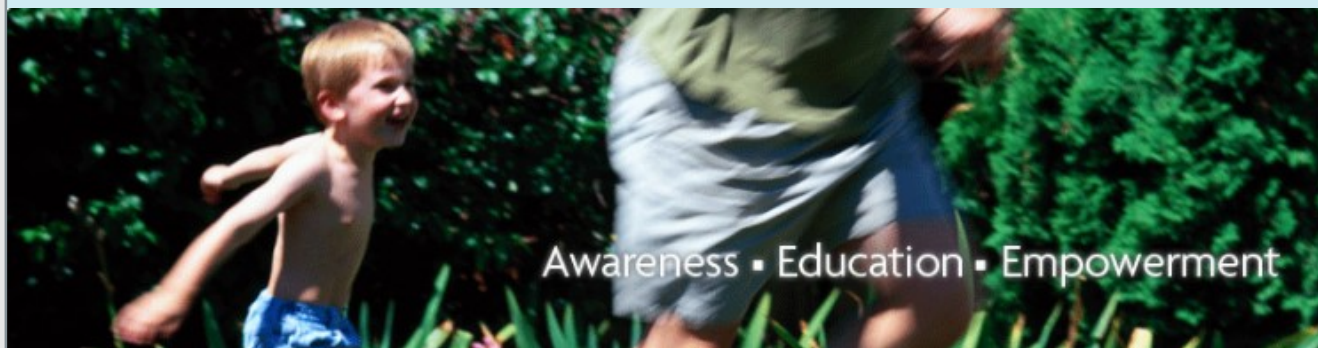




Patient Voice - July 2025 Issue

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NAF Fighting for Patients

Dear Member,

In June the Neuropathy Action Foundation joined over 15 other organizations encouraging Members of Congress to support and work to pass the Electrodiagnostic Medicine Patient Protection and Fraud Elimination Act (H.R. 3092).

Electrodiagnostic (EDX) medicine, which includes nerve conduction studies, needle electromyography, and similar procedures is used to diagnose and treat a variety of conditions. EDX testing may diagnose a common condition such as a pinched nerve or carpal tunnel, or rare diseases like ALS, muscular dystrophies, and neuropathies like multifocal motor neuropathy (MMN). Any delay in an accurate diagnosis could severely impact a patient's prognosis and alter their treatment or ability to access a clinical trial. Misdiagnosis can also drive unnecessary surgeries and inappropriate courses of therapy.

H.R. 3092 will improve patient care and eliminate fraud and abuse in EDX testing. This commonsense legislation seeks to ensure patients get the right tests at the right time by creating a compliance mechanism for existing CMS rules governing EDX studies thus requiring professionals performing the studies to simply demonstrate that they have the correct equipment along with the correct training to perform/supervise the tests and make a diagnosis. Such an approach has been successful in other areas of patient care where quality was problematic and fraudulent testing was rampant, namely sleep labs and mobile mammography labs.

Peripheral Nerve Society (PNS) Highlighted

The 2025 Peripheral Nerve Society's Annual Meeting took place in Edinburgh, Scotland from May 17-20. This annual meeting is the place to learn about the latest international research across specialties in peripheral neuropathy. As the largest peripheral nerve meeting globally, it is the premier venue for neurologists to connect with their peers and learn more about patient organizations in attendance as well.

The Peripheral Nerve Society was founded in 1994, having evolved from two groups of academic investigators interested in understanding the basic biology and function of the peripheral nervous system – the nature of nerve injury and repair. These groups met periodically in closed meetings to discuss advances in this understanding and how this knowledge might be applied to care for patients with genetic, traumatic, toxic, or metabolic nerve disease.

The interests of PNS members encompass all aspects of the peripheral nervous system, both clinical and scientific, and range from electrophysiologic tools for diagnosis to molecular mechanisms of disease and nerve fiber regeneration. The Society is incorporated, and open to general membership by any professional interested in the peripheral nervous system and its diseases.

