



# HEADACHE ON THE HILL

## Headache Education, Access, Diagnosis, and Care Health Equity (HEADACHE) Act (H.R. 5536)

Introduced by Rep. Trahan and Rep. Fitzpatrick

Original co-sponsors: Rep. Nikki Budzinski, Rep. Robin Kelly, Rep. Seth Moulton, Rep. Valerie Foushee

**AHDA ASK: Please co-sponsor the HEADACHE Act (H.R. 5536).**

### Migraine and Headache Disorders are Chronic Disabling Conditions That Cost the Economy Billions per Year

- Headache disorders affect more than **40 million Americans**. In national surveillance, about 1 in 6 adults and 1 in 5 women reported migraine or severe headache in the past 3 months.<sup>1</sup>
- Migraine and headache disorders **often start in childhood**. A national study estimated 17 percent of U.S. children experienced frequent or severe headaches in the prior year.<sup>2</sup>
- **Disease Progression:** Migraine and headache disorders can worsen over time without proper treatment. Earlier diagnosis and proper treatment may lead to improved outcomes and reduced disability.
- Migraine is one of the world’s top causes of years lived with disability across all age groups and the **leading cause among women aged 15-49**.<sup>3</sup>

#### THE PROBLEMS WE NEED TO SOLVE

- **Too few specialists and gaps in primary care knowledge:** There are fewer than 900 UCNS-certified Headache Medicine physicians nationwide, or 1 specialist for every 44,000 people with migraine or severe headaches. These disorders are a major drain on our workforce—every front-line clinician should be trained to recognize and treat them.
- **Limited treatment options:** Need for additional pharmacological and non-pharmacological treatment options for all patient populations.
- **Underfunded research:** NIH categorical spending for “Migraine/Headache” remains low relative to disease burden, slowing progress on prevention and treatment.<sup>4</sup> Headache disorders receive just 0.2% of NIH funding.

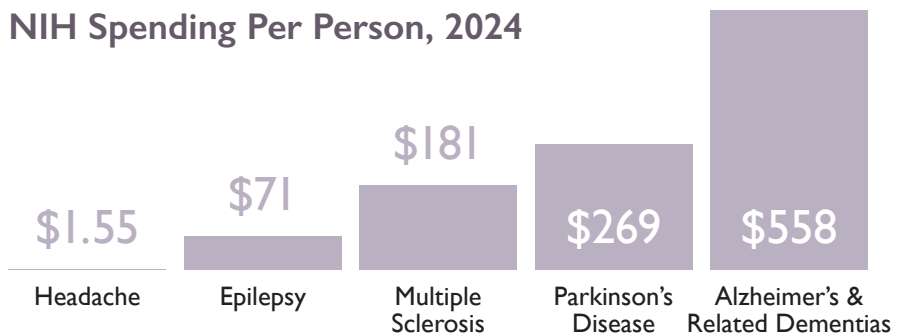


**1 Specialist**

**per 44,000**

with migraine or severe headache

NIH Spending Per Person, 2024



NIH spending is roughly 46x higher in epilepsy, 117x in MS, 173x in Parkinson’s, and 360x in AD/ADRD compared with headache disorders.

## WHAT THE HEADACHE ACT DOES

Creates a coordinated, time-limited initiative at HHS with a national plan, annual reporting to Congress, cross-agency data work, and an expert advisory council.

### 1) National Headache Disorders Initiative (NHDI) at HHS

- Establishes a comprehensive program that addresses the medical, social, and economic impacts of headache disorders and grows the clinical and research workforce.
- Coordinates existing federal efforts that touch headache research, care, education, and pain and aligns resources with disease burden.
- Prioritizes research to speed development of accurate, efficient, effective diagnostics and therapeutics at low cost.

### 2) Advisory Council on Headache Disorders Research, Care, and Services

- Includes federal agencies, patient advocates, clinicians and researchers.

### 3) Cross agency real world data sharing, standardization, and artificial intelligence (AI)

### 4) National plan and annual Report to Congress



## EFFICIENCY & ACCOUNTABILITY

- One coordinating hub that aligns federal efforts through an advisory council.
- Shared data, common measures
- HHS Annual plan and report to Congress
- Proven model: Congress has used this national-plan approach for other diseases, including Alzheimer's, Parkinson's, and Duchenne muscular dystrophy.



### Notes

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10. Alzheimer's Association. "2024 Alzheimer's Disease Facts and Figures." *Alzheimer's & Dementia*, 2024. <https://pubmed.ncbi.nlm.nih.gov/38689398/>
11. National Alzheimer's Project Act, Pub. L. 111-375, National Plan to End Parkinson's Act, Pub. L. 118-66, MD-CARE Act, Pub. L. 107-84; 42 U.S.C. §283g
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