

Reform Social Security Administration Evaluation of Americans Disabled by Migraine and Headache Disorders

- *The extraordinary disability burden of headache disorders.*
 - Migraine is the 2nd leading cause of all global disability ¹.
 - Active migraine attacks disable comparably to severe dementia or loss of both legs ².
 - Cluster headache is reputed to be the most severe pain that humans can experience.
 - 1 in 7 Americans will experience a migraine attack this year ³.
 - US workers with migraine ≥15 days / month lose ~ 14% of annual productivity ⁴.
 - 20% of people with migraine ≥15 days / month self-report as “occupationally disabled” ⁵.
 - Headache disorders often disable *without* headache (e.g. sensory, vertigo, GI, cognitive).
- *Americans with headache disorders face unjust barriers to SSDI/SSI qualification.*
 - In the qualifying process for SSA SSDI/SSI benefits, claimants must compare their impairments to impairments listed for their disease in the SSA “Blue Book” ⁶.
 - If one’s impairments meet or exceed the listed impairments, then benefits are granted.
 - But... the Blue Book contains no listing for any headache disorder.
 - So, if you are disabled by a headache disorder...
 - SSA directs you to compare your impairments to the listings for epilepsy.
 - SSA offers no guidance on how to apply epilepsy listings to headache impairments.
 - Epilepsy impairments are not sufficiently comparable to headache impairments.
 - SSA allows 17% of initial headache SSDI claims, vs 51% for MS, or 78% for Parkinson’s ⁷.
 - SSA policies infringe due process and equal protection rights of headache claimants.
- *Reform SSA Blue Book for fair adjudication of headache disorders claims*
 - SSA should issue a Social Security Ruling (SSR) to clarify how SSDI/SSI claimants with headache disorders should apply existing Blue Book listings most appropriately.
 - SSA should ensure that all listings are always updated at least every five years.
 - SSA should add a Blue Book listing for Headache Disorders at the earliest opportunity.

Please Co-Sign the Dear Colleague letter for

FY2020 LHHS Appropriations Report Language for Headache Disorders

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for Representative Peter Welch



Alliance for
Headache
Disorders
Advocacy

Alliance for Patient Access
American Academy of Neurology
American Headache Society
Clusterbusters
Cluster Headache Support Group
Headache Cooperative of New England

Headache Cooperative of the Pacific
Migraine Research Foundation
Miles for Migraine Races
National Headache Foundation
Runnin' for Research
Southern Headache Society

[Proposed FY2020 LHHS Appropriations Report Language](#)

“The Committee urges SSA to issue a Social Security Ruling (“SSR”) clarifying how best to apply the current Blue Book Listing of Impairments to assess headache disorders-related impairments. Such an SSR could be useful to claimants, representatives, and adjudicators at all levels of the disability determination process, providing detailed guidance regarding what evidence is useful and ensuring consistent decision-making. The Committee commends SSA for agreeing to comply with the SSA Office of the Inspector General recommendation (A-01-15-50022) that all listings updates are less than 5 years old by the end of FY2020. The Committee further urges SSA to ensure that all listings are always updated at least every five years. The Committee recognizes that migraine is the 2nd leading cause of global disability and therefore strongly urges SSA to add a listing specifically for headache disorders at the earliest opportunity.”

Citations:

1. 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.
2. Salomon JA, et al. Disability weights for the Global Burden of Disease 2013 study. *Lancet Glob Health* 2015;3:e712–23.
3. Global Burden of Disease study, 2016, <http://ihmeuw.org/43cn>
4. Stewart, WF, et al. Employment and Work Impact of Chronic Migraine and Episodic Migraine. *JOEM* 2010;52:8-14
5. Manack AN et al. Chronic migraine: epidemiology and disease burden. *Curr Pain Headache Rep* 2011;15:70-78.
6. <https://www.ssa.gov/disability/professionals/bluebook/11.00-Neurological-Adult.htm>
7. <https://www.ssa.gov/policy/docs/workingpapers/wp113.html>