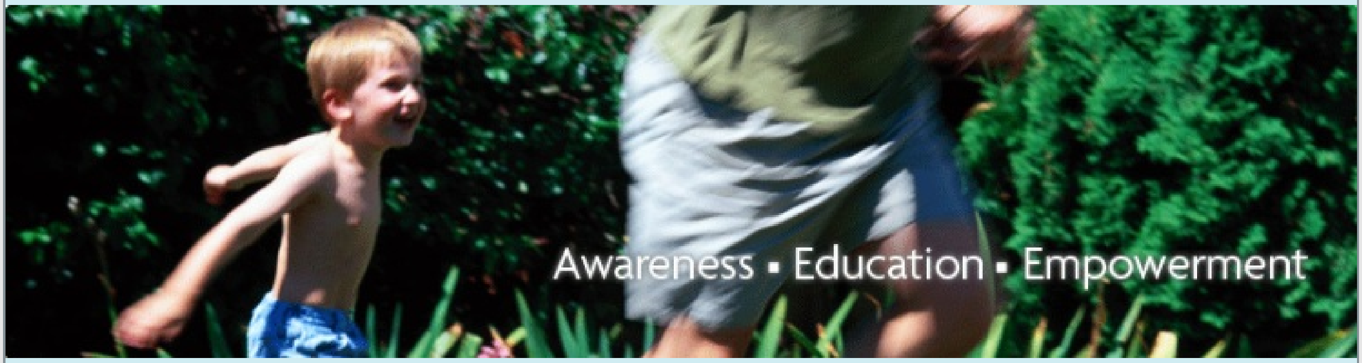
From: Scott Olney <oldweirdharold@hotmail.com>
To: "pdfconvert@pdfconvert.me" <pdfconvert@pdfconvert.me>
Subject: Re: Patient Voice Newsletter March 2026
Date: Sat, 21 Mar 2026 19:40:03 +0000

Neuropathy Action Foundation
Awareness ▪ Education ▪ Empowerment

Patient Voice - March 2026 Issue **Visit our Website**



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NAF - 20 Years of Impact!

Dear Member,

This year the Neuropathy Action Foundation (NAF) celebrates a remarkable milestone – our 20th Anniversary! For two decades, the NAF has been a steadfast champion for people living with neuropathy, empowering patients to become advocates, expanding education and awareness, improving access to care, and building a compassionate community that transforms lives.

This anniversary is not only a marker of time, but a testament to what focused purpose, tireless advocacy and collaborative spirit can accomplish. From the first day our website went live in 2006 a quote from Margaret Mead has been highlighted on our home page: *“Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it’s the only thing that ever has.”* That quote is still on our home page today and guides us daily.

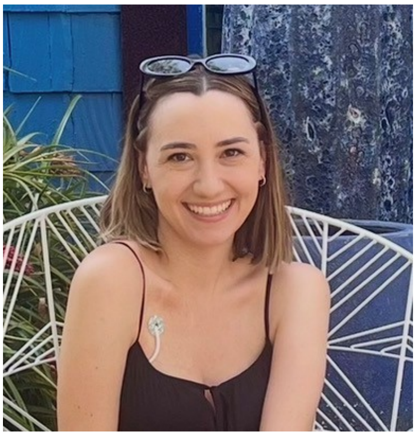
Our accomplishments would not be possible without the dedication of our staff, the expertise of our board members and medical advisors, the generosity of donors and sponsors, the hard work of volunteers, and the courage of every person who has shared their story just like Anna DiBlosi is doing this month in her below article.

To our community – thank you. Your trust, engagement, and advocacy have been the NAF’s lifeblood.

As we look forward to the next decade, our commitment remains clear: accelerate research toward more effective treatments and cures, expand educational outreach, deepen peer and caregiver support networks, and most importantly ensure neuropathy patients obtain the necessary resources to access individualized treatment to improve their quality of life.

To do this, we will continue forging partnerships, investing in promising science, and ensuring that neuropathy patients have access to individualized medications, Ig and other treatments through patient empowerment and advocacy. Please join us in celebrating this milestone – by sharing your story especially if you have CIDP or MMN, volunteering, advocating, or by making a charitable donation at **NAF Contribution Form**.

Together we will honor the progress made and renew our promise to advance better outcomes and brighter futures for everyone affected by neuropathy.



CIDP Patient Spotlight: Advocate in Action!

My journey with CIDP, a demyelinating neuropathy, started after a bout of food poisoning on a vacation abroad. I was 26 years old when the onset of severe pain, weakness and sensory changes throughout my body landed me in the hospital. Doctors ran every test and ordered every scan, but everything came back normal. They told me that my symptoms would resolve on their own because there was "no diagnostic cause." I knew something more was happening, but I was repeatedly dismissed.

