November 2025 Issue

Neuropathy Action Foundation
Awareness ▪ Education ▪ Empowerment

Patient Voice - November 2025 Issue **Visit our Website**

In this Issue

You Make Our Work Possible. Help Us Finish Strong.

Dear Member,

As this year draws to a close, we at the Neuropathy Action Foundation (NAF) reflect on the progress we've made—and the urgent work still ahead.

Each year, millions of Americans are affected by neuropathy, a debilitating condition that can rob individuals of their independence, mobility, and quality of life. Many feel isolated, misunderstood, and unsure where to turn. That's where we come in—and where your support makes all the difference.

Thanks to generous donors like you, in the past year alone:

- We expanded our Patient Advocacy Program, helping individuals navigate insurance and secure coverage for critical therapies.
- We educated two million individuals from twenty-seven countries through our website **empowering patients and caregivers** with knowledge and support.
- We produced three white papers on the **Future of Gene Therapy**, the **Promise and Potential Hazards of Artificial Intelligence (AI)**, and the **Value of Clinical Trials**.
- We continued to advocate at the state and federal level for policies that **protect patient rights** and **increase access to care**.

But the need is growing. Many neuropathy patients still struggle to get accurately and timely diagnosed. Access to treatments—especially immunoglobulin therapy (IVIG)—remains inconsistent and costly. And too often, patients feel like they are facing this battle alone.

That's why we need your help today! With your tax-deductible year-end gift, we can advocate for increased patient protections, and provide additional free resources, webinars, and support to patients in need. Together, we can give those living with neuropathy hope, resources, and a stronger voice.

Please join us by making your gift today! **click here** Your generosity brings us one step closer to a world where no neuropathy patient feels alone or forgotten.

With deep gratitude,
Dominick V. Spatafora
President

Participate in a Study on Peripheral Neuropathic Pain

Emely, a master’s student collaborating with a biotech startup developing safe, non-opioid treatment for **peripheral neuropathic pain**, is inviting participants to complete a brief **anonymous screening survey** (5–10 minutes). The goal is to better understand patients’ perspectives related to neuropathic pain and to identify those who might be eligible and interested in a **follow-up online in-depth interview to share their experiences and needs**.

The survey includes just a few short questions and takes only a few minutes to complete. All participation is **voluntary and anonymous**, with no personal information collected. If you meet the inclusion criteria and are willing to share more, you are invited to book a time slot for an online interview to talk about your experiences in more depth.

You can access the survey here:
https://novasbe.az1.qualtrics.com/jfe/form/SV_6VUYXypyVsBvLMi

2025 Prescription Drug Affordability and Unaffordability Patient Survey

Patients’ Voices Needed — Right Now!

There are major efforts underway across the U.S. to make prescription drugs more affordable. You’ve probably seen the ads saying the solutions will “put money back in patients’ pockets.” But here’s the problem — no one is actually asking patients why they can or can’t afford their medications. If they don't know what's working and what's not, then how are they really solving anything?

That’s where we come in. The Ensuring Access through Collaborative Health (EACH)/Patient Inclusion Council (PIC) coalition — made up of 80+ patient organizations including the Neuropathy Action Foundation (NAF) and over a hundred patients/caregivers — created and are leading a 10-minute survey to make sure real patient experiences - YOUR experiences - drive real solutions that matter to us.

Why should I participate? This isn’t a typical survey — it’s a chance to make your voice count before decisions are finalized in early 2026. It's YOUR chance to make sure we have enough data from patients to recommend solutions that will help us ... because if we can't provide this information, solutions will be largely based on savings that benefit the states and insurance companies/Pharmacy Benefit Managers. The diseases most targeted for cost reviews are autoimmune diseases, diabetes (both types), migraine, asthma/COPD, cancers, kidney disease, blood clots. But ANY condition that is treated with prescription medications matters!

