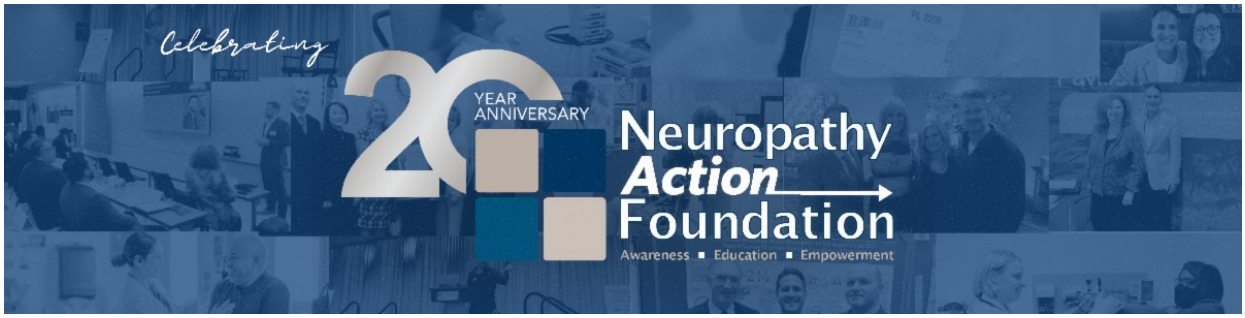
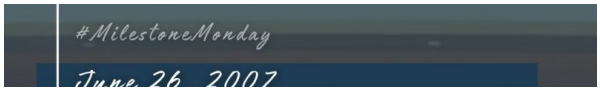



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## A Milestone Worth Celebrating.




# A Mission Worth Continuing.

**Dear Member,**

As we close out an extraordinary year, we celebrate not only the 20th Anniversary of the Neuropathy Action Foundation (NAF), but also two decades of awareness, education, advocacy, and unwavering commitment to improving the lives of people living with neuropathy. This milestone is an opportunity to reflect on how far we have come, recognize the impact of our collective efforts, and look ahead to the important work that remains.

**Twenty Years of Putting Patients First**

For 20 years, NAF has worked to elevate the voices of patients and their families, increase awareness of neuropathy, and advance policies that support access to treatment and medications. 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.

Over the past 20 years, the NAF has worked to ensure that the voices and needs of people living with neuropathy are not overlooked. We know that behind every policy discussion is a person seeking answers, a family trying to navigate treatment decisions, and a patient hoping to maintain independence and quality of life.

**Help Us Build the Next 20 Years**

Many neuropathy patients still struggle to get accurately and timely diagnosed. Access to treatments and medications can be costly, with financial constraints, limited availability, and other systemic barriers preventing many individuals from receiving the care they need. And too often, patients feel like they are facing this battle alone.

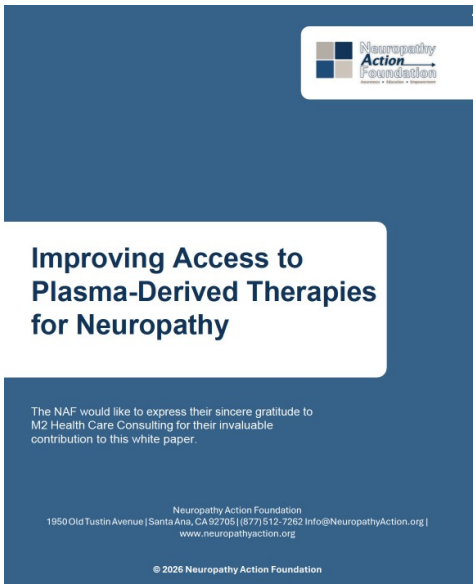
That is why we need your help today! With your tax-deductible gift, we can advocate for increased patient protections and provide additional free resources and support. Your generosity helps ensure that the needs of people living with neuropathy remain part of the conversation among policymakers, the media, and others who influence patient care.

Please join us by making your gift today by **clicking here**

Your generosity helps ensure that patients living with neuropathy have a voice and hope for the future.

With deep gratitude,

Dominick V. Spatafora
President




## NAF Releases White Paper Urging Action to Improve Access to Lifesaving Plasma-Derived Medicines

On November 17, the NAF released, *"Improving Access to Plasma-Derived Therapies for Neuropathy,"* a new white paper identifying outdated state regulations, plasma supply challenges, and insurance restrictions that can stand between patients and the treatments they need. Developed in partnership with M2 Health Care Consulting, the paper calls for practical policy changes to strengthen the nation's plasma ecosystem, reduce unnecessary barriers to source plasma collection, and improve patient access to plasma-derived medicines.

"More than 20 million Americans live with some form of neuropathy, and for many individuals with immune-mediated neuropathies such as chronic inflammatory demyelinating polyneuropathy (CIDP), Guillain-Barré syndrome (GBS), and multifocal motor neuropathy (MMN), plasma-derived medicines can be a first-line treatment," said Brenda Gleason, President of M2 Health Care Consulting. "The United States supplies more than 70 percent of the world's plasma, but vulnerabilities throughout the supply chain create challenges in maintaining a consistent supply. We need to look at the entire plasma ecosystem and develop policies that support a safe, reliable plasma supply, while ensuring patients can access the treatments they need."

