



Outlook

---

**Patient Voice Newsletter**

---

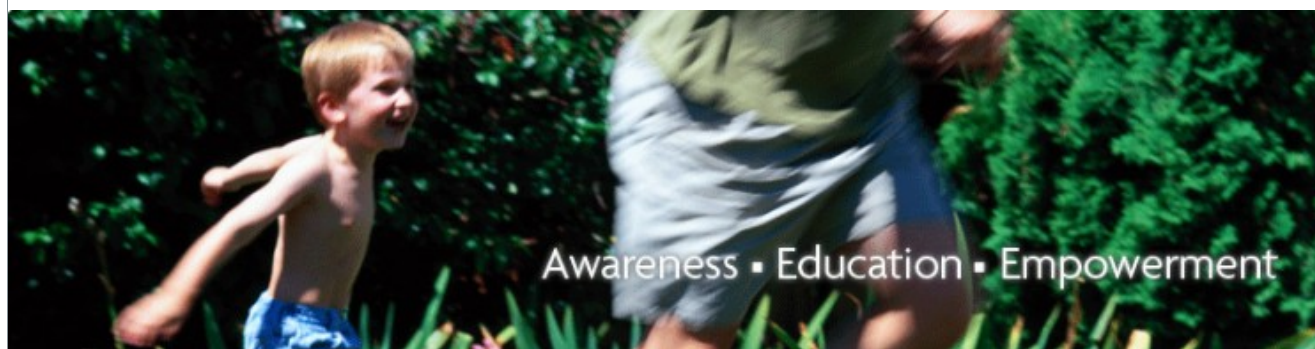
From Neuropathy Action Foundation <patientvoice@naf.ccsend.com>

Date Sun 9/13/2026 2:30 PM

To c\_olney@hotmail.com <c\_olney@hotmail.com>



**Patient Voice - September 2026 Issue -----Visit our Website**

**In this Issue**

- ▶ Group Letter to California Governor Newsom to Restore GLP-1 Coverage
- ▶ Patient Spotlight - How a Neuropathy Patient Turned Pain into Purpose
- ▶ CIDP Patient and/or Caregiver Paid Research Study
- ▶ Development of a Patient-Reported Outcome Measure for CIDP
- ▶ Two Critical Bills on Governor Newsom's Desk in California
- ▶ Arizona Rare Disease Days: Free Support for Neuropathy and Rare Conditions
- ▶ Louisiana HB 962 for Infusion Providers
- ▶ Diabetes 101 from Pacific Medical Training

## Group Letter to California Governor Newsom to Restore GLP-1 Coverage to MediCal Patients

Dear Scott,

An estimated 15 to 19 million Americans have diabetic peripheral neuropathy (DPN), which is the most common neuropathy in the United States. DPN can be prevented or delayed, particularly through better diabetes management and earlier intervention. Obesity is an independent risk factor for DPN, particularly in people with type 2 diabetes. The 2026 American Diabetes Association Standards of Care specifically state that obesity is consistently associated with neuropathy in both cross-sectional and longitudinal studies. Therefore, the NAF participates in efforts to help Americans maintain healthy lifestyles, lose weight, and have access to weight loss medications, treatments and services.

To this end, the NAF joined the Obesity Action Coalition, Obesity Society, American Society for Metabolic and Bariatric Surgery, the National Council on Aging, the Chronic Obesity Prevention and Education Alliance, the American Diabetes Association, and nearly twenty additional organizations to oppose Governor Newsom's decision to eliminate coverage for FDA-approved GLP-1 medications in the Medi-Cal program for those affected by the chronic disease of obesity as of January 1, 2026. The NAF equally opposes elimination of the previously existing "continuity of care" protection that would have allowed Medi-Cal patients already taking GLP-1 medications for the treatment of obesity to maintain coverage, thereby effectively removing a continuation/grandfathering pathway after December 31, 2025. The NAF and the other organizations urge the Newsome Administration to reinstate access for GLP-1 medication for the treatment of obesity for all Medi-Cal recipients or grandfather coverage to those recipients who were previously on a GLP-1 medications

Patients who have achieved stability and improved health outcomes through GLP-1 medications face serious harmful consequences when access is disrupted. Interruptions in treatment undermine continuity of care and place patients at increased risk for weight regain, poor glycemic control, and the return of obesity-related complications. Sudden loss of GLP-1 access not only reverses clinical progress and anticipated medical savings to the state but also creates emotional and financial uncertainty for patients and providers navigating treatment disruptions

Given the profound impact that investments in obesity treatments have had on patient health and quality of life, the NAF strongly urges the Administration to preserve and strengthen access to FDA-approved obesity treatments as part of comprehensive, patient-centered care.



