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**Subject:** Re: Patient Voice Newsletter March 2025
**Date:** Sat, 21 Mar 2026 19:41:08 +0000

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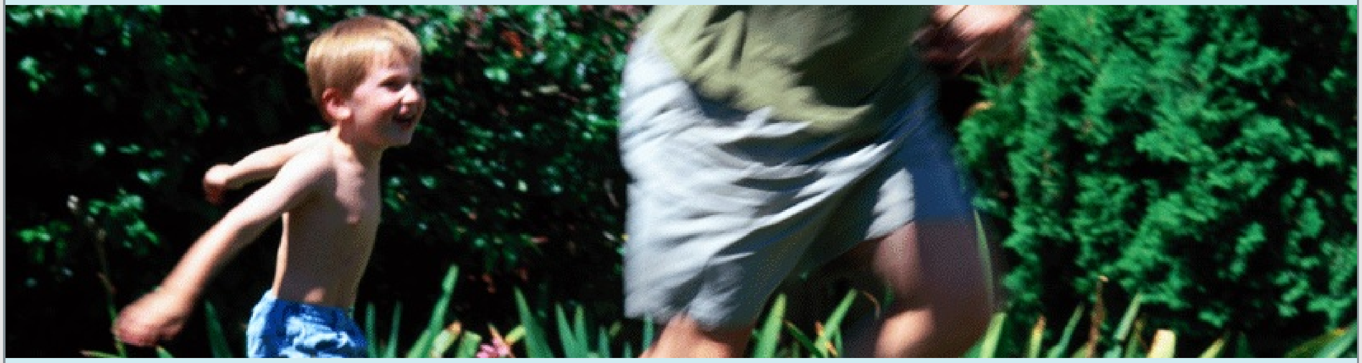

## In this Issue

**► Newly Launched “Handwashing” Campaign/Movement**

## Inflation Reduction Act (IRA) and the Pill Penalty

**Dear Member,**

The NAF along with hundreds of other patient organizations have been educating patients and elected officials on an important aspect of the Inflation Reduction Act (IRA) that impacts the development of crucial medical treatments: the pill penalty. This provision creates an unfair advantage for biologic drugs over small-molecule drugs, which could slow down the progress of essential therapies at a time when innovation is critical for patient care.

A bipartisan group of Congressional Representatives[1] have introduced H.R. 1492. The Senate also has a companion bill, S.B. 832. The intent of these bills is to fix this issue by equalizing the negotiation timelines under the Drug Price Negotiation Program. Without this change, the IRA would favor biologics, potentially limiting access to new treatments for patients with cancer, mental health conditions, and rare diseases.

Small molecule drugs, like affordable generics such as ibuprofen, are vital to healthcare. They have an outsized impact on patient health—accounting for more than 90% of all prescriptions and two-thirds of new drug approvals each year. Often formulated as pills, tablets, capsules, or topical creams, these products are typically taken orally rather than via injections or infusions. Their ease of use offers patients and caregivers improved convenience, which plays a pivotal role in everyday health management. Small-molecule drugs can cross the blood-brain barrier, making them essential for treatments ranging from psychiatric disorders and neurodegenerative diseases to brain cancers.

Since the IRA's introduction, investment in small-molecule research has declined by 70%, which could result in the loss of up to 188 new small-molecule medicines over the next 20 years and more than 115 million life years lost due to fewer treatments being developed.[2] Approximately 63% of biopharmaceutical companies now expect to shift their investments away from small molecules as a consequence of these IRA provisions[3]. While reducing patient costs is important, we must also consider the broader impact on patients and the biotechnology industry.

These issues not only have a direct impact on patients—who rely on these treatments for conditions such as heart disease, depression, neurological disorders, and many types of cancer—but also undermine the broader prescription system.

While reducing patient costs is undoubtedly important, we cannot overlook the broader impact on healthcare innovation and patient access. Addressing the pill penalty would support ongoing research and development of life-saving small molecules, offering hope to patients with rare, chronic, or complex conditions. Congress has a duty to balance the dual objectives of affordable medication and scientific progress. We respectfully urge Congress to support legislative efforts that remove the pill penalty provisions from the IRA, thereby ensuring that patients across the states and the nation continue to benefit from the full spectrum of innovative therapies.

[1] Representatives Gregory Murphy. Donald Davis, and Richard Hudson

[2] Vital Transformation. IRA's Impact on the U.S. Biopharma Ecosystem. June 1, 2023. https://vitaltransformation.com/wp-content/uploads/2023/10/VT-BIO_ IRA_v14.pdf.

[3] Longo, N. Inflation Reduction Act Already Impacting R&D Decisions. PhRMA, January 17, 2023. https://catalyst.phrma.org/wtas-inflation-reduction-act-already-impacting-rd-decisions.

