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Celebrating 20 Years - And Building the Future for Neuropathy Patients

Twenty years ago, the NAF was founded on a simple premise: that no one should face neuropathy alone. Twenty years later, because of supporters like you, we have grown from a small organization primarily focused in California into a national organization that has helped thousands of patients nationwide and internationally navigate their journeys and learn how to advocate for themselves. Through educational platforms like large scale events, webinars, media campaigns, and policy work, we have created spaces for learning, awareness, and empowerment. Behind the scenes, our policy work has driven real change — improving access, equity, and outcomes for those who need it most.

But the need is growing. Many neuropathy patients still struggle to get accurately and timely diagnosed. Access to treatments - especially immunoglobulin therapy (Ig)—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 gift, we can advocate for increased patient protections and provide additional free resources and support to patients in need. Together, we can give those living with neuropathy hope, resources, and a stronger voice.

As we celebrate our **20 Year Anniversary** we are asking for your support. Please join us in celebrating our history by securing our future. A donation of any amount can be made at [NAF Contribution Form](#).

Warmest Regards,
Dominick Spatafora
Founder and President



Seeking Participants: Join The CASCA Study for CIDP Treatment

Chronic Inflammatory Demyelinating Polyneuropathy (CIDP) is a rare condition that affects the peripheral nerves. These are the nerves outside your brain and spinal cord. Each nerve has a protective layer called the myelin. In people with CIDP, the immune system mistakenly

attacks the myelin, leading to damage. As a result of this damage, communication between the nerves and the brain may be disrupted. Symptoms are not the same for everyone. Because of this, CIDP can be difficult to diagnose.

If you or a loved one have been diagnosed with CIDP, consider enrolling in a clinical study to help find potential treatment options and an enhanced quality of life for people living with this condition.

What is The CASCA Study?

The CASCA Study is a clinical study researching an investigational drug called TAK-411, which is:

- Being evaluated as a potential treatment for CIDP
- Given as an intravenous (IV) infusion
- Not approved by any regulatory authority for use outside of research studies like this one

Although there are available CIDP therapies, disease outcomes and response to treatment can be different. In this study, TAK-411 is being evaluated to learn about:

- What are the effects when given to people with typical CIDP
- How safe it is and how the body tolerates it
- How the immune system reacts to it

Who Can Join?

You may qualify to participate in this study if you are at least 18 years of age and you:

- Have been diagnosed with typical CIDP
- Responded to immunoglobulin G (IgG) treatment in the past
- Are currently receiving immunoglobulin intravenous (IGIV) treatment

You will also need to meet additional criteria, which the study doctor and staff will explain. Talk to your healthcare provider to learn more about this clinical study. You can find more information by visiting <https://www.thecascastudy.com/en-US>.



Dr. Gregory Maassen Completes First Leg of 5,800-Mile E-Bike Journey Across America

On March 24 Dr. Gregory Maassen completed Segment 1 of his solo 5,800-mile cross-country e-bike journey! The milestone marks the first of ten planned segments in a coast-to-coast tour undertaken in partnership with the Merkin Peripheral Neuropathy and Nerve Regeneration (PNNR) Center at Johns Hopkins University to raise national awareness of peripheral neuropathy, a painful neurological condition affecting more than 30 million Americans.

In this first segment of the tour, Dr. Maassen rode through the Everglades, past natural wonders, and beautiful beaches. He discovered the finest of roadside cuisine, and stayed in tents, campgrounds, motels, and generously lent couches. The weather was an issue this segment, with unexpected cold, wind, and rain, battling the intrepid rider on his journey. But as with all of Dr. Maassen's rides, he met strangers that became friends, scientists that advance research, and communities that come together to greet our rider on his adventures.

Dr. Maassen, a native of the Netherlands and founder of E-bike Lovers, was diagnosed in 2019 with post-infection peripheral neuropathy by Dr. Ahmet Hoke at Johns Hopkins, after spending almost 18 months bedridden with an undiagnosed condition contracted while on assignment in South Africa in 2017. Dr. Hoke prescribed exercise as part of his treatment, and Dr. Maassen credits e-biking with aiding his recovery and helping him manage his symptoms.

The tour is conducted in partnership with the Merkin PNNR Center at Johns Hopkins, which is dedicated to advancing research and developing new therapies for peripheral neuropathy. Dr. Maassen hopes his journey will raise public awareness, support research funding, and shorten the diagnostic journey that he and millions of other patients have endured.

The tour is expected to conclude in Los Angeles on July 21, 2026, covering 5,800 miles across 11 states and nearly 100 stops.



