get through this together. The Global Medical Advisory Board and The Foundation will continue to be here to support you in any and every way we can. Our physicians continue to care for patients with GBS, CIDP and related immune neuropathies, although perhaps research continues, utilizing creative ways to run research facilities and clinical trials; our commitment to continuing education for physicians, patients, families and caregivers proceeds, utilizing technology such as the virtual education series; and our advocacy pushes forward to improve governmental policies to benefit our patients. We are here for you."

Ken Gorson, MDPresident of GBS/CIDP Foundation
International Global Medical Advisory Board



Through this pandemic, we will continue to provide programming. No matter how different it may look, we will be here for you. We are producing a virtual education series and rescheduling our spring Walk events. We refuse to "cancel" but work instead to "postpone or reschedule."

But this all comes at a cost, an unexpected cost.

And now, we are asking you to be here for us by considering a donation in these unprecedented times. We hope that you will rise to our call to action to raise emergency funds to increase technology infrastructure so that we can fully operate virtually and to secure discretionary revenue needed right now.

And through this time, please remember, new patients will continue to be diagnosed, current families will need resources and expert referrals, and all should be confident that the Foundation support remains more available than ever. We need your support to help the Foundation as we face funding challenges presented by COVID-19. We are all in a state of the unexpected and unprecedented. In a time where we all want to help, please consider donating now, right now, we need your support!

As Marriott Corporation says so well, "We've all borne witness to how this insidious virus is impacting our families, our communities and our very way of life. What we're facing is daunting, but I am heartened by the moments of triumph in everyday acts of courage, humanity and love. Although these are trying times for us all, we remain optimistic that our world will thrive once again."

In this time of uncertainty, please think generously about your gift and help us drive the change of the future.

We are strong, but with your help, we are unstoppable. Together, we will continue to be there for GBS|CIDP patients worldwide in their time of need, for generations to come.

The Foundation Team



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LOOKING FOR SUPPORT IN YOUR REGION?

We have over 160 volunteers throughout the world who are committed to supporting each and every one of you. Please contact Lori Basiege and she will put you in touch with volunteers from your region. Lori.basiege@gbs-cidp.org.

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@qbs-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@ qbs-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@qbs-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...





TO HELP YOU ON YOUR WAY TO A NEW NORMAL.