The mission of the PNS is to improve the lives of people with peripheral neuropathies.

Medicare Part D Utilization Management Advocacy

In June the NAF communicated with Dr. Oz at the Centers for Medicare & Medicaid Services (CMS) to request that CMS take action to protect Medicare beneficiaries' access to necessary treatments now that Part D benefit redesign enacted under the Inflation Reduction Act are now in effect. With the expanded use of utilization management (UM) tools in Medicare Part D, we remain concerned that CMS needs to take steps to better protect beneficiaries by improving transparency around the impact of these changes in their Part D plan choices and institute additional guardrails to ensure that beneficiaries have appropriate and timely access to treatment.

Effective this year Medicare Part D plans are responsible for 60% of costs in the catastrophic phase, up from 15% in 2023. This higher level of cost sharing creates incentives for plans to increase their use of UM tools such as step therapy, fill limits, formulary changes, non-medical switching, and prior authorization requirements. While UM is intended to lower drug expenditures, and can be appropriate in some circumstances, restrictive cost-control measures can delay or prevent beneficiaries from accessing necessary treatments. This can have significant clinical consequences, especially for the populations served by the Part D program.

We are already seeing the expanded UM in Part D. The Medicare Payment Advisory Commission (MedPAC) reports that the use of UM tools such as quantity limits, step therapy, and prior authorization in Part D has grown. Meanwhile, more Part D formularies are shifting from copayments to coinsurance, which often lead to higher and less predictable out-of-pocket costs for beneficiaries.

While the agency previously indicated that it is monitoring changes in formulary design, there are a number of additional, commonsense steps that CMS can take to better support beneficiaries in response to our UM concerns. For example, CMS should outline clear expectations around the use of UM tools in Part D to ensure their appropriate use by plan sponsors. We also urge CMS to increase transparency around plans' use of UM, such as by incorporating relevant information into the Medicare Plan Finder. Enhanced beneficiary education also can help Part D enrollees be more informed about how their care may be affected by UM tools and, therefore, more empowered in their decision making as it relates to selecting the prescription drug coverage that will best meet their needs.

Busy Professionals Can Use This Guide To Live The Life They Want Without Burning Out

Patricia Sarmiento

PublicHealthCorps.org - Putting the public back into public health

You're tired, aren't you? Not sleep-deprived in the obvious way, but a deep, sneaky kind of tired that lurks behind your well-crafted calendar invites and color-coded to-do lists. The kind that creeps in after too many 8 p.m. emails disguised as "quick questions." You know burnout is circling when your Sunday dread starts early—like Friday night early. Managing a successful career doesn't need to feel like slow-motion suffocation. Let's build something sturdier than hustle: a life that breathes, stretches, and stays intact.

Own Your Hours, Don't Rent Them

If your calendar feels like a confessional booth, it's time for a rethink. Time blocking isn't new, but it's criminally underused. Instead of just logging meetings, start assigning your best brain hours to deep work—and guard them like your last slice of pizza. Group similar tasks together to reduce mental lag, then sprinkle in margin time for fires, flakes, and full-on chaos. Treat lunch like a non-negotiable appointment, not a myth. You're not lazy for scheduling breathers; you're strategic for planning how to last.

Create A Home Office That Doesn't Suck the Life Out of You

Your work environment is quietly shaping your stress levels whether you realize it or not. Start by upgrading your furniture to support your spine instead of punishing it. Ergonomic chairs and standing desks aren't indulgences—they're survival gear. Create a system for organizing digital and paper files so your brain isn't playing hide-and-seek every morning. Ample lighting, especially natural light, can subtly boost your alertness and mood. These seemingly small changes can have a big impact on the way you feel every day.

Boundaries Are Not Negotiable

When you reply to emails at midnight, you teach people that your time is up for grabs. Boundaries are less about shutting doors and more about deciding what stays inside. Try setting "focus hours" where Slack doesn't own you and make your end-of-day visible—no more ghost logouts. Learn to articulate what you need without apology: "I'm unavailable then" beats "I'm so sorry, but..." every time. You're building trust, not a fortress. A well-defined workday doesn't limit your output—it protects it.