### Patient Spotlight - How a Small Fiber Neuropathy Patient Turned Pain into Purpose

By Sheldon Ekirch

In the summer of 2023, I was diligently studying for the Bar exam when I began experiencing numbness and tingling in my limbs. Initially, I dismissed these sensations as mere symptoms of stress and sleep deprivation. At that time, I was sleeping very little, as I



was studying for several hours a day while also working full-time. Despite the elevated level of stress I was under, I felt invincible. I was excelling in my career, having just completed a successful brief for a federal court, while also maintaining an active social life with friends and family.

Soon after taking the Bar, my world came crashing down. My once-seemingly benign symptoms quickly transformed from numbness and tingling to outright burning. My limbs felt like they were on fire, a painful sensation that took my breath away more times than I can count. Over the next year and a half, I went from specialist to specialist, desperately seeking answers as to what was wrong with me and what, if any, treatment options existed. Meanwhile, my symptoms continued to progress, leaving me unable to function due to chronic pain, let alone work a full-time job.

After months of fervently searching for answers, I was eventually diagnosed with immune-mediated small fiber neuropathy and dysautonomia. Finally, I had found a doctor who understood my condition and took my pain seriously. As she began to elaborate upon potential treatment options, an overwhelming sense of relief flooded my body. For the first time in years, my hopes and dreams for my future began to materialize before my very eyes, no longer were my aspirations beyond my grasp. All I had to do was to receive my doctor's recommended course of treatment of intravenous immunoglobulin (IVIG). Little did I know the path to accessing IVIG would prove to be an arduous one.

Over the course of more than a year, my doctors and I fought my insurer's refusal to cover IVIG. Appeal after appeal, we seemed no closer to accessing the one treatment that had the potential to give me my life back. With each prior authorization denial, a sense of despair began to take hold. My health was rapidly deteriorating and my pain continued to worsen. Even with four doctors attesting to the medical necessity of IVIG, my insurer continued to callously render IVIG "not medically necessary." At this point, I felt myself momentarily succumbing to the fear that my life would consist of nothing more than pain.

Constantly fighting for coverage, at a time when I should have been focused on healing, took a profound toll on me physically, mentally, and emotionally. When you are repeatedly forced to justify why you deserve access to a medically necessary treatment, you begin to internalize the denials. You begin to question not only whether relief will ever come, but whether your pain, your dignity, and your life are worth fighting for. There were many nights when I cried myself to sleep, afraid of a future where I'd continue to suffer without treatment, day-in and day-out. During some of my darkest days, I found myself immersed in patient advocacy work, seeking solace in a world outside of my own pain as my insurer continued to refuse to cover IVIG.

Out of desperation to finance treatment, my parents started draining money from their retirement account to pay out of pocket for IVIG at the cost of approximately \$10,000 a month. When insurance refuses to cover the one drug that can effectively treat your condition, you have no choice but to use every tool in your arsenal to fight back. For me, this involved appealing every denial, reviewing relevant clinical trials, staying abreast of every update and deadline, and coordinating with my provider to ensure that we were on the same page.

With each IVIG treatment, my pain diminished, and my overall quality of life improved significantly. For the first time in years, my pain no longer dictated my life. IVIG has given me the ability to live my life on my own terms, free from the debilitating pain that once plagued every aspect of my life.

