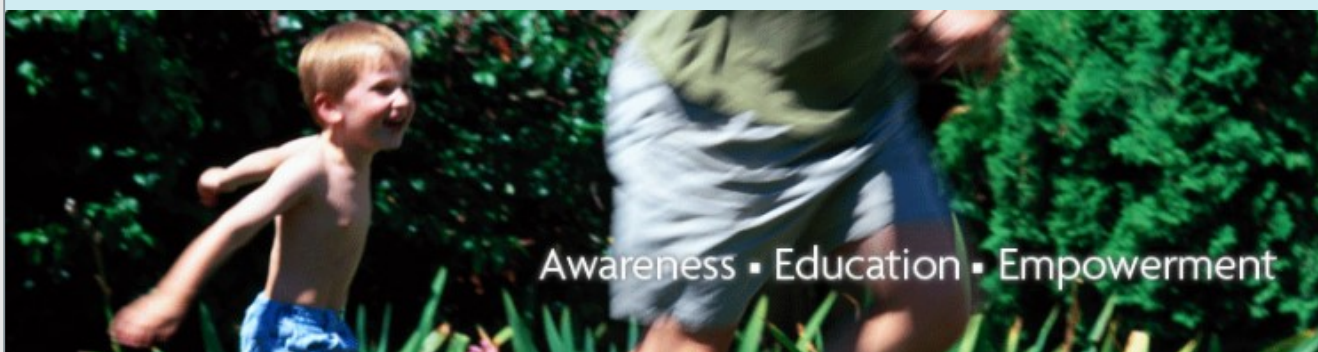




Patient Voice - May 2025 Issue

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Ensuring Patient Access to Pharmacists

Dear Member,

Last month, the Neuropathy Action Foundation (NAF), along with 55 other organizations signed a letter spearheaded by RetireSafe to congressional leaders to call for support of the **Ensuring Community Access to Pharmacist Services Act (ECAPS)**. This critical and bipartisan legislation will ensure senior access to essential pharmacist services and protect the vital role that pharmacies play in helping to keep American seniors healthy.

America's seniors rely on pharmacists as the first and most accessible healthcare provider to access critical care and services to manage their health, especially vulnerable seniors living in rural and other medically underserved areas. Unfortunately, Medicare beneficiaries continue to be without access to essential pharmacist services for diseases that, while common, can quickly turn life-threatening if not properly managed. The letter urges congressional leaders to work with members of Congress to support and pass the Ensuring Community Access to Pharmacist Services Act (ECAPS). This critical and bipartisan legislation will ensure senior access to essential pharmacist services and protect the vital role that pharmacies play in helping to keep American seniors healthy.

Nine in ten Americans live within five miles of a pharmacy, and patients visit their community pharmacist approximately twice as frequently as they visit primary care physicians. For American seniors living in rural areas, the pharmacy is often the first and only stop they make for critical health services, including medications, tests, and treatments for common and seasonal infections. Rural Medicare patients visit their community pharmacist 14 times per year on average, compared to just five visits to their primary care physician. More than half of pharmacists (55%) work in a community-based setting and 77% of community pharmacies serve populations of 50,000 or fewer. Nearly 200 rural hospitals have closed in the past two decades, increasing the role that pharmacists play as a nearby, qualified healthcare provider in rural communities.

The Ensuring Community Access to Pharmacist Services Act would provide payment for essential pharmacist services under Medicare Part B, ensuring pharmacists can protect seniors from the threat of influenza, RSV, and other common infectious diseases. Operating within state scope-of-practice laws, this bipartisan legislation will ensure seniors can access essential testing and treatment services at the pharmacy. While Americans with private insurance, Medicaid beneficiaries, and federal employees may be covered, Congress must act swiftly to ensure access to these essential pharmacist services for Medicare beneficiaries.

Reclaiming Your Wellness: Small Shifts That Help Women Break the Grind

Written by Justin Bennett, Healthyfit.info

For a lot of women, the daily hustle feels relentless. Whether you're balancing a career, family obligations, education, caregiving, or some hybrid of them all, it's easy to put your own wellness at the bottom of the list. But neglecting yourself over the long haul can sap your energy, muddy your focus, and even affect your relationships. The good news is, improving your well-being doesn't have to mean drastic changes or luxury spa weekends. Instead, it's about creating small moments of balance and building better habits that fit into the reality of your life. These tips are designed to help you carve out a little more peace and energy, even on your busiest days.