The Bedroom is for Sleep, Not Slack

You can't outwork bad sleep. You can chug coffee, you can slap on under-eye patches, but your brain knows. Poor sleep doesn't just make you tired; it wrecks decision-making, impulse control, and emotional regulation. Start enforcing a nightly shutdown ritual: screen curfew, soft lighting, maybe even silence. Resist the urge to review presentations in bed like a masochist. Deep rest isn't a luxury, it's a productivity tool—without it, your sharpest skills dull.

Unplug to Realign

There's a moment—maybe mid-scroll, maybe mid-meeting—when you realize you haven't looked away from a screen in nine hours. Digital fatigue isn't dramatic, it's cumulative. Set boundaries with your tech like you do with colleagues: no notifications during meals, no inbox peeking during walks, no doomscrolling in the bathroom. Take weekends off social media and rediscover what a sky looks like without backlight. This isn't about moral superiority—it's about brain hygiene. The less reactive your mind, the more resilient your mood.

Say No and Stay Employed

You're not paid to be agreeable; you're paid to deliver value. Saying no isn't career sabotage—it's stewardship of your attention. Start with low-stakes refusals: decline a recurring meeting that accomplishes nothing, or push back on deadlines that assume you don't need sleep. When you protect your capacity, your best work surfaces. People respect someone who knows what they can handle—and what they can't. The goal isn't to please everyone, it's to keep producing at a high level without disintegrating.

Move, Even If You Don't Want To

No, you don't need to train for a marathon. But your brain is a tenant in your body, and your body is bored. Movement isn't just about fitness—it's about circulation, clarity, serotonin, and sweat. Take walking calls, stretch between Zooms, do push-ups out of spite. Exercise recalibrates your nervous system faster than any inspirational quote. Even ten minutes of motion can knock the edge off burnout and return you to yourself.

This isn't about perfection. You will overbook, overpromise, and overthink. But you can course-correct. You can shift from frantic to focused, from drained to deliberate. Burnout doesn't win in a single day—it inches in. Better to slam the door now, with intention, than wait for collapse to force your hand.

Discover empowering resources and support for neuropathy patients by visiting the Neuropathy Action Foundation today!

Navigating Your First IVIG Infusion: Preparation, Support and What to Expect

By Abbie Cornett, MBA
IG Living Magazine

Being well-prepared for your first infusion can help to ensure a successful outcome. These tips can prepare you for every step of the journey.

Treatment can be overwhelming, especially when it involves something unfamiliar such as an intravenous immune globulin (IVIG) infusion. For patients with immune deficiencies or autoimmune conditions, IVIG can be a lifesaving therapy. However, if it's your first time, you may have questions or even feel nervous about what to expect. Knowing what IVIG is, how to prepare and what the infusion process entails can make a big difference in helping you feel confident and ready. Following is some valuable information you need to know before starting IVIG therapy, including preparation tips, what to expect during your infusion, how to manage potential side effects and navigating financial considerations.

Understanding IVIG and Its Purpose

Made from plasma collected from thousands of healthy donors, IVIG strengthens the immune system by providing a wide range of antibodies, making it an important therapy for individuals whose immune responses are weakened or compromised. These antibodies work together to boost the body's defenses, offering protection against harmful bacteria, viruses and other invaders. The treatment is prescribed to manage primary immunodeficiencies, such as common variable immunodeficiency (CVID), to help patients combat infections their immune systems cannot handle on their own. Additionally, IVIG is prescribed for autoimmune diseases, such as myositis, polymyositis and chronic inflammatory demyelinating polyneuropathy (CIDP), to reduce the damaging effects of the immune system attacking the body's tissues, as well as to alleviate symptoms and prevent further complications.

To read the entire article please visit: [IG Living February-March 2025](#)



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