



HEADACHE
ON THE HILL

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 a 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.¹
- 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.²
- **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**.³

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.⁴ Headache disorders receive just 0.2% of NIH funding.

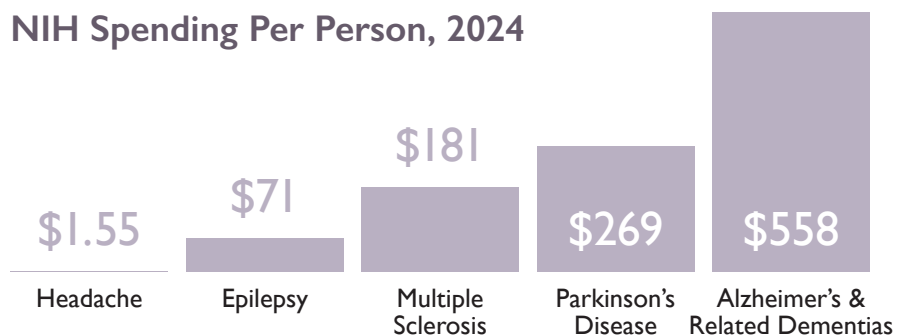


1 Specialist

per **44,000**

with migraine or severe headache

NIH Spending Per Person, 2024



NIH spending is roughly 46× higher in epilepsy, 117× in MS, 173× in Parkinson's, and 360× 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

1. Burch, Rebecca C., Paul Rizzoli, and Elizabeth W. Loder. "The Prevalence and Impact of Migraine and Severe Headache in the United States: Figures and Trends from Government Health Studies." *Headache: The Journal of Head and Face Pain*, vol. 58, no. 4, 2018, pp. 496–505. <https://doi.org/10.1111/head.13281>.
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2. Lateef, Tarannum M., et al. "Headache in a National Sample of American Children: Prevalence and Comorbidity." *Journal of Child Neurology*, vol. 24, no. 5, 2009, pp. 536–543. <https://doi.org/10.1177/0883073808327831>
3. Steiner, T. J., L. J. Stovner, R. Jensen, D. Uluduz, and Z. Katsarava. "Migraine Remains Second among the World's Causes of Disability, and First among Young Women: Findings from GBD2019." *The Journal of Headache and Pain*, vol. 21, 2020, article 137, BioMed Central, <https://doi.org/10.1186/s10194-020-01208-0>
4. National Institutes of Health. "Funding for Various Research, Condition, and Disease Categories (RCDC), FY2008–FY2024." *NIH RePORT*, U.S. Department of Health and Human Services, 17 June 2025, <https://report.nih.gov/funding/categorical-spending>. Accessed 18 Sept. 2025.
5. National Institutes of Health. "Funding for Various Research, Condition, and Disease Categories (RCDC)." *NIH RePORT*, 17 June 2025, <https://report.nih.gov/funding/categorical-spending>. Accessed 18 Sept. 2025.
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Alzheimer's Association. "2024 Alzheimer's Disease Facts and Figures." *Alzheimer's & Dementia*, 2024, <https://pubmed.ncbi.nlm.nih.gov/38689398/>
6. 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