Eating Better on a Schedule That Works for You

You don't need to follow the latest celebrity diet or count every calorie [to eat better](#). You just need to make more conscious choices about what you're putting into your body, and when. Start by asking yourself how certain meals make you feel—bloated, sluggish, energized, focused? Small shifts like swapping out sugar-loaded breakfast bars for protein and fiber-rich foods can change your entire morning. Keeping prepped veggies, nuts, or hummus on hand helps combat the temptation of vending machine snacks. If your schedule's erratic, consider using a food prep day or even a meal delivery service that focuses on balanced portions and whole ingredients.

Incorporating Little Moves That Add Up

You don't need a fancy gym membership or an hour of free time every day to start taking better care of your body. [Starting a fitness routine](#) might be as simple as parking farther away from your office building or choosing the stairs instead of the elevator. Use your lunch break for a quick walk—it resets your mind and gets your blood flowing. If mornings are quiet, try a 10-minute yoga flow before the rest of the house wakes up. Movement doesn't have to be grand to be effective; it just has to happen. The real win is consistency, not intensity.

Managing Stress Without a Week Off

Stress can be sneaky—sometimes you don't realize how tense you are until your shoulders start aching or your sleep turns erratic. One of the simplest, most overlooked ways to manage stress is [through your breath](#). Deep, slow breathing helps cue your nervous system to calm down. Try taking five-minute breaks during your day where you do nothing but close your eyes and breathe deeply. Other ideas: turn off notifications for an hour each day, journal for ten minutes before bed, or put on music you love and just let yourself exist. Your stress management doesn't have to be a production; it just has to be real and regular.

Sleeping Smarter, Not Longer

Getting better sleep [isn't always about more hours](#)—it's about better habits. If you're falling asleep with your phone in hand or staying up late to finish chores, your brain isn't getting the recovery time it needs. Start winding down at the same time each night, even if your bedtime doesn't feel "perfect." Create a buffer routine: a cup of herbal tea, reading a few pages of a novel, dimming the lights. Avoid caffeine in the afternoons, and turn off screens at least 30 minutes before bed. Quality sleep boosts your mood, sharpens your thinking, and strengthens your immune system—so it's worth the effort to make it easier.

Breaking Bad Habits Mindfully

Habits like stress-snacking, mindless scrolling, or smoking don't go away overnight—but they can be replaced. The trick is not to punish yourself when you slip, but to understand what drives the habit in the first place. Maybe you snack when you're bored, or [scroll social media](#) when you're overwhelmed. Once you identify your triggers, you can start inserting new behaviors. Keep a water bottle nearby when you tend to snack, or swap doom-scrolling with stretching or stepping outside. The goal isn't perfection, it's progress—choosing what you want for yourself more often than what's easy.

Rediscovering What Sparks Joy

Doing something just because you enjoy it [isn't a waste of time](#)—it's fuel. Hobbies can be anything that takes you out of autopilot and lets you express something real. It could be gardening, dancing in your kitchen, trying out new recipes, painting, or joining a book club. When your brain is focused on something that brings you joy, it relaxes in a way that chores and deadlines never allow. Start small: a single afternoon each week where you play instead of produce. You don't have to be good at it—you just have to love it.

Seeing Relationships as Wellness Tools

It's easy to fall into isolation when life gets busy, but [connections are a cornerstone](#) of emotional wellness. Even a five-minute call with your sister, a text to a friend, or a quick walk with a neighbor

can lift your spirits in ways nothing else can. Set reminders to check in with loved ones, or turn errands into mini hangouts by inviting someone along. If you've lost touch with someone, don't overthink the reconnection—just reach out with a simple hello. Feeling seen and supported isn't a luxury—it's a necessity for staying grounded.

