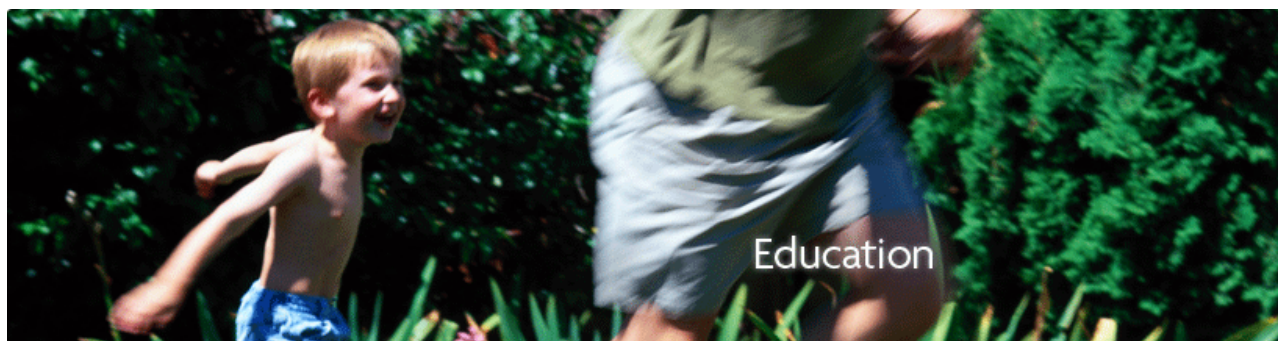


Patient Voice Newsletter

Neuropathy Action Foundation <info@neuropathyaction.org>



[Website](#) [About NAF](#) [Neuropathy 101](#) [Resources & News](#) [Advocacy](#) [Support](#) [Contact](#)



June "Neuropathy Action Awareness Day" Cancelled

Protecting the health, safety, and well-being of our community is paramount. We shared with you earlier that the 13th "Neuropathy Action Awareness Day" event may not take place as planned. Although we were looking forward to seeing everyone in Los Angeles, it is simply not possible to move forward with the in-person meeting given the pandemic and ongoing travel restrictions. Therefore, the NAF has decided to cancel the meeting and will explore new dates for a 2021 in-person event instead.

For those that have already committed to participating in the 2020 Annual Meeting either as a speaker, exhibitor, or sponsor, we will be contacting you soon regarding next steps, so please stay tuned. For those that have already registered for the conference, the NAF Office will proceed in issuing you a full refund. Please contact the INTERCONTINENTAL LOS ANGELES directly to cancel your fully refundable hotel reservation.

Our common goal is Patient Empowerment and Public Awareness and Provider Education. Together we will continue to advance our mission of ensuring neuropathy patients obtain the necessary resources to access individualized treatment to improve their quality of life. The NAF increases awareness among providers, the general public and public policy officials that neuropathy can potentially be a serious, widespread and disabling condition, which may be treatable when appropriate medical care is provided.

We are grateful for your ongoing support of the NAF, particularly during this difficult period.

In This Issue of the Patient Voice

[Potential COVID-19 Hyperimmune Therapy](#)

[IgNS Plasma Donation Initiative](#)

[Needy Meds and COVID-19 Resources](#)

[Drug Shortages Were a Problem Even Before COVID-19](#)

Potential COVID-19 Hyperimmune Therapy

Biotest, BPL Group, LFB, and Octapharma have joined an alliance formed by CSL Behring and Takeda Pharmaceutical Company 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. "We collectively agree that by collaborating and bringing industry resources together, we could accelerate bringing a potential therapy to market as well as increase the potential supply. We invite companies and institutions focusing on plasma to support or join our alliance."

May 2020



Dear Scott ,

During the COVID -19 pandemic it is important that we all look out for one another - especially those who have chronic health conditions like neuropathy. The NAF has been reaching out to several neuropathy patients regularly to check in on them and make sure they are aware of community services available to them. After receiving an email from one elderly patient thanking us for our concern I was reminded of a heartwarming story about two brothers in South Dakota.