To take the survey please visit: **Online Survey**

2026 PNS Call for Training Grant Applicants

In alignment with the mission of the Peripheral Nerve Society (PNS) one of the goals of the organization is to help researchers' careers and foster excellence in peripheral nerve research including clinical, translational, and basic science. The PNS Laura Feltri Training Grants Program offers funding to junior investigators to develop a 2-year project under a PNS Member mentor. New in 2026, PNS will offer up to three 2-year training grants and junior investigators may work under a mentor at their current institution or a new institution.

Who is Eligible to Apply:

Junior clinical investigators
This grant supports junior clinical investigators to acquire or consolidate expertise in clinical observational studies, clinical outcome measures and/or in clinical diagnostic and therapeutic development.

Junior scientists or junior clinician scientists
This grant supports junior scientists or junior clinician scientists to develop expertise and knowledge in peripheral nerve research by answering key questions in Schwann cell/axonal biology and/or by elucidating relevant disease pathomechanisms.

The training grant application deadline is January 2, 2026. More information on the PNS training grants can be found, **here**.

Governor Newsom Signs SB 41 to Lower the Cost of Prescription Drugs

On October 11 Governor Gavin Newsom signed SB 41 (Wiener) Pharmacy Benefits Managers (PBMs) into law which was co-sponsored by the California Chronic Care Coalition, California Pharmacists Association, San Francisco Aids Foundation, and the Los Angeles LGBT Center.

“We are incredibly grateful to Governor Newsom for signing this critical legislation and to Senator Wiener for his leadership in getting it across the finish line,” said Liz Helms, President and CEO, California Chronic Care Coalition. “SB 41 is one of the most comprehensive PBM reform bills in the nation — a model for other states looking to protect access to care and reduce costs for patients. This law will protect patients, support health care providers, and foster a more equitable health care system for all.”

Please see the links below from the offices of Governor Newsom and Senator Wiener as well as links to news articles from the weekend the bill was signed into law:

- Oct. 11 | **Governor's Office**: Governor Newsom signs SB 41 to lower the cost of prescription drugs (**link**)
- Oct. 11 | **Senator Wiener's Office**: Governor Newsom Signs Nation-Leading Bill To Crack Down on Prescription Drug Price Gouging By Megacorporation's (**link**)
- Oct. 11 | **POLITICO Pro**: After failed attempts, California to regulate pharmacy middlemen with new law (**link**)
- Oct. 11 | **Bloomberg Gov**: California Gov. Newsom Signs Measure on Drug-Price Middlemen (**link**)
- Oct. 11 | **San Francisco Chronicle**: Newsom signs slate of new laws affecting medication prices, women's health care and school threats (**link**)
- Oct. 12 | **The Sacramento Bee**: Gavin Newsom signs CA bill to lower medication costs, rein in insurance middlemen (**link**)
- Oct. 12 | **AIDS Healthcare Foundation**: AHF Commends CA Gov. Newsom for Signing PBM Reform Bill (SB 41, Weiner) (**link**)

A big thank you to everyone for your support. It took a village but then we are all Fierce Warriors!

Caregiver Voices: A Joint Webinar by the GBS|CIDP Foundation and the Foundation for Peripheral Neuropathy

Join other patients and caregivers on **November 13 at 2 PM EST** for an empowering caregiver panel discussion co-hosted by the GBS|CIDP Foundation International and the Foundation for Peripheral Neuropathy. Together, these organizations are uniting their communities to spotlight the vital role of care partners supporting loved ones living with GBS, CIDP, and peripheral neuropathy.

The conversation will be hosted by Dr. Albert Freedman, a clinical psychologist who has worked extensively with individuals and families affected by rare and chronic conditions. With decades of experience supporting patients and caregivers through the emotional and practical challenges of illness, Dr. Freedman brings both professional expertise and compassionate insight to this important discussion.

Moderated by Kelly McCoy, Director of Patient Engagement at the GBS|CIDP Foundation, and Amanda Homscheid, Program Manager at the Foundation for Peripheral Neuropathy, the session will feature two inspiring caregivers:

Register today at: **gbscidp.tfaforms.net/4990382?eid=a5DVU000000vQ0z**

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