



HEADACHE ON THE HILL

CREATE A HOUSE HEADACHE CAUCUS

Headache disorders are more than “just a headache.”

Headache disorders are an invisible epidemic. Ranging from migraine, cluster headache, and spinal CSF leak, to new daily persistent headache and tension-type headache, headache disorders are common, affecting up to 46% of the worldwide adult population.[1] And yet, people with these frequently disabling conditions do not have access to the equitable care and rights they deserve. Quality medical care can be hard to find due to a shortage of certified headache specialists in our country, and research funding from the National Institutes of Health (NIH) for these conditions has the lowest allocation relative to its prevalence and economic burden. [2][3] Enough is enough. Help us end the silence and impact change.

Stigma and a lack of understanding of the seriousness of these disorders prevents headache disorders from being taken seriously and receiving the funding and equity they deserve under federal law and policies.

- Migraine is the 2nd leading cause of US disability and yet there is no Social Security Blue Book listing for migraine. More than 40 million Americans have migraine or severe headache.[4][5]
- Significant disparities in prevalence and health outcomes exist for some patients.
 - For example, Indigenous communities have the highest prevalence of disabling headache.[6]
 - Migraine is 3 to 4x more prevalent in women and the longstanding history of women's diseases being ignored and stigmatized may play a factor as to why they are not taken as seriously. [7]
 - African American and Hispanic patients are respectively 25% and 50% less likely to be diagnosed with migraine compared to white patients even though their prevalence of migraine is roughly equivalent.[8]
- Cluster headache is widely reputed to be the most severe pain that humans can experience.[9]
- Severe headache accounts for approximately 3.5 million emergency department visits per year in the US.[10]
- US companies lose approximately \$78 billion annually due to direct and indirect costs of migraine which primarily impact workers during their most productive years of life.[11] The impairment caused by acute headache attacks is often, though not always, easily mitigated with effective treatment; as such, headache disorders represent the most readily reversible form of work loss.

A House Headache Caucus is an important step in increasing awareness about the prevalence and seriousness of headache disorders, ending stigma around these conditions and addressing the myriad of inequities existing under federal law for those impacted by migraine and headache disorders in the United States.

[1]Yang S, Orlova Y, Lipe A, Boren M, Hincapie-Castillo JM, Park H, Chang C-Y, Wilson DL, Adkins L, Lo-Ciganic W-H. Trends in the Management of Headache Disorders in US Emergency Departments: Analysis of 2007–2018 National Hospital Ambulatory Medical Care Survey Data. *Journal of Clinical Medicine*. 2022; 11(5):1401.

[2] <https://report.nih.gov/report-nih-funding-vs-global-burden-disease>

[3] <https://report.nih.gov/funding/categorical-spending/>

[4] GBD 2016. Global, regional, and national incidence, prevalence, and years lived with disability for 328 diseases and injuries for 195 countries, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016. *Lancet* 2017;390:1211-59.

[5] Burch R, Rizzoli P, Loder E. (2021). "The prevalence and impact of migraine and severe headache in the United States: Updated age, sex, and socioeconomic-specific estimates from government health surveys" *Headache*. DOI: 10.1111/head.14024

[6] Burch R, et al. *Headache*. 2021;61:60-68.

[7] Al-Hassany L, Haas J, Piccininni M, Kurth T, Maassen Van Den Brink A, Rohmann JL. Giving Researchers a Headache - Sex and Gender Differences in Migraine. *Front Neurol*. 2020 Oct 22;11:49038. doi: 10.3389/fneur.2020.549038. PMID: 33192977; PMCID: PMC7642465.

[8] <https://www.health.harvard.edu/blog/health-disparities-and-headache-treatment-202202152685#:~:text=Although%20the%20frequency%20of%20migraine,migraine%20compared%20to%20white%20patients.>

[9] Burish, M.J., Pearson, S.M., R.E. Shapiro, et al. Cluster Headache Is One of the Most Intensely Painful Human Conditions: Results From the International Cluster Headache Questionnaire. *Headache* 2021;61:117-124.

[10] Yang S, Orlova Y, Lipe A, Boren M, Hincapie-Castillo JM, Park H, Chang C-Y, Wilson DL, Adkins L, Lo-Ciganic W-H. Trends in the Management of Headache Disorders in US Emergency Departments: Analysis of 2007–2018 National Hospital Ambulatory Medical Care Survey Data. *Journal of Clinical Medicine*. 2022; 11(5):1401. <https://doi.org/10.3390/jcm11051401>

[11] https://migraineatwork.org/articles_migraine/how-much-does-migraine-cost/#:~:text=According%20to%20the%20Harvard%20Business,direct%20and%20indirect%20costs%204%20.



AHDA ASK

Co-Chair and/or join a new House Headache Caucus.

AHDA

ALLIANCE FOR HEADACHE
DISORDERS ADVOCACY

director@headachealliance.org

www.allianceforheadacheadvocacy.org