At this point, I could no longer fully take care of myself and I had lost my ability to work, participate in my hobbies, and my ability to move through life independently. Life became a challenge and my parents had to step in to help. I finally received my CIDP diagnosis in 2024 after landing in the right doctor's office and undergoing a repeat EMG/NCV. The relief of finally having an answer after years of fighting cannot be overstated.

However, while I was still trying to find answers to my symptoms, I decided to share my story on social media in hopes that it would reach the eyes of someone who could offer some guidance. Instead, I was met with something unexpected. I received messages from young women around the world experiencing nearly identical journeys. They had years of “mysterious” symptoms, normal test results, and medical dismissal. It became clear that the inability to get help as an atypical patient was a systemic problem.

Even though I was barely functioning myself, I felt an innate responsibility to do something about it. So, I started a support group in my community specifically for young women with chronic, complex, or undiagnosed illnesses. Coincidentally, most of the women in the support group suffer from neuropathies themselves. We exchange doctor referrals, discuss treatment experiences, and share encouragement during our meetups. This group takes everything I have in me as I’m still focused on my own recovery, but it’s such a lifeline for myself and the other women who join.

As far as treatment goes, Plasmapheresis was my first effective treatment, which I underwent for a year before transitioning to IVIG, my current therapy. Like many patients, I've also explored alternative treatments such as acupuncture, specialty diets, saunas, cold plunges, massage therapy, TENS units, and various supplements. While these are complementary, my pharmaceutical treatments have been the most effective in managing my condition.

Four years in, I've improved significantly from where I started, but I'm still far from the person I was before this. Severe pain remains my primary symptom and largely impacts my daily life. I'm still working through the grief of losing my "old life" at such a young age while still hoping that I'll continue to improve. My long-term goal is to be able to return to the workforce, my path has shifted. Instead of going back to my previous career in advertising, I hope to become a patient advocate to help others like myself who fell through the cracks of the medical system. My goal is to help others navigate the same medical dismissals I faced and to join the broader conversation that organizations like the Neuropathy Action Foundation are leading.

-- Anna DiBlosi, Los Angeles CA. You can find more information about my story and my community on Instagram or TikTok @annadiblosi.

CIDP Patients Wanted - CIDP Health Index: Development of a Patient-Reported Outcome Measure for CIDP

What: Researchers at the University of Rochester are interested in creating a patient-reported outcome measure that will assess the health, symptoms, and disease burden of individuals with chronic inflammatory demyelinating polyneuropathy (CIDP). This study is being conducted by Dr. Chad Heatwole from the University of Rochester's Department of Neurology. This study aims to identify the symptoms that have the greatest impact on the quality-of-life for individuals with CIDP. This will help guide future research involving individuals with CIDP.

What's involved: As a participant in this study, you will participate in a Zoom interview with a study coordinator, where you will talk about the symptoms of CIDP that you experience and that have the greatest impact on your daily life. This interview will take approximately 30-60 minutes and will be audio-recorded, transcribed, and analyzed. All responses will be anonymous and strictly confidential.

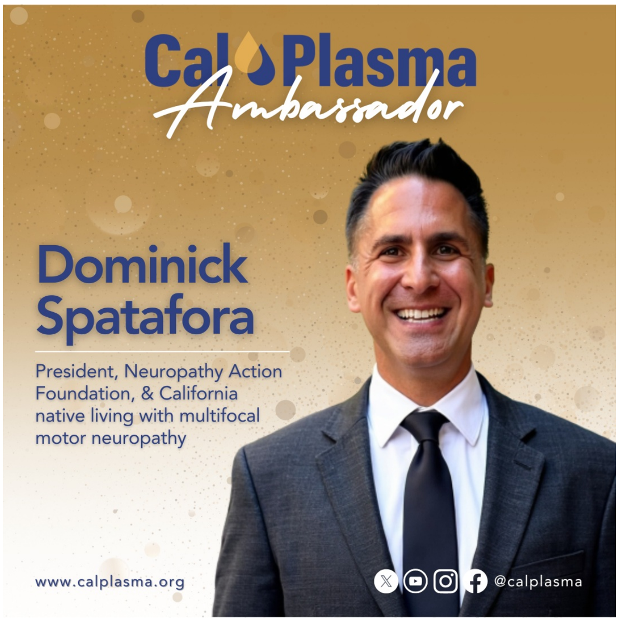
Who can participate: Individuals with CIDP ages 18 years and older, who live in the United States, and speak, read, and understand English.