The white paper highlights the complexity of the plasma supply system, from healthy human donors to the manufacturing of finished medicines, a process that can take up to a year. It also highlights recent legislative victories, including California's Assembly Bill 2009 and Connecticut's Senate Bill 368 which modernize state regulations for source-plasma collection, while preserving donor safety and product quality.

A reliable plasma ecosystem is only part of the solution. Patients also face insurance denials, restrictive medical necessity criteria, repeated prior authorization requirements to try other treatments before receiving prescribed therapy.

To access full white paper, please visit **www.neuropathyaction.org** or click on **Improving Access to Plasma-Derived Therapies for Neuropathy - November 2026.pdf**.

## When "Chronic" Hits You All Over Again

By Abbie Cornett, MBA
IG Living August-September 2026

The National Institutes of Health defines chronic illness as a disease or condition that usually lasts three months or longer and may get worse over time. Other organizations describe chronic illness as a long-lasting condition that can often be managed or controlled but not

cured. Most of us living with chronic illness have read those definitions before. We have heard them from doctors, read them in articles, and have probably repeated them to our friends and family. I know I have. But understanding something and truly believing it are two very different things.

Something happens after you have lived with chronic illness long enough. Life starts to settle down. Treatments work. Symptoms become manageable. You go months, or even years, feeling pretty good. Slowly, without realizing it, you forget what chronic means. You say yes to things you might have thought twice about before, stay out later and think about things besides doctors, medications, and appointments. You start feeling more like yourself again before your diagnosis.

During those periods, it becomes easy to forget. Not forgetting in the sense that you stop taking medications or stop going to appointments but forgetting in the sense that illness is no longer at the center of your life. You almost start thinking maybe things are different now. Maybe somehow your illness eased up. Maybe you are one of those miracle stories, and you are no longer sick.

To continue reading visit **IG Living August-September 2026**

## Video Illustrating the Importance of Plasma and Plasma Donation

Plasma is one of the most valuable and lifesaving components of human blood, playing an essential role in treating a wide range of medical conditions and saving lives. For the neuropathy community, plasma is particularly important because it is used to manufacture therapies such as Intravenous Immunoglobulin (IVIG), which can be life changing for people with certain autoimmune and immune-mediated neuropathies, including CIDP, MMN, GBS and other related conditions.

Plasma donation is an extraordinary gift of generosity that has a direct impact on people whose lives depend on these therapies. Unlike many medications that can be manufactured synthetically. Immunoglobulin therapies require human plasma donations, and there is no substitute for the generosity of donors. It takes donations from many individuals to provide enough plasma to create the treatments needed by one patient over time. For the neuropathy community, every donation represents hope, access to treatment, and the possibility of a better tomorrow. Whether you donate plasma yourself, encourage others to donate, or simply help spread awareness, you are making a meaningful difference in the lives of people with neuropathy.

One person whose life was changed was NAF Founder Dominick Spatafora. At the age of 30 he was diagnosed with MMN, a rare autoimmune disease. Thankfully, treatment with IVIG gave him hope and helped him manage his condition. However, less than a year into treatment, Dominick faced unexpected challenges accessing the treatment he relied on.

Dominick's story is just one of many, but we grateful to share it. The NAF sincerely hopes that this video helps others understand that plasma donation can make a real difference in someone's life. Plasma donors never meet the people they help, but their generosity can change lives in ways they may never fully realize.

Watch Dominick's story here: **https://lnkd.in/eJaDBP44**




## California Chronic Care Coalition "Stars of Advocacy" Gala

On November 5 in Sacramento the California Chronic Care Coalition (CCCC) hosted their 2026 Stars of Advocacy Gala which was an incredible evening celebrating advocacy, leadership, and the power of bringing people together to make a difference in healthcare. This special 20th anniversary celebration brought together passionate patient advocates, healthcare leaders, elected officials, community organizations, and supporters who share a commitment to improving the lives of individuals living with chronic and rare diseases. The evening was filled with inspiration, meaningful connections, and well-deserved recognition of those who dedicate their time and efforts to advancing patient-centered care, improving access to treatment, and giving a voice to those who need it most.

A particularly proud and exciting moment was the recognition of Dominick Spatafora, Founder of the Neuropathy Action Foundation (NAF), who received a "Star of Advocacy" Award. This well-deserved honor recognizes his dedication and longstanding commitment to raising awareness of neuropathy, advocating for patients, and improving the lives of those affected by this often misunderstood condition. His recognition was a wonderful reminder of the importance of passionate advocates who turn their personal commitment into meaningful change for others.

Congratulations to Dominick and all of this year's honorees. Most importantly, the NAF would like to thank the CCCC and its Founder Liz Helms who has spent 20 years of giving patients a voice and advocating for healthcare access and affordability in California!

