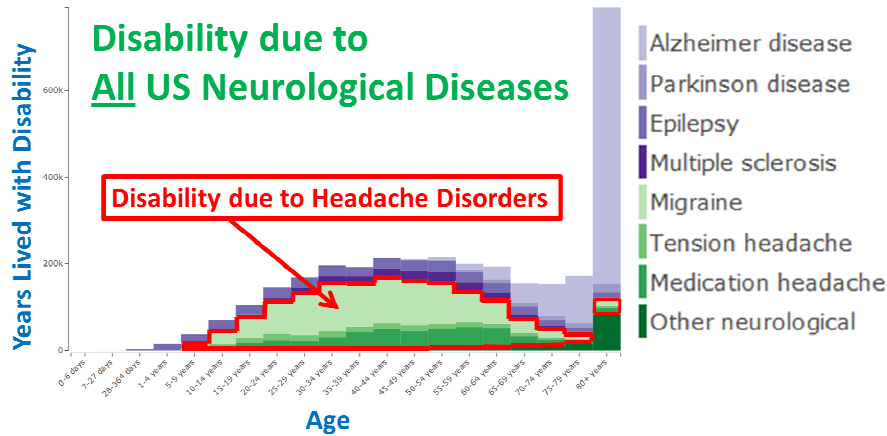
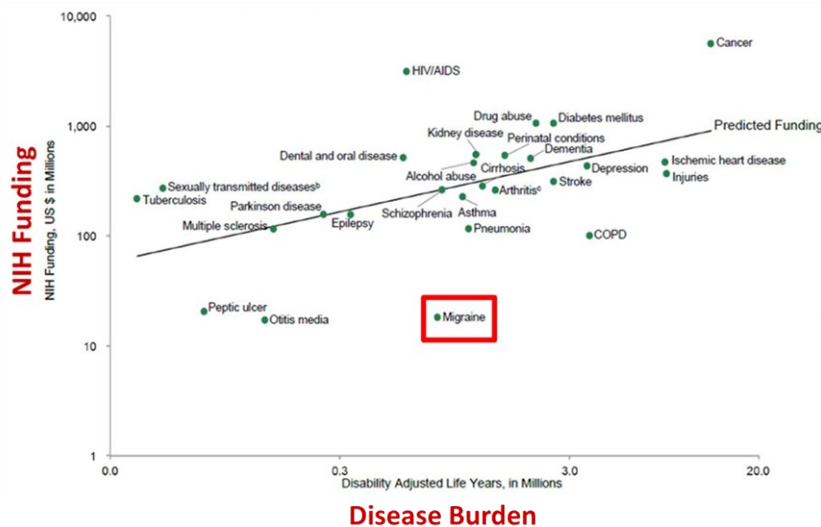


INCREASE NIH RESEARCH ON DISABLING HEADACHE DISORDERS [REPORT LANGUAGE TO IMPLEMENT NIH'S NEW FUNDING POLICY]

- Migraine is the #1 cause of US neurological disability, and #10 cause of all US disability (2013 GBD data).



- In 2014, NIH research on headache disorders was \$24M (less than 0.08% of the NIH budget) and for Migraine it was \$20M. There has been \$2M of NIH research for Cluster Headache in the past 25 years.
- The new NIH-Wide Strategic Plan calls for disease burden to be a “crucial” consideration in prioritizing NIH research. In accordance, NIH headache disorders research should be markedly increased.



- **Please include FY17 L-HHS Report Language (see template on reverse of page) with your Member’s request letter to L-HHS Appropriations Chairman Cole and Ranking Member DeLauro.**



**Alliance for
Headache
Disorders
Advocacy**

Alliance for Patient Access
American Academy of Neurology
American Headache Society
American Migraine and Headache Association
Clusterbusters
Headache Cooperative of New England
Headache Cooperative of the Pacific

Migraine Research Foundation
Miles for Migraine Races
National Headache Foundation
National Migraine Association
Ohio Headache Association
PFO Research Foundation

Contact: William B. Young, MD [william.young@jefferson.edu]

Dear Chairman Cole and Ranking Member DeLauro,

I am very mindful of the fact that the House Appropriations Subcommittee on Labor, Health, Human Services, Education, and Related Agencies will be faced with many difficult choices in 2016. However, I respectfully request that the Committee rectify at this time the federal inattention towards the concerns of Americans disabled by headache disorders.

Headache disorders are the most prevalent of all neurological disorders. The World Health Organization has found that migraine is the 3rd most prevalent global disorder and the 7th leading cause of global disability. At least 36 million Americans will experience a Migraine attack this year, 12 million will suffer from chronic daily headaches, and millions further will be affected by Cluster Headache, post-traumatic headache, and other disabling headache disorders. Collectively, headache disorders cost the United States economy more than \$31 billion annually.

In 2014, the NIH directed just \$24 million towards all headache disorders research, including \$20 million focused on migraine research. Analyses by both NIH and by independent investigators show that Migraine is among the *very least funded* diseases by NIH, relative to its huge population and disability burdens.

Recently, and for the first time, NIH signaled in its NIH-Wide Strategic Plan that it will start incorporating disease burden measures as a “crucial” consideration in prioritizing its research portfolio. In implementing this new policy, the NIH should be assisted by a \$2 billion budget increase in the Consolidated Appropriations Act, 2016.

At this pivotal juncture as NIH implements its new policy and increases headache disorders research, I have received the consensus opinion of headache medicine research scientists of the Alliance for Headache Disorders Advocacy, representing 13 US non-profit organizations, that the following statement of programmatic requests be appended as Report Language to the FY 2017 bill that appropriates funding for NIH:

“The Committee commends NIH for including formal consideration of disease burden as a “crucial” factor for aligning its research priorities within the new NIH-Wide Strategic Plan. The Committee notes that “Migraine” and “Headaches” are among the very least funded disease categories of those diseases with the very highest burden in NIH’s own analyses. In furtherance of these NIH reports, the Committee expects that NIH will now prioritize substantial increases in fundamental, translational, and clinical research funding towards headache disorders over the next decade. The Committee strongly urges NIH to (1) issue Requests for Applications with 5-year terms for investigator-initiated research projects in this research area; (2) emphasize and incentivize recruitment of both junior and established investigators to join this field through Program Announcements with Set-Aside Funds that support career training and transition fellowships and awards (e.g. T, F and K awards) which are specifically devoted to the investigation of headache disorders (comparable to NIH programs for muscle disorders); (3) always include at least three headache research scientists as permanent members of a single permanent CSR study section to ensure fair reviews of headache disorders research grant proposals; (4) expand the highly successful Anticonvulsant Screening Program to include screening of drugs and devices for headache disorders; and (5) fully fund the national collaborative American Registry for Migraine Research.”

I hereby request inclusion of this Report Language. Thank you for your consideration.

Sincerely,

United States Representative