You don't have to wait for your life to calm down to start feeling better. Your well-being doesn't hinge on expensive retreats or major life changes; it hinges on the small, repeatable choices you make every day. Whether it's taking the stairs, prepping a few meals ahead, texting a friend, or turning your phone off an hour earlier, these are not indulgences. They're tools for staying whole in a world that often asks you to split yourself up. Wellness is not a destination—it's a practice. And it's one you're allowed to begin, wherever you are, with whatever you have.

Empower yourself with knowledge and support by visiting the [Neuropathy Action Foundation](#), your resource for managing neuropathy effectively.

Make Co-Pay Assistance Count

The NAF, along with more than 75 organizations representing patients, providers, and public health advocates, is urging U.S. Secretary of Labor Lori Chavez-DeRemer to issue a promised federal rule that would close a harmful loophole that allows insurers, pharmacy benefit managers (PBMs), and third-party vendors to exploit patient copay assistance programs for financial gain.

In a **letter** sent on April 22, the groups call on the Department of Labor (DOL) to address a gap in the enforcement of the Essential Health Benefits (EHB) provision of federal law—one that enables insurers, PBMs, and third-party vendors to designate certain covered drugs as “non-essential,” evading cost-sharing protections for patients.

“It is ironic that insurers and their PBMs oppose manufacturer copay assistance programs while simultaneously utilizing these schemes that maximize the exploitation of assistance for themselves,” **80 advocacy organizations wrote in the letter to the DOL**. “Many insurers and their PBMs implement “copay maximizers” by designating certain covered drugs—usually the very ones with copay assistance—as “non-essential,” enabling these players to divert and split all available copay assistance among themselves.”

The letter continues, “Issuing this rulemaking clearly aligns with the Trump administration’s healthcare priorities, ensuring all patients can access and afford life-saving prescriptions and eliminating insurer and middlemen profit schemes.”

According to **2024 data**, 47 percent of a large sample of PBMs and insurers are now using copay maximizer programs—more than double the number from 2020. An **IQVIA report** showed that insurers and PBMs pocketed \$4.8 billion in cost-sharing assistance for themselves through copay accumulator and copay maximizer programs in 2023.

In 2024, the Centers for Medicare & Medicaid Services (CMS) finalized a rule protecting individuals in individual and small group plans from these exploitative benefit design schemes. However, enrollees in large group and self-funded plans—which cover the majority of Americans with employer-sponsored insurance—remain unprotected.

The letter calls on DOL Secretary Chavez-DeRemer to issue the promised regulation clarifying that all covered prescription drugs in large group and self-funded markets must be considered essential health benefits, preventing insurers from evading cost-sharing rules.

The groups also urge the secretary to work with the Treasury and Health and Human Services Departments to comply with a federal court order requiring copay assistance to count as cost-sharing when no generic alternative is available.

The letter points out that when the secretary was a member of Congress, she co-sponsored legislation that would close the “non-EHB” loophole and ensure that copay assistance counts.

National Institutes of Health Call to Action for Peripheral Neuropathy Research Funding

Peripheral neuropathies (PNs) pose a significant clinical challenge in the field of neurological disorders, with a prevalence of 2.4% in the general population that rises with age to over 8% in patients aged 55 years and older. Symmetrical, distal-to-proximal axonal loss is the most common form of PN and accounts for most cases. It is characterized by damage to the peripheral nerves that typically, especially for diabetes (the leading cause of PN), impacts small-diameter axons beginning in the feet and progresses proximally in a length-dependent manner.

PN results in a range of debilitating symptoms such as numbness, tingling, weakness, as well as burning or shooting pain. Along with these painful symptoms, patients may experience depression, anxiety, and sleep disturbances. As PN progresses, individuals may present with diminished sensation to mechanical and thermal stimuli, making it challenging to perceive or effectively heal injuries or trauma, which increases the risk of non-healing ulcers. In severe cases, the cumulative effects of sensation loss and non-healing ulcers can necessitate lower limb amputations. In fact, patients with PN are almost four times at greater risk of undergoing lower-limb amputation than those without.