Enraged by the injustice of it all, I reached out to a reporter at KFF Health News, hoping to further expose the inequities of a deeply flawed health insurance system—one that too often forces patients to fight for the very care their doctors insist they need. When sharing my story, I felt morally compelled to leave no part of it out: the good, the bad, and the ugly. Over the course of the next year, my story would be featured in three national news articles, each one exposing the devastating human cost of insurance delays and denials. The most recent article, published this past March, concluded my story by announcing that my insurer's refusal to cover IVIG was overturned during an external review. All the sleepless nights and hours on the phone had paid off. For the first time in a long time, it felt like I could finally breathe again, no longer stifled by my insurer's refusal to cover IVIG. I could now focus on my health and getting better.

In sharing my story, I never imagined that it would resonate with so many people. What began as a personal struggle for my own treatment has evolved into something bigger. Instead of wilting away under the toll exacted while fighting my insurer, my resolve for advocacy only solidified. My grief and rage hardened into a fierce determination to fight back against the relentless delays and denials of care arbitrarily imposed by health insurance companies. Now, driven by a purpose greater than my own, I am hopeful for a future in which patients come together as a community to successfully advocate to dismantle barriers to care and ensure equal access to healthcare for all.

To learn more about Sheldon's story and her advocacy efforts, you can follow her on Instagram [@ChronicallySheldon](#) or on LinkedIn [here](#).

## CIDP Patient and/or Caregiver Paid Research Study

Folia Health is searching for chronic inflammatory demyelinating polyneuropathy (CIDP) patients and caregivers to participate in a **PAID** study that aims to make sure the full picture of living with CIDP is seen and understood. Not just what clinicians report, not just what lab values say, but how you feel after taking a trip to the grocery store, or what you have to miss when you're feeling exhausted. We know CIDP affects all areas of your life, and by sharing your experiences with researchers, you can help advance the future of CIDP care to better reflect what living with CIDP is really like.

*Join this study if your experience includes the following:*

- Adult aged 18 or older with diagnosis of CIDP, regardless of symptom or treatment history
- US-based with a proficient understanding of and ability to comprehend study materials
- NOT currently receiving efgartigimod alfa or efgartigimod alfa and hyaluronidase-qvfc (Vyvgart or Vyvgart Hytrulo) and NOT actively participating in a clinical trial for CIDP

*Caring for someone with CIDP and your experience includes the following:*

- Adult aged 18 or older
- Serve as the primary caregiver of an adult living with a diagnosis of CIDP, regardless of symptom or treatment history who meets the following criteria:
  - US-based with a proficient understanding of and ability to comprehend study materials
  - NOT currently receiving efgartigimod alfa or efgartigimod alfa and

hyaluronidase-qvfc (Vyvgart or Vyvgart Hytrulo) and NOT actively participating in a clinical trial for CIDP

#### *How to enroll?*

1. Take our 30 second qualification survey at: **[Join Folia's remote CIDP research study today — Folia Health](#)**
2. If the study looks like a fit, you'll be guided to download the Folia Health app.
3. Use invite code "COMPASS" at signup to ensure you're enrolled into the study
4. Review and sign the consent form (you'll see it right after you create your account)

Want to know more about how study rewards work? Check out our **[FAQ article](#)** here or reach out to **[research@foliahealth.com](mailto:research@foliahealth.com)** with any questions.



## **CIDP Health Index:**

### **Development of a Patient-Reported Outcome Measure for CIDP**

Researchers at the University of Rochester Medicine Center for Health + Technology (CHeT) 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 quality-of-life for individuals with CIDP. This will help guide future research involving individuals with CIDP

#### *Who can participate:*

- Be 18 years old or older
- Be diagnosed with CIDP
- Reside in any country except those where participation is restricted due to specific regulatory and operational constraints (Belarus, Iran, North Korea, Russia, and Ukraine)

- Read and understand English

*What's involved:*

The study involves completing demographic questions and an online survey asking about the symptoms of CIDP you experience. The survey will take approximately 20-30 minutes to complete, and you may skip any questions that you do not wish to answer. All responses will be strictly anonymous.

*How to participate:*

Interested individuals can click the following to participate: <https://redcap.link/cidp-hi>

Any questions may be directed to either Matt Rathbun at [Matthew\\_Rathbun@URMC.Rochester.edu](mailto:Matthew_Rathbun@URMC.Rochester.edu) or Marissa Moore at [Marissa\\_Moore@URMC.Rochester.edu](mailto:Marissa_Moore@URMC.Rochester.edu).

