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Subject: Re: Patient Voice Newsletter - SEP 2025

Date: Sat, 21 Mar 2026 19:41:26 +0000

Neuropathy Action Foundation

Awareness ▪ Education ▪ Empowerment

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

In this Issue

Ensuring Pathways to Innovative Cures Group Letter to Congress

Dear Member,

Earlier this month the Alliance for Aging Research along with over 50 other organizations, including the Neuropathy Action Foundation, sent a group letter to Congressional leadership urging them to support the Ensuring Pathways to Innovative Cures (EPIC) Act. The letter highlights the importance of small molecule drugs for America's aging population and people living with chronic and complex conditions.

According to the most recent census data from 2020, 16.8% of the U.S. population are age 65 and older and, from 1920 to 2020, this age group grew five times faster than the general population – due, in part, to advancements in medicines that help to extend lifespans and improve quality of life. As the U.S. population ages, it is essential to have policies and systems in place that support and promote healthy aging, resulting in improved outcomes for older adults. The discovery of new medicines will continue to play an essential role in our ability to live longer and healthier lives, especially as rates of chronic conditions in older Americans are projected to double by 2050.

As the 119th Congress considers policy solutions to address the affordability of prescription treatments, the NAF and other organizations urge Congress to consider the impacts of such policies on the American healthcare innovation ecosystem and patient access, particularly for older Americans and people living with chronic and complex conditions.

In February, Representatives Greg Murphy (R-NC), Don Davis (D-NC), and Richard Hudson (R-NC) reintroduced the Ensuring Pathways to Innovative Cures (EPIC) Act (H.R. 1492) in the U.S. House of Representatives. In March, Senators introduced companion legislation (S. 832) in the U.S. Senate. The legislation seeks to eliminate the unnecessary distinction between the negotiation timelines of small and large molecule drugs, making all treatments eligible for negotiation eleven years after FDA approval.

H.R. 1492 would implement the change in negotiation timelines immediately upon passage, while S. 832 proposes implementing the change in negotiation timelines starting in the initial price applicability year (IPAY) 2028. While we are supportive of any action to correct the unnecessary distinction between small and large molecule drugs, immediate action is crucial to ensure that patients are not further impacted by lack of access to their treatments. We commend these members of Congress for recognizing the need for a legislative solution to the arbitrary distinction between small and large molecule drugs.

The letter states that policies that hinder the development of new treatments must be eliminated, especially when many patients currently lack a treatment option for their condition. A thriving biomedical innovation environment in the United States underpins our ability to age well and maintain our health. The letter further asks Congress to support efforts to advance the EPIC Act to safeguard future innovation of treatments and protect access to critical small-molecule drugs for our aging population and people living with chronic and complex conditions.

Discovery Raises Prospect of New Neuropathy Treatments

Recent research by **Sandra Rieger**, Ph.D., of the **MDI Biological Laboratory** identifying the underlying mechanisms of peripheral neuropathy, or nerve damage, has raised the prospect that drug therapies can be developed for the treatment of this condition, which causes pain, numbness and/or tingling in the hands and feet.

The research was published in the Proceedings of the National Academy of Sciences. **Neuropathy** is a common condition affecting over 20 million people in the United States, but until now a lack of understanding of the underlying mechanisms has held back the development of treatments. Drugs exist for the treatment of symptoms – pain relievers, for instance – but not for the condition itself, which can be caused by chemotherapy, diabetes, traumatic injury, heredity and other conditions.

“Our goal is to develop treatments that activate the repair and regeneration of damaged tissues,” said **Kevin Strange**, Ph.D., president of the MDI Biological Laboratory. “Sandra Rieger’s research has advanced that mission by elucidating a mechanism underlying peripheral neuropathy, opening the door to the development of therapeutic agents that can reverse nerve damage linked to chemotherapy, and possibly diabetes and other conditions.”

Rieger and other scientists working in the institution’s Kathryn W. Davis Center for Regenerative Medicine study tissue repair, regeneration and aging in a diverse range of organisms that have robust mechanisms to repair and regenerate lost and damaged tissues.

“The general thinking is that no single drug can be effective for the treatment of all peripheral neuropathies, which stem from multiple causes,” Rieger said. “But our research indicates that there may potentially be a common underlying mechanism for some neuropathies affecting the sensory nervous system that could be manipulated with drugs targeting a single enzyme.”

Rieger conducted her research in zebrafish exposed to **paclitaxel**, a chemotherapeutic agent used for ovarian, breast, lung, pancreatic and other cancers. Paclitaxel-induced peripheral neuropathy affects the majority of treated patients; however, those who are most severely affected (about 30 percent) have to terminate chemotherapy or reduce the dose because of this condition, which can impact cancer survival.

Rieger used zebrafish larvae to model peripheral neuropathy because the embryos develop rapidly and because the larval fish are translucent, making them ideal for studying the progression of nerve degeneration in live animals.

Rieger’s research showed that paclitaxel induces the degeneration of sensory nerve endings by damaging the outer layer of the skin, or epidermis. The epidermis is innervated by free sensory nerve endings that establish direct contact with skin cells. Her research showed that degeneration is caused by perturbations in the epidermis due to an increase in matrix-metalloproteinase 13 (MMP-13), an enzyme that degrades the collagen, or “glue,” between the cells. The increase in MMP-13 activity could be triggered by oxidative stress, which is also a hallmark of diabetic peripheral neuropathy.

In the research, Rieger treated the zebrafish with pharmacological agents that reduce MMP-13 activity, with the result that skin defects were improved and chemotherapy-induced nerve damage was reversed. The treatment of neuropathy with MMP-13- targeting compounds is

the subject of a provisional patent filed by the MDI Biological Laboratory in January.