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## Senator Marshall Reintroduces the *HELP Copays Act*

Senators Tim Kaine (D-VA) and Roger Marshall, MD (R-KS) reintroduced the *Help Ensure Lower Patient (HELP) Copays Act*, bipartisan legislation that would ban the use of copay accumulator adjustment programs. Kaine and Marshall both serve on the Senate Health, Education, Labor and Pensions (HELP) Committee, which has jurisdiction over the legislation. While 21 states have already banned the use of copay accumulators, patients enrolled in plans regulated by the federal government do not enjoy those protections. The NAF joined over 100 patient and provider advocacy organizations thanking Senators Marshall and Kaine for their leadership on this important policy.

The *HELP Copays Act* requires health plans and pharmacy benefit managers (PBMs) to count payments received on a patient's behalf—including payments from nonprofit organizations or pharmaceutical manufacturers copay assistance—toward the patient's annual deductibles and out-of-pocket limit. This would bring much-needed relief to financially vulnerable individuals by ensuring that all payments count towards their out-of-pocket costs. It also closes a loophole that allows many employer health plans to deem certain covered drugs as "non-essential," which means that the health plan will not count any cost-sharing toward the patient's deductible and out-of-pocket maximum. The legislation will ensure all private plans to count all cost-sharing for covered medications to accrue to a patient's deductible and out-of-pocket maximum.

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## Understanding Venous Access for IVIG Infusions

By Michelle Greer, RN, IgCN

October-November IG Living Magazine

Venous access is an important consideration when creating an immune globulin (IG) treatment plan. And, since most patients who receive intravenous IG (IVIG) use their venous access solely for this therapy, a decision should be made if access should be peripheral or central.

### Treatment Considerations

When a physician prescribes IG, the dose, frequency and length of therapy can, but does not always, dictate the type of venous access to be used. The patient should have input based on lifestyle and personal preferences, but the physician must first determine clinically what the best options are for the patient. In addition, insurance companies may narrow the patient's options.

For instance, when deciding on the route of administration (either intravenously or subcutaneously), some health plans require members to have a clinical reason for approving subcutaneous IG (SCIG), one of which is poor venous access. Another accepted justification is if the patient has had previous tolerability issues with IVIG. Lifestyle preference, however, is not accepted as a reason to approve SCIG.

Read more at **IG Living Magazine** page 20-21

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## Patients Needed – Chronic pain Study (San Francisco)

This research study seeks to evaluate a non-surgical, non-drug wearable therapy using Low Intensity Focused Ultrasound Stimulation (LIFUS) of the deep brain to alleviate chronic pain. Conducting this research study will enable further development of a novel wearable device, to allow in-clinic or at-home use for pain reduction. This technology is already being used in multiple studies for other conditions.

LIFUS is a form of non-invasive stimulation that uses sound waves, the same form of energy used in fetal ultrasound imaging during pregnancy, to target and alter activity in areas of the deep brain. As FUS is highly precise, it can accomplish this task without impacting the surrounding brain tissue. Since this research study is centered on chronic pain, specific brain regions associated with pain-related brain circuits such as the cingulate cortex and ventrolateral thalamus will be targeted.

The research study is currently enrolling in San Francisco, CA. The study consists of 4 required visits and some optional visits. Each visit will take less than 2 hours and be completed at least a week apart. This study does not require that participants stop any medication they are currently taking. Subjects participating in the study are encouraged to maintain any pain medication regimen they may have. Participants will be compensated $50 per visit. Scheduling is very flexible and visits can be arranged for weekends and outside of work hours.

In order to be eligible for this study, participants must be:

- Experiencing chronic pain (persisting for at least 3 months)
- 22 to 80 years old
- Able to undergo a brain MRI
- Able to visit the study location in San Francisco

For additional information about the study contact please email **pain@attuneneuro.com** or call 415-658-7001.

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## Neuropathy Patient Opportunity

Would you like to help advance neuropathy treatment? Thrivable connects patients with research opportunities that are working to develop better treatments. By joining their panel, you may be invited to participate in clinical research or trials on neuropathy, diabetes, obesity, and other conditions.

Currently, Thrivable is recruiting for a clinical trial that is evaluating a new oral medication for the treatment of pain associated with diabetic peripheral neuropathy.

Signing up is simple and only means that you'll receive information about relevant opportunities to participate in this study or future research—after you complete a brief screener.

**Join Thrivable today** to help make a difference in the treatment of neuropathy.

## Newly Launched “Handwashing” Campaign/Movement

Did you know that if everyone routinely washed their hands, we could save 1 million lives around the world each year?

In fact, about 80% of infectious diseases are spread by dirty hands. Proper, routine handwashing is a fundamental way to help keep people healthy, reduce the spread of illness, and save lives.

The **National Foundation for Infectious Diseases** (NFID) is a non-profit organization that promotes healthier lives for all through the effective prevention and treatment of infectious diseases. The NFID recently launched a national campaign to elevate awareness about the importance of handwashing to help prevent the spread of viruses and bacteria.

The NFID invited the NAF to become part of this movement and the NAF enthusiastically joined as a founding campaign partner to promote healthy handwashing practices in our organization and beyond and get #HandsInForHandwashing.

Stay tuned for more information soon.

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