“Kudos” to The Foundational for Peripheral Neuropathy for their work on this. To read more please visit: [A call to action for peripheral neuropathy research funding—Time to consolidate funding under one NIH initiative?](#)

NAF Opposes Tariffs on Pharmaceuticals and IVIG

The NAF is concerned about the Trump Administration’s proposal to impose tariffs on imported medicines and treatments. The NAF has been requesting that the Administration exempt Japan, Europe, India, and all other allied nations that do not pose a threat to U.S. security, from tariffs on medicines and active pharmaceutical ingredients. Such tariffs would

deprive American patients of the medicines they need to manage debilitating chronic disease and other conditions like neuropathies.

Consider the impact tariffs could have on IVIG. The tariffs could lead to increased costs for patients, supply chain disruptions, and uncertainty and response meaning actors in healthcare will seek exemptions for medical products and explore ways to mitigate the financial and logistical challenges. IVIG is a high-value product, and tariffs can significantly increase its price, making it less accessible to patients in countries with high tariffs.

People do not choose their diagnosis or their prescribed course of treatment. If a patient with multifocal motor neuropathy (MMN) relies on a specialized, European-made drug with no therapeutic equivalents, they will not have the option to switch to a more affordable alternative. They will be forced to absorb the higher cost or go without. Drug price increases would also increase costs for taxpayers and the government. [Over 60%](#) of patients with rare chronic diseases that primarily affect seniors receive health coverage through Medicare, compared to roughly 20% of patients in the general population. Other patients rely on Medicaid for coverage. Tariffs on medicines would almost certainly increase public health spending.

Tariffs would also weaken, not strengthen, domestic manufacturers -- which frequently import the active pharmaceutical ingredients used to create finished drugs. [About half](#) of the active pharmaceutical ingredients used in Americans' prescriptions are made domestically, but a substantial portion of ingredients come from allies like Europe and India. By raising the costs of these ingredients, tariffs would discourage domestic manufacturing.

If drug manufacturers are forced to contend with rising costs of ingredients, they may decide to reduce production as a cost-saving measure. That risk is exacerbated by the difficulty of restructuring supply chains on short notice. [Eight in 10](#) U.S. biotech firms predict that it would take at least a year to find new, domestic suppliers in the event of tariffs, during which time their manufacturing capacity could be severely constrained.

Finally, tariffs would have a chilling effect on efforts to develop breakthrough treatments and cures. Pharmaceutical companies have already [warned](#) that they would be forced to absorb a large portion of tariff costs, with research and development efforts the likely first casualty. For patients with diseases that still have [no cure](#) -- that is not an outcome we can afford.

We strongly support the goal of expanding domestic pharmaceutical manufacturing. But building new plants and establishing new domestic supply chains are long-term undertakings that could take years to accomplish. In the meantime, widespread tariffs would inflict immediate harm on patients and set back years of critical research. We therefore urge the Department of Commerce to limit its use of tariffs to countries that pose genuine national security threats -- and exempt allies whose exports have life-changing benefits for millions of American patients.

Historically, the United States has exempted medicines from tariffs because of the extraordinary risks they pose to vulnerable patients. We ask that you preserve that precedent to the fullest extent possible and protect millions of Americans.

Medicare Terms You Need to Know

By Abbie Cornett, MBA
IG Living Magazine (December-January 2025)

Recently, a good friend of mine — one of the healthiest people I know — called me in a complete panic. She was applying for Medicare for the first time. Even though she's in great health, trying to navigate the maze of Medicare options left her stressed and confused, and she was overwhelmed by the required paperwork and all the different terms. As we talked, I started thinking about how much more complicated this process must be for people with chronic illnesses. For those with complex medical needs, understanding Medicare policies and jargon is not only important, it's critical for ensuring proper coverage.

When transitioning to Medicare, patients with chronic diseases such as immune deficiencies and autoimmune disorders treated with immune globulin (IG) therapy (either intravenous IG [IVIG] or subcutaneous IG [SCIG]) must know Medicare plans and policies — and also understand what they mean — to secure the best care and avoid unnecessary expenses. Careful planning is key. A mistake in coverage choice can directly affect your access to treatments, cost of medications and flexibility of care.

To read the full article.....

[IG Living December-January 2025](#)



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