From: Scott Olney <oldweirdharold@hotmail.com>
To: "pdfconvert@pdfconvert.me" <pdfconvert@pdfconvert.me>
Subject: Fw: Patient Voice Newsletter
Date: Sun, 26 Jun 2022 03:36:35 +0000

Neuropathy Action Foundation
Awareness ▪ Education ▪ Empowerment

Patient Voice - April 2022 Issue **Visit our Website**

In this Issue

Dear Friend,

The Neuropathy Action Foundation (NAF) is partnering with a research company to find participants for a nation-wide, paid usability research study (not a clinical trial) for a new medical device related to CIDP and MMN therapies. The following individuals are eligible to be screened for participation:

- Individuals with CIDP or MMN and who are on IG therapy (Please note that experience administering subcutaneous IG therapy is **NOT** required).

AND/OR

- Caregivers/family members who help administer their friend or family member's IG therapy

Participants will each be paid $180 for taking part in the two-hour usability study interview as an honorarium. Interviews will be scheduled in areas and at times that are convenient for interested participants. Transportation to and from the study interview location may also be arranged and provided if needed. In some regions, remote interviews may be conducted.

The usability study interview will involve:

- Watching a short video on how to use the new device
- Trying it out on your own (using a foam pad, **NOT** your body – **NO** medication or actual infusions are involved)
- Giving your feedback and opinions about what you like or don't like about it

The interviews are one-on-one (not a group). Extensive precautions have been put in place to minimize the risk of spreading COVID-19. **CLICK HERE** to provide your contact information if you are interested in participating or learning more about the study. You may also contact Yuki Sun directly at **ysun@evolutionengineering.us** or (814) 777-1965.

Thank you for your consideration of this research opportunity on behalf of CIDP and MMN patients.

The Source of Hope

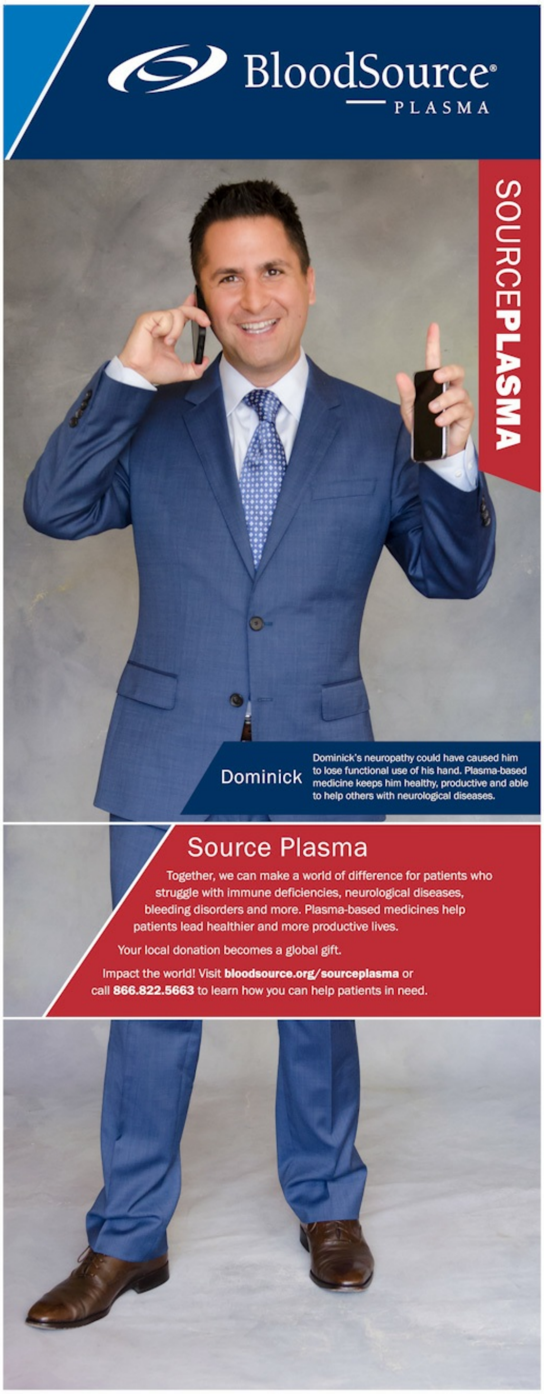
Patients all over the world rely on plasma protein therapies to treat rare, chronic diseases. These individuals rely on the generosity and commitment of plasma donors. You may donate plasma in one of more than 1,000 licensed and certified plasma collection centers located in the U.S. and Europe. Plasma often is referred to as the "gift of life" because it is the essential starting material needed to manufacture therapies that help thousands of people worldwide with rare, chronic diseases to live healthier, productive and fulfilling lives.