MMP-13 over-activation has also been linked to various other disease conditions, such as tendon injury, intestinal inflammatory and cancer, raising the possibility that drugs developed to treat peripheral neuropathy could yield other health benefits as well.

The next step is to study the effect of MMP-13 on peripheral neuropathy in mammalian models. Studies are also underway in collaboration with the Mayo Clinic in Rochester, Minn., to test the clinical relevance of these findings in humans.

The **MDI Biological Laboratory**, located in Bar Harbor, Maine, is an independent, non-profit biomedical research institution focused on increasing healthy lifespan and increasing our natural ability to repair and regenerate tissues damaged by injury or disease. The institution develops solutions to complex human health problems through research, education and ventures that transform discoveries into cures. For more information, please visit **www.mdibl.org**.

Addressing the Emotional Cost of Chronic Illness

By Abbie Cornett, MBA

IG Living Magazine 2025

Understanding how severe the emotional impact of a chronic illness can be is essential to patient outcomes. Being chronically ill can affect every aspect of your life — from your career to your personal relationships, activities, education and even your feelings of self-worth. Because changes brought on by a chronic illness are often sudden and dramatic, it can leave you struggling to adjust to your new reality. And these feelings can be magnified if you have to make time for treatments that can introduce stress due to the financial burden and potential

side effects.

When diagnosed with a chronic illness, you may experience feelings of frustration, anger and sadness as you come to terms with your illness. It's not uncommon if you experience grief over the loss of your health and mourn for your former life. These feelings can evolve into depression or anxiety, and they can be compounded by the practical challenge of managing your illness. The constant juggling of medical appointments, work, family and friends can leave you feeling overwhelmed — as though your illness has taken control of your life.

What's more, having a chronic illness can…

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Patients Needed for CIDP Disease Burden Research Study

What: Researchers at the University of Rochester are interested in creating a patient-reported outcome measure that will assess the health, symptoms, and disease burden of individuals with chronic inflammatory demyelinating polyneuropathy (CIDP). This study is being conducted by Dr. Chad Heatwole from the University of Rochester's Department of Neurology. This study aims to identify the symptoms that have the greatest impact on the quality-of-life for individuals with CIDP. This will help guide future research involving individuals with CIDP.

What's involved: As a participant in this study, you will participate in a Zoom interview with a study coordinator, where you will talk about the symptoms of CIDP that you experience and that have the greatest impact on your daily life. This interview will take approximately 30-60 minutes and will be audio-recorded, transcribed, and analyzed. All responses will be anonymous and strictly confidential.

Who can participate: Individuals with CIDP ages 18 years and older, who live in the United States, and speak, read, and understand English.

How to participate: Individuals interested in participating can reach out to one of the study coordinators:

- Matt Rathbun / (585) 481-1109 / **matt.rathbun@chet.rochester.edu** or
- Jennifer Weinstein, MS / (585) 419-5335 / **jennifer.weinstein@chet.rochester.edu**

If you have any questions or need additional information please reach out to one of the above mentioned study coordinators.

Study Finds Infection Rates Were Lower in Patients Treated with cSCIG than fSCIG or IVIG

A recent study found that patients treated with conventional subcutaneous immunoglobulin (cSCIG) had significantly lower rates of viral infections than those treated with facilitated subcutaneous immunoglobulin (fSCIG) or intravenous immunoglobulin (IVIG). The findings suggest that cSCIG may be a more effective immunoglobulin replacement therapy (IRT) for immunocompromised patients who are prone to viral infections, especially during high-risk periods like winter.

Key findings from the 2025 study on viral infections in patients with inborn errors of immunity include:

- **Lower Viral Infection Rates: The cSCIG group had the lowest viral infection rate at 2.5%, compared to 4.4% for fSCIG and 4.2% for IVIG.**

- **Maintained IgG Levels: The study noted that cSCIG therapy effectively maintained optimum immunoglobulin G (IgG) threshold levels in patients, providing consistent protection. In contrast, patients receiving fSCIG or IVIG tended to have infections detected in the third and fourth weeks of their treatment cycle, suggesting less consistent protection.**
- **Most Common Viral Infections: The most frequently observed viral infections were adenovirus, influenza A, and human rhinovirus/enterovirus.**

Why cSCIG may offer better infection protection

The lower and more stable serum IgG levels with cSCIG compared to IVIG may explain its superior protection against infection.

- **Constant Immunoglobulin Levels: CIG is administered more frequently (typically weekly or biweekly) compared to IVIG (typically monthly), leading to more stable and consistent IgG levels in the blood.**
- **Lower Infection Rates Correlation: Higher and more consistent IgG trough levels have been associated with lower rates of infection.**
- **Higher Trough Levels With cSCIG: A 2019 meta-analysis found that weekly cSCIG achieved higher trough levels than monthly IVIG, and that higher cSCIG troughs correlated with lower infection rates.**

Other findings on immunoglobulin therapies

While cSCIG showed advantages in preventing viral infections in this study, other research highlights additional differences between immunoglobulin therapies:

- **fSCIG: This formulation uses a special enzyme to increase tissue permeability, allowing for larger, less frequent infusions (every 3–4 weeks) compared to cSCIG. However, the 2025 study showed it offered less consistent protection against viral infections.**
- **Side effects: Systemic adverse events, such as fever, headache, and chills, are more common with IVIG infusions. Mild local reactions at the injection site are more common with subcutaneous therapies like cSCIG, but these tend to decrease over time.**
- **Patient preference: SCIG therapies, including both conventional and facilitated forms, allow for self-administration at home. Many patients prefer this flexibility over hospital-based IVIG infusions.**

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