How to participate: Individuals interested in participating can reach out to one of the study coordinators:

- Matt Rathbun / **Matthew_Rathbun@URMC.Rochester.edu** / (585) 275-8585
- Jennifer Weinstein, MS / **Jennifer_Weinstein@URMC.Rochester.edu** / (585) 275-5196

The Importance of Plasma Donation and CalPlasma

NAF Founder, Dominick Spatafora, is proud to share that he has joined the California Plasma Coalition (CalPlasma) as an Ambassador. In this role, he will continue raising awareness about the critical role plasma plays for patients like Dominick who



are living with rare and chronic conditions. The NAF has also joined CalPlasma as a Partner organization. **CalPlasma | California Plasma Coalition**

Every plasma donation tells a life-saving story. CalPlasma is a dedicated community of patients, donors, health care professionals, and advocates working to ensure that every Californian has timely access to the life-saving plasma medicines they need when they need them most. Through powerful patient stories, expert insights, and community advocacy, CalPlasma is building a movement to shine a light on the importance of plasma donation and, more importantly, save more lives.

The NAF applauds CalPlasma for the introduction of Assembly Bill 2009, co-authored by Assemblymembers Phillip Chen (R-Brea) and Jose Luis Solache, Jr. (D-Lynwood). Californias current laws on regulating source plasma donation apply requirements originally designed for blood banks that collect blood for transfusion. AB 2009 will modernize these regulations allowing centers to operate more efficiently. For patients, this legislation is about more than regulatory modernization, it is about reliability and peace of mind. When plasma supply is stable, patients can focus on living their lives, managing their conditions, and staying healthy, rather than worrying about whether their next treatment will be available.

Ig Therapy Patient Survey

The Immunoglobulin National Society (IgNS) and the NAF invite you to complete an IgNS confidential Patient Experience Survey and share what matters most to you. The survey takes just **5-10 minutes** and helps IgNS better understand patient experiences with Ig therapy. Your input helps our community:

- Gain deeper insights into patient experiences with Ig therapy
- Understand challenges patients face across care settings

- Improve education and support resources for patients and caregivers

The survey can be found at: **2026 Patient 360: Patient Experience Survey**. Thank you for your time and perspective!

What You Should Know About Copay Accumulators

Health insurers use copay accumulator programs that can change how much patients pay for their prescription medicines. In this PBS interview, Marisa Wojcik talks with Rob Gundermann, CEO of the Coalition of Wisconsin Aging & Health Groups, about how these programs work and how they can impact patients' costs. This is an important topic that impacts many neuropathy patients that needs more attention. Watch the 8-minute interview at: **Rob Gundermann on copay accumulator impacts on health costs | Here & Now**.

Scrambler Therapy: One Helpful Tool in a Bigger Pain-Care Picture

By Laura Brown

(This article is for educational purposes and not for the purpose of rendering medical advice. Information printed below is not intended to replace the counsel of your provider. Information provided does not imply medical recommendation or endorsement. The NAF does not endorse any medications, products, equipment, or treatments.)

Living with chronic pain is exhausting. Not just in your body, but in your thoughts, your plans, and your hope. If you are reading this, you already know pain is more than an ache. It can change how you move, sleep, work, and even how safe your body feels. This article explains Scrambler Therapy in clear, simple terms and places it where it belongs: as one helpful tool inside a larger, team-based approach to pain care.

What Is Scrambler Therapy?

Scrambler Therapy is a non-invasive, drug-free treatment designed to help calm pain signals. Chronic pain often means the nervous system keeps sending danger messages even when tissues are no longer injured. Scrambler Therapy uses small surface electrodes placed on the skin near, but not on, the painful area. These electrodes send gentle, non-painful signals to help interrupt pain messages and support calmer signaling patterns.

What Scrambler Therapy Is Not

Scrambler Therapy is not surgery, injections, medication, electrical shock, or a cure for all pain. It does not replace other forms of care and works best when combined with other supportive treatments.

Why It Works Best as Part of a Bigger Plan

Chronic pain involves more than nerves alone. Movement, stress, sleep, emotions, and past experiences all play a role. That is why many pain specialists support a multi-disciplinary approach that may include physical therapy, massage, education, counseling, lifestyle support, and Scrambler Therapy working together.

A Final Word

Scrambler Therapy is not a stand-alone answer to chronic pain, but for many people it can be a meaningful and supportive part of their care. When the nervous system begins to feel safer, other approaches such as movement, hands-on care, education, and emotional support often become more effective as well. Chronic pain is complex, and managing it takes time, patience, and the right combination of tools. Your pain is real. Your experience matters. And there are options that may help support your path forward.

Sidebar: Questions to Ask Your Provider About Scrambler Therapy

- Is my pain likely nerve-related or influenced by the nervous system?
- Could Scrambler Therapy support the treatments I am already using?
- What goals would we set before starting this therapy?

- How would we measure progress or improvement?
- How many sessions are typically recommended?
- What does it feel like during treatment?
- Are there reasons this therapy might not be a good fit for me?
- How can this therapy fit into a broader pain management plan?

Laura Brown is a physical therapist and massage therapist with 29 years of experience. She practices in Clifton Park, NY, and focuses on integrative, patient-centered approaches to chronic pain care. Learn more at **www.laurabrownptpllc.com**.

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