Two brothers worked together on a family farm. One was married and had a large family while the other was single. At the day's end, the brothers shared everything equally, produce and profit. Then one day, the single brother said to himself, "It's not right that we share everything equally. I'm alone and my needs are simple." So each night he took a sack of grain from his bin and dumped it into his brother's bin. Meanwhile, the married brother said to himself, "It's not right that we share everything equally. After all, I'm married and have my wife and children to look after me. My brother has no one to take care of him." So each night he took a sack of grain and dumped it into his brother's bin. Both men were puzzled for years because their supply of grain never dwindled. Then one dark night the two brothers bumped into each other. Slowly it dawned on them what was happening.

You'll often find that when you have the consideration to look out for another person, they are looking out for you in return. During this time of crisis it is imperative that we all look out for one another. We hope you are healthy and safe and enjoy this edition of the NAF's Patient Voice.

"Leaders lead during uncertainty. There is no question that we are all experiencing the impact of COVID-19," said Bill Mezzanotte, CSL Behring's Executive Vice President and Head of Research and Development. "This effort aims to accelerate a reliable, scalable and sustainable option for caregivers to treat patients suffering from the impact of COVID-19. In addition to pooling industry resources, we will also collaborate with government and academic efforts as a single alliance whenever we can, including important activities like clinical trials. This will make it more efficient in these hectic times for these stakeholders as well."

The collaboration will leverage leading-edge expertise and work that the companies already have underway. Experts from the alliance will begin collaborating across key aspects such as plasma collections, clinical trial development and manufacturing. Further companies and institutions may join the alliance as well.

Developing a hyperimmune will require plasma donation from many individuals who have fully recovered from COVID-19, and whose blood contains antibodies that can fight the novel coronavirus. Once collected, the "convalescent" plasma would then be transported to manufacturing facilities where it undergoes proprietary processing, including effective virus inactivation and removal processes, and then is purified

Dominick V. Spatafora
President - NAF

IgNS Plasma Donation Initiative

During this unprecedented time of fear and uncertainty, we witness daily the incredible sacrifices of healthcare professionals, EMS, military, law enforcement, and others working tirelessly to keep patients healthy and save lives. We have witnessed people coming together to support each other in any way possible, around the globe. This has become increasingly difficult with many cities, states, and whole countries in lockdown, and all of us practicing social distancing to prevent the spread of COVID-19.

Many in the neuropathy community are asking what they can do to help others? What good they can bring to the country? The answer is simple - become a plasma donor! The decrease in plasma donations during the COVID-19 pandemic will most certainly impact the supply of plasma protein therapies within the next year. It is our responsibility during this time to do whatever we can to protect the vulnerable patients who rely on these lifesaving therapies. Now is the time to mobilize. We can all make a difference and here's how:

1. Locate your nearest [Plasma Donation Center](#)
2. Donate plasma. Take a picture or a quick video of yourself donating.

Post to your social media, tag @IgNSorg, use **#ItsMyTurn** and **#IgNS** hashtags, and invite your colleagues, friends and families to also donate. Please remember that plasma donation is a commitment. First donations are discarded if the donor does not return for a second time. You must donate more than once to make a difference! For more information please visit the Immunoglobulin National Society (IgNS) at https://ig-ns.org/itsmyturn-igns-plasma-donation-initiative/?mc_cid=6801b746e9&mc_eid=e5fd2153cf.

into the product.

If you have recovered from COVID-19, you could help others do the same! Visit www.CoVlg-19PlasmaAlliance.org to learn how. #CoVlg19 #donateplasma

Forward To A Friend

Join My Mailing List

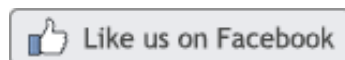
Support the Neuropathy Action Foundation.

When you shop at smile.amazon.com, Amazon donates.