## Department of Treasury and the COINS Act

Innovation bridges unmet need and better care. Patients who are waiting for meaningful therapies should not face a growing innovation gap in addition to a treatment gap. As the U.S. Department of the Treasury considers the *Comprehensive Outbound Investment National Security Act (**COINS Act**),* the Neuropathy Action Foundation (NAF) urges a balanced approach that protects patients, innovation, and future treatments. The NAF also requests a balanced approach, so restrictions do not slow therapies for peripheral neuropathy and other rare neurological conditions.

With that being said the NAF released the following Position Statement on October 29.
"*For people living with rare diseases, innovation is not an abstract policy debate. It is the difference between maintaining mobility, preserving independence, and managing chronic pain. That's why the Neuropathy Action Foundation supports efforts to strengthen the United States' leadership in biomedical innovation. As the Department of Treasury considers implementation of the Comprehensive Outbound Investment National Security Act (**COINS Act**), it is critical that proposed investment restrictions do not unintentionally slow the development of therapies for patients living with peripheral neuropathy and other rare neurological conditions.*

*Millions of Americans live with chronic neuropathic conditions, yet many forms of neuropathy remain poorly understood and lack effective treatments. For patients with rare neuropathies, treatment options are often nonexistent. Research collaborations, scientific exchange, and investment across borders have historically helped advance the discovery of new therapies for diseases with significant unmet need.*

*Americans living with neuropathy already face challenges accessing treatment, and any new barriers to research and development could further delay progress. As the Administration seeks to protect national security interests through the COINS Act, and as the Department evaluates comments on the proposed rule, we encourage a balanced approach. Patients who are waiting for meaningful therapies should not face a growing innovation gap in addition to a treatment gap."*

## What "I'm Doing Okay" Leaves Out: Bringing the Weeks Between Appointments into the Conversation

By Mamuna Oladipo

"How have you been?" can be a difficult question to answer when it covers several weeks of your life.

You might feel okay that morning and still want to talk about the nights you couldn't sleep or the everyday tasks that have become harder. Once you're in the appointment, those details can be difficult to put into words. "About the same" may be the easiest answer, even when there's more you meant to say.

For someone living with neuropathy, the story between appointments matters. A brief record of symptoms, treatments and changes in daily life gives you something concrete to bring into the conversation. It can also help you decide what you most want to discuss.

### Start with what you want to remember

You don’t need to document every hour. Start with a change you’d want your doctor to know about, or a question you keep meaning to ask.

Write down what you noticed and roughly when it happened. Add a detail about what it meant for your day. For example, a note might say, “The discomfort in my feet interrupted my sleep twice this week,” or “I needed help fastening my shirt this morning.” These are examples of the kind of detail you could record, rather than a checklist everyone needs to follow.

Your own words are enough. You can describe a sensation without knowing the medical term for it. If you’re unsure when something started, say that. An approximate date is more honest than trying to reconstruct a precise timeline you don’t remember.

Make room for improvements, too. If an activity feels easier or you’re sleeping more comfortably, that may be something you want to discuss alongside the difficulties.

## Keep the record manageable

Choose a place you’re likely to use: a small notebook, a note on your phone, a voice recording, or an app. A sentence can be enough to preserve something you would otherwise forget.

If you miss a few days, you can pick up where you are. There’s no need to turn catching up into another task. Ask your care team whether there’s anything specific they’d like you to record and how often. That can help you focus your effort.

If a caregiver helps, agree on what would be useful to capture. They might write down an observation you describe or help gather questions before the visit. Review those notes together so they reflect what you want the doctor to understand.

## Include treatment changes and questions

Keep an up-to-date list of the medicines and supplements you take. When a treatment changes, note the date if you know it, along with anything you want to ask about afterward.

Be careful about drawing conclusions from timing alone. If you notice a change after starting a treatment, bring that observation to your clinician as a question. You don’t have to work out the explanation before raising it.

Your notes should also support contact between visits. If symptoms are new or worsening, or you’re concerned about a possible side effect, contact your care team rather than waiting to finish a record for the next appointment. Ask what changes should prompt a call and how best to reach them.

## Bring the main concern into focus

Before your visit, read through what you’ve collected and identify the concern you most want to address. Choose a concrete example that helps explain it. Keep the rest of your notes available if your doctor wants more detail.

A simple starting point is: “Since my last appointment, I’ve noticed ___. It’s affecting ___. I’d like to ask about ___.”

That last part matters. You may want to understand a symptom, ask about your treatment, or

explain that something important to you has become harder. Naming the question gives the conversation a clear place to begin.

Before you leave, write down the next steps you've agreed on and ask about anything that's unclear. You can use those notes when preparing for your next visit.

You deserve to be heard whether you arrive with a detailed record, a few sentences, or no notes at all. When keeping notes is useful to you, start small. Capture the thing you don't want to forget and bring it into the conversation.

*Mamuna Oladipo is the founder of Theme Health.*

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