The NAF has partnered with various plasma donation centers and organizations over the years to help bring awareness to the importance of plasma donation. Plasma-based therapies give enormous hope to people who struggle with more than 80 diseases, including autoimmune diseases, bleeding disorders, and neurological disease, such as Multifocal Motor Neuropathy (MMN) and Chronic Inflammatory Demyelinating Polyneuropathy (CIDP). With more than 65% of the world's plasma coming from the U.S., the global need for plasma shows no sign of abating.

Patients rely on plasma-based medicines for a one-time need - or perhaps a lifetime - with access and availability critical to their health, well-being, productivity and personal fulfillment. There is only one source for plasma and it's another human being who rolls up his/her sleeve, gives an hour and a precious gift, impacting the smaller world of a patient surrounded by family and friends, and the larger world of many thousands of patients in need. Together, we do save lives.

The following link illustrates a video featuring NAF President Dominick Spatafora discussing how he relies on plasma to help treat his MMN: **http://youtu.be/SiLKbk5PVDMÂ**

To learn more about plasma or to find a donation center near you please visit **www.DonatingPlasma.org**.



Dominick's neuropathy could have caused him to lose functional use of his hand. Plasma-based medicine keeps him healthy, productive and able to help others with neurological diseases.

Source Plasma

Together, we can make a world of difference for patients who struggle with immune deficiencies, neurological diseases, bleeding disorders and more. Plasma-based medicines help patients lead healthier and more productive lives.

Your local donation becomes a global gift.

Impact the world! Visit **bloodsource.org/sourceplasma** or call **866.822.5663** to learn how you can help patients in need.

We Want to Hear from You!

Have Medi-Cal Rx Providers Writing Prescriptions or

Patients in Your Community Recently Been Denied Access to Medications?

The California Assembly Budget Subcommittee No. 1 on Health and Human Services held an oversight of the new Medi-Cal Rx program which went “live” on January 1, 2022. Medi-Cal Rx is the new Medi-Cal pharmacy benefit program which provides all prescription drugs, and some devices, to Medi-Cal beneficiaries.

At the hearing, the Department of Health Care Services (DHCS), which oversees Medi-Cal Rx, reported that there have been unexpected delays in prescriptions being filled. Reports of long call wait times, erroneous rejections of prescription refills, and prior authorization denials have created a backlog of Medi-Cal beneficiaries accessing their needed prescriptions–with some delays lasting a week or more.

Here are the new provider alerts with the new policy:
1. **Revised Prior Authorization Policy for Pharmacy Providers**
2. **Revised Prior Authorization Policy for Prescribers**
3. **Revised Emergency Fill Quantity and Frequency Policy**

Please contact us to share your story at www.mypatientrights.org or megan@perrycom.com

NAF Launches CIDP Digital Education Campaign

In 2021, the NAF decided to shift its education efforts from Multifocal Motor Neuropathy (MMN) to Chronic Inflammatory Demyelinating Polyneuropathy (CIDP). To that end we conducted an international Quality of Life (QOL) Patient Survey. The survey focused on three primary areas: timely and accurate diagnosis, efficacy of treatment, and the impact of the disease on patient’s quality of life. While 70% of respondents reported that they were diagnosed between the ages of 41 and 65 years old, more than 54% of those completing the survey reported that it took more than one year to be accurately diagnosed. The majority of the misdiagnoses were made by Neurologists (60%) and Family Care Providers (21%). "It is very clear that we need to do a better job at accurately diagnosing these patients. The sooner we can identify CIDP, the sooner we can start individuals on the proper therapy, alleviate their symptoms and improve their lives,” said Jonathan Katz, Chief of Neuromuscular Services at California Pacific Medical Center.