[Go to smile.amazon.com](https://smile.amazon.com)

amazonsmile

Stay Connected



Needy Meds and COVID-19 Resources

NeedyMeds, a 501(c)(3) national non-profit that connects people to programs that will help them afford their medications and other healthcare costs just created a wonderful website that highlights COVID -19 services and resources. The website provides a comprehensive list of programs for those experiencing financial hardships and struggling with healthcare expenses due to the COVID-19 coronavirus.

What Kinds of COVID-19 Services or Programs are Offered?

There are many private- or government organizations offering help with healthcare costs and financial hardships for those impacted by the COVID-19 Coronavirus. Some programs are national in scope, while others are limited to people in specific states. Most have some type of eligibility requirements, usually regarding financial need caused by the diagnosis.

How to Search for COVID-19 Services or Programs

* If you are looking for COVID-19 services or programs geographically, click on [Programs by State or Nationwide](#).

* If you are aware of and want to apply to a specific program, search by clicking on [By Program Name](#).

Drug Shortages Were a Problem Even Before COVID-19, Its Just Getting Worse and It's Time for Solutions

Many Americans have heard about the shortage of ventilators, but a lesser known issue is the current shortage of sterile injectable drugs. These drugs are needed to intubate patients in order to use a ventilator (among a variety of other medical procedures). A recent [report](#) from Vizient Health Consulting, which buys medications for hospitals estimated there has been a 51% increase in sedatives and anesthetics despite most elective surgeries being cancelled. While COVID-19 has exacerbated this drug shortage problem, this is not a new issue.

According to the Food and Drug Administration's (FDA) [2019 Drug Shortages Report](#), most drug shortages fell under the category of sterile injectables or the medications typically administered through an IV or injection. These medicines are critical for many common medical procedures including surgeries, chemotherapy, and laboring patients. Unfortunately, several issues have made their supply inconsistent and

policymakers need to take action to ensure a reliable supply of these critical medications.

Consider just a couple of the market distortions caused by drug shortages that are threatening the health of prescription drug patients:

- When faced with an acute shortage, hospitals are often forced to go without certain drugs or must purchase them at a premium from third party vendors, putting both hospitals and their patients in a desperate situation.
- Smaller hospitals like Critical Access Hospitals are especially impacted during shortages due to large hospital systems hoarding drugs to extend their supply. Their massive buying power and allocation numbers leaves smaller hospitals with little or no supply of drugs due to the relative low volumes used throughout the year. This further threatens the health and safety of patients already confronting the consequences of drug shortages.

Manufacturing sterile injectables requires complex processes, highly sophisticated equipment and facilities and yet two thirds of generic sterile injectables cost less than a gallon of milk. The low margin has limited the number of manufacturers willing to produce many of these products and can create shortages when even one manufacturer experiences a production issue. This market uncertainty has led several manufacturers to leave the market over the last few years only compounding the shortages. Policymakers must look at ways to better incentivize manufacturers to produce these critical medications.

Besides looking at the financial challenges of producing generic sterile injectables, policymakers should look at regulations that could speed up production when shortages occur. For example, Congress should consider codifying and expanding the FDA's existing Emerging Technologies program to encourage manufactures to invest in advanced manufacturing technologies. New technologies could improve the reliability of these products and allow manufacturers to more quickly start new lines of production during shortages.

Drug shortages is a complex problem but will not be solve by continued inaction. The current model is not working and putting patients at risk.

The above was written by Dr. Matthew Makelky Sr., PharmD, MSCS is the Director of Pharmacy and Outpatient Infusion at Estes Park Health in Estes Park, Colorado

Neuropathy Action Foundation
1950 Old Tustin Avenue | Santa Ana, CA 92705
(877) 512-7262 | info@neuropathyaction.org

Copyright © 2020. All Rights Reserved.

Neuropathy Action Foundation, 1950 Old Tustin Avenue, Santa Ana, CA 92705

SafeUnsubscribe™_oldweirdharold@hotmail.com

[Forward this email](#) | [Update Profile](#) | [About our service provider](#)

Sent by info@neuropathyaction.org in collaboration with