The poster is blue with white and yellow text. It features the University of Rochester Medicine logo at the top left, which includes a shield with a caduceus and the word 'MELIORA'. The text on the poster reads: 'University of Rochester Medicine', 'Center for Health + Technology Outcomes Unit', 'Make Your Impact in CIDP Research', 'Share your experience living with CIDP through an anonymous online survey.', 'Eligibility' (in a yellow box), '\*Participation is open globally, except for those living in Belarus, Iran, North Korea, Russia, or Ukraine due to regulations', a list of three eligibility criteria with checkmarks: 'Be diagnosed with CIDP', 'Be 18 years old or older', and 'Be able to read and understand English', 'Interested in Participating?', 'Enter this link into your web browser complete the survey: redcap.link/cidp-hi', and 'Any questions can be directed to one of the study coordinators: Matt Rathbun (Matthew\_Rathbun@URMC.Rochester.edu) Marissa Moore (Marissa\_Moore@URMC.Rochester.edu)'.

**University of Rochester Medicine**  
Center for Health + Technology  
Outcomes Unit

**Make Your Impact  
in CIDP Research**

**Share your experience** living with CIDP through an anonymous online survey.

**Eligibility** \*Participation is open globally, except for those living in Belarus, Iran, North Korea, Russia, or Ukraine due to regulations

- ✓ Be diagnosed with CIDP
- ✓ Be 18 years old or older
- ✓ Be able to read and understand English

**Interested in Participating?**  
Enter this link into your web browser complete the survey:  
[redcap.link/cidp-hi](https://redcap.link/cidp-hi)

**Any questions can be directed to one of the study coordinators:**  
Matt Rathbun (Matthew\_Rathbun@URMC.Rochester.edu)  
Marissa Moore (Marissa\_Moore@URMC.Rochester.edu)

## Two Critical Bills on Governor Newsom's Desk in California

### AB 2009

Plasma helps far more patients than those living with neuropathy. Individuals living with chronic and rare health conditions, such as hemophilia and Alpha-1 antitrypsin deficiency, patients facing pregnancy-related complications, such as alloimmunization, and those recovering from severe burns all rely on plasma-derived medicines. Because plasma cannot be made in a lab, patients depend on donations from thousands of healthy individuals. A strong plasma ecosystem is therefore essential to improving donation efficiency and maintaining a stable supply for patients.

However, for this to happen, California's regulatory framework must be modernized. Existing regulations were designed for blood banks and do not adequately reflect the source plasma donation process. To help ensure Californians have reliable access to plasma-derived medicines, AB 2009 was introduced this year to remove outdated barriers to plasma collection and support a strong plasma ecosystem, especially as demand for plasma-derived medicines continues to grow and new uses continue to emerge.

Millions of patients rely on plasma-derived medicines, yet access remains fragile. In his latest Capitol Weekly op-ed, NAF Founder & President, Dominick Spatafora explains why strengthening access must remain a priority. Read it at <https://lnkd.in/gYiYkxqA>.

### **AB 1887**

Health care shouldn't be held up by unnecessary delays. AB 1887 would require health plans and insurers to complete prior authorization for rare-disease prescription drugs within 30 days of an initial request.

For conditions like neuropathy, often overlooked or diagnosed late, timely access matters. One 2024 study found that 75% of participants with neuropathy had not previously been diagnosed, highlighting how much disease can go unidentified, especially in underserved communities. AB 1887 could help patients get the care they need, when they need it. In his latest Los Angeles Sentinel op-ed, NAF Founder and President, Dominick Spatafora encourages Governor Newsome to sign AB 1887 into law. Read more at: <https://lnkd.in/gpJ8PqbU>

## **Arizona Rare Disease Days: Free Support for Neuropathy and Rare Conditions**

### **Barby Ingle, VP, International Pain Foundation (iPain)**

Living with neuropathy or a rare disease in rural Arizona can mean long drives, few specialists, and sometimes years without answers. This fall, the International Pain Foundation (iPain) Rural Rare Disease Project is hosting four free, accessible gatherings; with grant support from the EveryLife Foundation for Rare Diseases and the Power of Pain Foundation, Inc.