When asked about treatment options, 76% reported receiving intravenous immunoglobulin (IVIg) and 11% reported receiving subcutaneous immunoglobulin (SCIg). A reduction in symptoms was reported within three months of their first Ig treatment by 68% of respondents. Only 7% reported that Ig did not help them manage their symptoms. If recommended by their Neurologist, 67% would consider SCIg treatment. Interruptions in treatment due to COVID-19 were experienced by 39% of the respondents.

It was clear from the results that we need to do a better job of bringing awareness to CIDP. Therefore, last month the NAF launched a nationwide targeted digital education awareness campaign on CIDP. The NAF’s goal is to raise awareness of CIDP through digital advertising campaigns narrowly targeted to key audiences. Such audiences include people who may be unknowingly living with the condition, people who are seeking treatment options or additional information, and members of support groups or professional medical communities engaged on the topic. As with MMN, digital education and advocacy are highly important for people living with the condition, given the benefits of early diagnosis and treatment. Stay tuned for a summary of this strategic ten week awareness and lead generation campaign via Google search and Google responsive display advertising in the near future! And as always please feel free to share your CIDP patient story/journey with us at **info@neuropathyaction.org**.

Transitioning From IVIG to SCIG Improves Quality of Life for CIDP Patients

A new study shows transitioning to subcutaneous immune globulin (SCIG) from intravenous IG (IVIG) significantly improved several quality-of-life measures for patients with chronic inflammatory demyelinating polyneuropathy (CIDP) while maintaining the drug's efficacy.

Investigators at the University of South Florida (USF) followed a group of 15 subjects who were making the switch from IVIG to SCIG in a prospective open-label study over a six-month period. Three of the 15 original subjects withdrew: One did not perceive benefit, one was withdrawn by the investigators for worsening neutropenia, and one withdrew consent.

The remaining study participants experienced significant improvements in the Chronic Acquired Polyneuropathy Patient-Reported Index and Treatment Satisfaction Questionnaire for Medicine, as well as in the "role limitations[1]physical" section of the Short Form 36-Item Health Survey. Meanwhile, no significant changes in disability or motor function outcomes were reported, except for limb motor strength function, which favored SCIG.

Of the 12 subjects who completed the study, eight chose to continue SCIG. One participant returned to IVIG because of lack of insurance coverage for SCIG, one chose to return to IVIG due to preference, and two elected to stop IVIG therapy to test their IgG dependence. "One of the two went into remission, and we never had to restart her on IG; the other relapsed within six months, and we did have to restart him on SCIG," said lead author Tuan Vu, MD, a professor of neurology and the director of the Neuromuscular Division, the ALS Clinic and the EMG Laboratory at USF in Tampa, Fla. His group currently has a total of 27 patients receiving SCIG. "If you want to do it, you can make the switch, and typically the patients do quite well.

"In this study, we found that the transition from IVIG to SCIG was easily achieved. Initially, there were concerns that a lot of these patients have hand weakness and that that might aect their ability to prep the syringe and load the pump. But it turned out to be pretty easy. Almost all of our patients were able to learn how to do it after just two sessions. We showed them how to do it the first time, and they did it the second time."

These real-world findings align with those of the PATH (Polyneuropathy and Treatment with Hizentra) study, which showed SCIG was effective and well tolerated in CIDP maintenance (Lancet Neurology, 2018;17[1]:35-46), and quality-of-life measures were maintained or improved in most patients (Journal of Neurology, 2020;27[1]:196-203).

Shaw, G. Moving From IVIg to SCIg Improves Quality of Life. Specialty Pharmacy Continuum, Aug. 13, 2021. Accessed at ***www.specialtypharmacy*** *continuum.com/Online-First/Article/08-21/Moving-From-IVIg-to**[1]**SCIg-Improves-Quality-of-Life/64372*

Support the Neuropathy Action Foundation.

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

Go to smile.amazon.com

Share Tweet

Share

Donate Today

Neuropathy Action Foundation | http://neuropathyaction.org

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

Update Profile | Constant Contact Data Notice

Sent by info@neuropathyaction.org powered by