

January 27, 2026

The Honorable Brett Guthrie
Chairman
Committee on Energy and Commerce
U.S. House of Representatives

The Honorable Frank Pallone
Ranking Member
Committee on Energy and Commerce
U.S. House of Representatives

The Honorable Morgan Griffith
Chairman
Subcommittee on Health
Committee on Energy and Commerce
U.S. House of Representatives

The Honorable Diana Harshbarger
Vice Chair
Subcommittee on Health
Committee on Energy and Commerce
U.S. House of Representatives

The Honorable Diana DeGette
Ranking Member
Subcommittee on Health
Committee on Energy and Commerce
U.S. House of Representatives

Dear Chairman Guthrie, Ranking Member Eshoo, Chairman Griffith, Vice Chair Harshbarger
Ranking Member DeGette, and Members of the Subcommittee:

On behalf of the undersigned organizations, we write in strong support of the **Headache Education, Access, Diagnosis, and Care Health Equity Act (HEADACHE Act)**, H.R. 5536, introduced by Representatives Lori Trahan (D-MA) and Brian Fitzpatrick (R-PA). This bipartisan legislation represents a historic step forward in improving research, care, and public health infrastructure for the millions of Americans living with disabling headache disorders.

The Need for Action

Headache disorders are among the most common and disabling medical conditions, affecting over 40 million Americans. There are more than 100 distinct types of headache disorders, including migraine, cluster headache, tension-type headache, post-traumatic headache, idiopathic intracranial hypertension, trigeminal neuralgia, new daily persistent headache, spinal csf leak and headache secondary to long COVID. Migraine alone is the second leading cause of years lived with disability worldwide and the leading cause of disability for women ages 15 - 49.

These conditions are not only painful and debilitating for individuals and families, they also carry immense costs to society. In the United States, the economic burden of migraine and other headache disorders is estimated at more than \$78 billion annually in direct medical expenses and lost productivity. Despite this burden, headache disorders remain dramatically underfunded and underprioritized in federal research, public health planning, and clinical workforce development.

What the HEADACHE Act Will Do

The HEADACHE Act takes long overdue steps to address these disparities by:

- Establishing a National Headache Disorders Initiative at the Department of Health and Human Services to coordinate federal efforts and align resources with the true disease burden.
- Creating an Advisory Council on Headache Disorders Research, Care, and Services to bring together federal leaders, clinicians, researchers, patient advocates, and caregivers to ensure inclusive and informed policy development.
- Improving epidemiological data collection, care coordination, and workforce development to ensure timely and accurate diagnosis and treatment.
- Advancing fundamental, translational, and clinical research to develop new and better therapies.
- Supporting public awareness campaigns to reduce stigma and improve understanding of headache disorders across communities.

Why It Matters

For too long, people living with headache disorders have struggled in silence, often misdiagnosed, stigmatized, or without access to effective treatment. These conditions affect people of every age, gender, race, and socioeconomic background, with disproportionate burdens on women, children, older adults, and historically underserved populations.

At the same time, the nation faces a severe shortage of specialists trained to care for this population. There are fewer than 900 UCNS-certified headache specialists in the United States; far too few to meet the needs of more than 40 million Americans living with migraine and other headache disorders; that's just 1 specialist for every 44,000 patients. Research into these diseases has also been chronically underfunded compared to their enormous impact on disability and economic costs with just 0.2% of NIH's budget allocated for migraine and headache disorders. Without prioritizing expanded research investment, better access to treatment options, and growing the number of qualified clinicians, patients will continue to fall through the cracks. The HEADACHE Act is essential to closing these gaps.

By passing the HEADACHE Act, Congress can ensure that the millions of Americans living with these conditions are finally seen, heard, and supported with the research, care, and resources they deserve.

We respectfully urge you to advance the HEADACHE Act through the Energy & Commerce Committee and to the House floor for swift passage.

Thank you for your attention to this urgent public health priority.

Sincerely,

Alliance for Headache Disorders Advocacy

Alliance for Patient Access

American Academy of Neurology

American Brain Coalition

American College of Obstetricians and Gynecologists

American Headache Society

American Migraine Foundation

Black Men's Brain Health Conference

Child Neurology Society

Chronic Migraine Awareness

Chronic Pain Research Alliance

Clusterbusters

Cyclic Vomiting Syndrome Association

Danielle Byron Henry Migraine Foundation

Facial Pain Association

Fibromyalgia National Health Organization

Headache Cooperative of the Northeast (HCNE)

Headache Cooperative of the Pacific

HealthyWomen

Miles for Migraine

National Consumers League

National Grange

National Headache Foundation

National Menopause Foundation

National Pain Advocacy Center

Society for Women's Health Research

Southern Headache Society

Spinal CSF Leak Foundation

The Coalition for Headache and Migraine Patients

The Headache and Migraine Policy Forum

The Society to Increase Mobility, Inc., DBA Neurotech Network

United States Association for the Study of Pain

U.S. Pain Foundation

Vestibular Disorders Association

Women's Brain Foundation