Share Your Voice: Global Survey on Plasma-Derived Medicines and Donation

The Plasma Protein Therapeutics Association (PPTA) launched a global patient survey to better understand how patients view the medicines they depend on, including their awareness of how these therapies are made and the vital role plasma play in making them possible.

Your input will help us better understand:

- Patient awareness of where plasma-derived medicines come from
- Perceptions of plasma and the role they play in saving and improving lives
- Trust in the safety and quality of plasma-derived therapies
- Opportunities to strengthen patient education and awareness worldwide

By sharing your experience and perspective, you can help raise awareness about the people and processes that make these lifesaving treatments possible. The insights gathered will help inform future education, advocacy, and awareness efforts to ensure patients and the public better understand the lifesaving impact of plasma donation.

If you are a patient, caregiver, or part of the patient community, we encourage you to participate and share your perspective. The survey closes: August 14, 2026 and can be found at: <https://www.surveymonkey.com/r/IPAWpatientsurvey>.

Research Spotlight: Emerging Insights on Elevated P-Tau and Neuropathy

For people living with neuropathy, a major challenge is identifying what's causing nerve damage and whether it stems from an underlying, potentially treatable disease. We're pleased to share significant new research [published in *Nature Medicine*](#) suggesting that a simple blood test could help identify amyloid-related neuropathy, which commonly occurs in AL and ATTR amyloidosis.

These conditions involve the buildup of misfolded proteins in tissues, often damaging peripheral nerves and leading to progressive polyneuropathy. In this study, co-lead author Stephanie Schultz, PhD, of the [Mass General Brigham Neuroscience Institute](#) and international collaborators examined whether a blood marker called phosphorylated tau (p-tau)—best known for its role in neurodegenerative brain diseases—could also signal amyloid disease outside the brain.

The researchers found that blood p-tau levels were elevated in people with AL or ATTR amyloidosis (particularly those with amyloid-related neuropathy), but not in people with neuropathy from other causes. Together, these findings suggest that a blood test could help point to amyloid as an underlying cause of neuropathy, supporting earlier diagnosis and more targeted care.

NAF Joins 70 Other Organizations in Support of DOL's PBM Transparency Rule

Ahead of the U.S. Department of Labor's (DOL) review of its [proposed rule](#), *Improving Transparency into Pharmacy Benefit Manager (PBM) Fee Disclosure*, the PBM Accountability Project led a coalition of 75 national organizations, including the NAF, sent a letter to Secretary Lori Chavez-DeRemer applauding the Department's leadership in advancing long-

overdue, common-sense guardrails to rein in the unchecked influence of PBMs over employer-sponsored prescription drug benefits.

We have seen undeniable evidence that PBMs and their parent corporate insurers have leveraged market consolidation and vertical integration to accumulate outsized power in the healthcare and prescription drug marketplace. In doing so, they have constructed self-reinforcing pricing structures that inflate drug costs, penalize or restrict cost-saving practices, and undermine patient choice and access. The inclusion of PBM reform components in the Consolidated Appropriation Act of 2026, the Federal Trade Commission's recent consent decree with Express Scripts over insulin pricing, and the FTC's earlier documentation of PBM price manipulations should be considered positive first steps to much needed reforms and make clear the desire in the public policy sphere to fix this broken system.

However, we are concerned that PBMs will exploit any loophole, as they have many times in the past, to avoid necessary disclosures under the proposed rule. Therefore, the letter suggests improvements to the proposed rule such as:

- DOL should stipulate that all PBM compensation must be reported
- All disclosed information should flow to DOL.
- DOL should provide more specific information on the PBM fiduciary role.

Read the full letter [here](#).

Help Shape the Future of Diabetic Foot Care

Living with diabetic neuropathy means navigating challenges that most people never see — including the very real risk of foot wounds that can go unnoticed until they become serious. Atiq Bhatti, MD, an Innovation Fellow at the University of Minnesota's Bakken Medical Devices Center, is conducting research on identifying clinical unmet needs and ways to improve the detection and management of diabetic foot ulcers at home. The goal: a device that gives patients an earlier warning, before small wounds become big problems.

But the most important part of this research isn't the technology. It's your experience. We're inviting patients to share their story through a brief, anonymous survey (about 5 minutes). Your responses will directly shape what gets built, ensuring the solution actually fits your life, not just a textbook description of it.

Whether you've had a foot ulcer or simply live with the daily reality of neuropathy, your voice matters here.

 [Take the Survey](#)

Questions? Reach out directly: bhatt476@umn.edu

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