I live with the rare disease, Algoneurodystrophy (CRPS/RSD) and know how isolating pain can be. These events are for people facing rare conditions as a patient or caregiver. Do you live with CRPS, peripheral and small-fiber neuropathy, chemotherapy induced neuropathy, arachnoiditis, valley fever, or other rare and poorly understood conditions; or are you a family who cares for them or a caregiver? Be a part of these community events. Stations include whole-genome sequencing information, healthy eating on a budget, pain management through movement and nature, wellness tables, and Q&A. All events are free, family-friendly, and fully accessible.

- **Saturday, Sept. 26, 7:00–11:00 AM** — Outdoor Wellness Day, 4980 N Ironwood Dr, Apache Junction (Pinal). Guided easy and intermediate hikes, meditation, exhibitors, accessible options.
- **Monday, Sept. 28, 11:30 AM–1:30 PM** — Payson Library (Gila). Indoor gathering.
- **Monday, Sept. 28, 5:00–7:00 PM** — Columbine at Raymond County Park, 3305 Kachina Trail, Flagstaff (Coconino). Outdoor evening.
- **Wednesday, Oct. 1, 11:00 AM–2:00 PM** — Mogollon Rim Visitor Center, picnic tables area (Navajo County). Outdoor gathering.

Come as you are. You are not alone. Have questions or want to RSVP please contact Barby at 480-760-1197 or [Barby@InternationalPain.org](mailto:Barby@InternationalPain.org).



The flyer is titled "INTERNATIONAL PAIN FOUNDATION • RURAL RARE DISEASE PROJECT" and "Arizona Rare Disease & Chronic Illness Events". It features a header with a landscape illustration of mountains, a sun, and trees. Below the title, it states "Four free gatherings across rural Arizona • Family-friendly • Fully accessible". There are two buttons: "FREE ADMISSION" and "LIMITED MOBILITY WELCOME". The events are listed in four numbered boxes, each with a county name, event title, date, time, location, and description. Box 01 (Pinal County) is "Outdoor Wellness Day" on Saturday, September 26, 2026, from 7:00 to 11:00 AM at 4980 N Ironwood Dr, Apache Junction, AZ 85120. Box 02 (Gila County) is "Indoor Gathering – Payson" on Monday, September 28, 2026, from 11:30 AM to 1:30 PM at Payson Library, Payson, Arizona. Box 03 (Coconino County) is "Outdoor Evening – Flagstaff" on Monday, September 28, 2026, from 5:00 to 7:00 PM at Columbine at Raymond County Park, 3305 Kachina Trail, Flagstaff. Box 04 (Navajo County) is "Outdoor Gathering – Mogollon Rim" on Wednesday, October 1, 2026, from 11:00 AM to 2:00 PM at Mogollon Rim Visitor Center, Picnic tables area. Each box includes a small landscape illustration at the bottom.

INTERNATIONAL PAIN FOUNDATION • RURAL RARE DISEASE PROJECT

## Arizona Rare Disease & Chronic Illness Events

Four free gatherings across rural Arizona • Family-friendly • Fully accessible

FREE ADMISSION LIMITED MOBILITY WELCOME

**01 PINAL COUNTY**  
**Outdoor Wellness Day**

**Saturday, September 26, 2026**  
7:00 – 11:00 AM  
4980 N Ironwood Dr  
Apache Junction, AZ 85120  
Guided easy & intermediate hikes  
with fully accessible options

**02 GILA COUNTY**  
**Indoor Gathering – Payson**

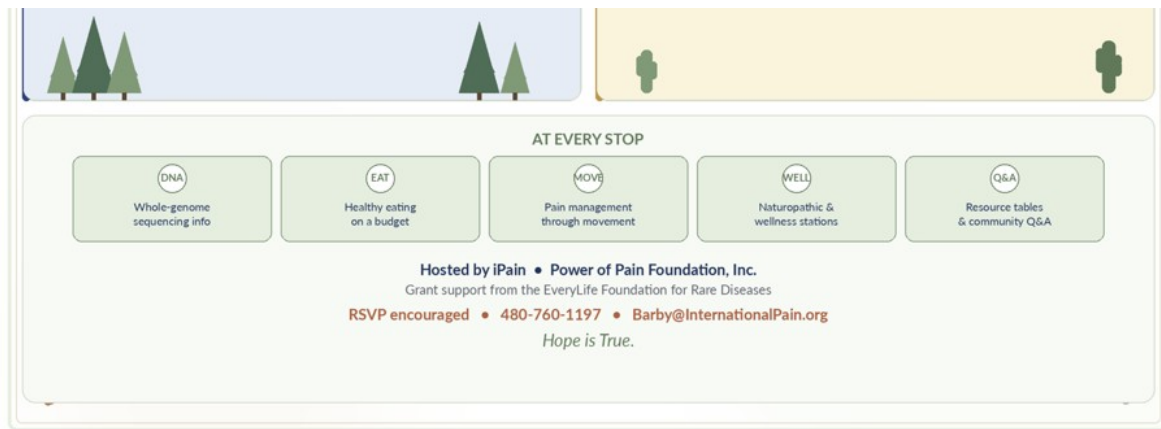
**Monday, September 28, 2026**  
11:30 AM – 1:30 PM  
Payson Library  
Payson, Arizona  
Welcoming indoor session  
Resource tables & Q&A

**03 COCONINO COUNTY**  
**Outdoor Evening – Flagstaff**

**Monday, September 28, 2026**  
5:00 – 7:00 PM  
Columbine at Raymond County Park  
3305 Kachina Trail, Flagstaff  
Outdoor evening under the  
northern Arizona sky

**04 NAVAJO COUNTY**  
**Outdoor Gathering – Mogollon Rim**

**Wednesday, October 1, 2026**  
11:00 AM – 2:00 PM  
Mogollon Rim Visitor Center  
Picnic tables area  
Outdoor community stop  
along the Rim



## Louisiana HB 962 for Infusion Providers

The NAF would like to thank the National Infusion Center Association (NICA) for their recent advocacy in Louisiana. Because of NICA's efforts starting earlier this summer on August 1, House Bill 962 took effect, explicitly authorizing registered nurses to prepare, mix, reconstitute, and perform similar acts related to medications for immediate administration when acting pursuant to an authorized prescriber's order.

This legislation builds on an issue NICA brought to the Louisiana Board of Nursing's attention regarding their interpretation of "compounding." After working with the Board to clarify that preparing medications according to FDA-approved labeling for immediate administration should not be considered compounding, we're pleased to see that principle now reflected in Louisiana law. For infusion providers, this change provides greater certainty that nurses may continue preparing medications for immediate administration as part of routine patient care. Most importantly, it helps support timely access to treatment for patients across Louisiana.

We're proud that NICA helped drive this important policy solution for Louisiana infusion providers. If you have any questions about this new law, please don't hesitate to reach out at [advocacy@infusioncenter.org](mailto:advocacy@infusioncenter.org).

## Diabetes 101 from Pacific Medical Training

An estimated 40.1 million Americans (about 12% of the U.S. population) have diagnosed or undiagnosed diabetes, according to the [Centers for Disease Control and Prevention](#) and 589 million adults worldwide have diabetes, according to the [International Diabetes Federation](#).

As diabetes continues to affect millions of people worldwide, access to accurate and accessible information is increasingly important. To this end, Sarah Gehrke, MSN, RN and Pacific Medical Training recently published a comprehensive Diabetes Guide that covers symptoms, causes, treatment options, prevention strategies, and practical tips for managing the condition. The guide is designed to present reliable, easy-to-understand information that can help readers better understand diabetes and its impact on overall health.

You can view the guide at: <https://pacificmedicaltraining.com/diabetes>

Share This Email

Share This Email

Share This Email

Donate Today

Neuropathy Action Foundation | <http://neuropathyaction.org>



Neuropathy Action Foundation | 1950 Old Tustin Avenue | Santa Ana, CA 92705 US

[Unsubscribe](#) | [Update Profile](#) | [Constant Contact Data Notice](#)



Try email marketing for free today!