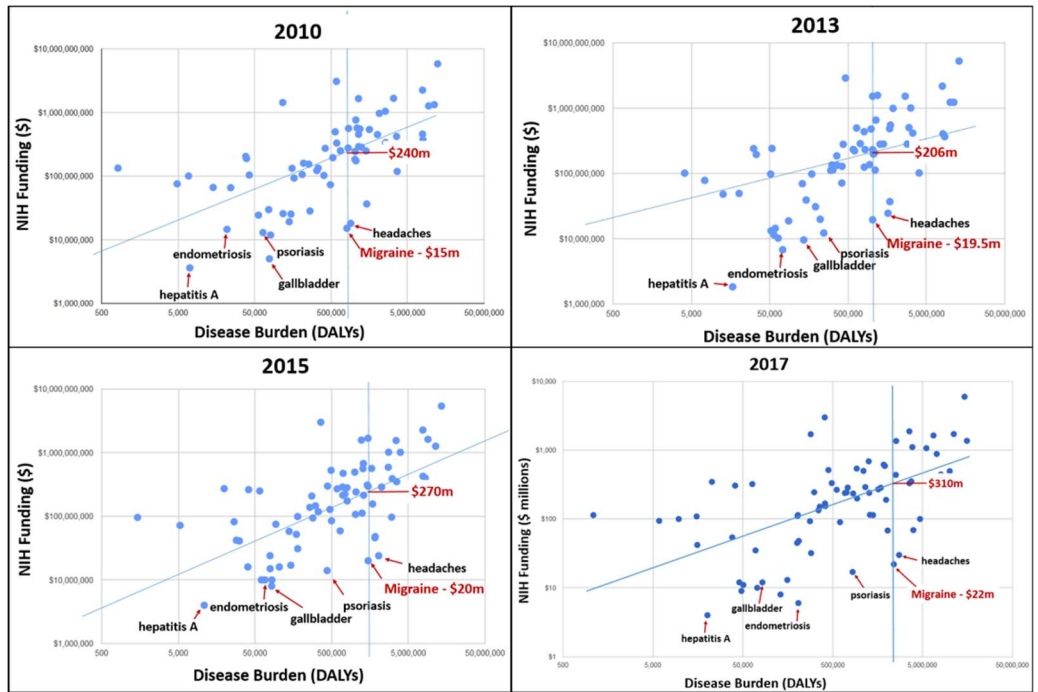


NIH calls Disease Burden a “Crucial Consideration”.

When will it prioritize research funding like it is?

- Congress has directed NIH to consider disease burden in funding decisions, and NIH has committed to doing so.
 - The Appropriations Committee “expects NIH to consider the burden of a disease when setting priorities”.¹
 - The NIH HEAL Initiative statutory authority [42 USC § 284q–1] mandates disease burden as a funding priority.²
 - The NIH-Wide Strategic Plan cites disease burden as “a crucial, but not the only, consideration”.³
- Yet some diseases languish, year after year, with chronic under-funding of NIH research relative to their burdens.



- NIH too rarely deploys its proven measures to incentivize investigators to study under-researched diseases.
- For examples, NIH can issue disease-specific FOAs⁵ with set-aside funds, and/or disease-specific payline shifts.
- Migraine is the least-funded research area relative to its very high burden - 14-fold disparity in 2017 (\$22m vs \$310m)⁴.
 - Congressional Appropriators have issued seventeen (17) Report Language statements since FY2009⁶ urging increased NIH programmatic funding specifically for migraine and headache disorders research.
 - Migraine research is mandated to be prioritized as an under-funded pain disorder, under [42 USC § 284q–1].
 - NIH has refused to issue migraine FOAs w set-aside funds, or shift the payline to remedy funding disparities.
- The GAO has not reviewed NIH funding priorities, including disease burden, in more than 5 years.⁷
- Please sign the Dear Colleague letter, to be circulated in March, urging the House E&C, Health Subcommittee to request a GAO report on NIH research funding relative to disease burden, in particular for headache disorders.

¹ <https://www.congress.gov/114/crpt/srpt274/CRPT-114srpt274.pdf>

² <https://www.law.cornell.edu/uscode/text/42/284q-1>

³ <https://www.nih.gov/sites/default/files/about-nih/strategic-plan-fy2016-2020-508.pdf>

⁴ <https://report.nih.gov/report-nih-funding-vs-global-burden-disease>

⁵ Funding Opportunity Announcements (FOAs)

⁶ <https://headachejournal.onlinelibrary.wiley.com/action/downloadSupplement?doi=10.1111%2Fhead.13913&file=head13913-sup-0001-Supplement1.pdf>

⁷ GAO-14-490R, GAO-14-246, GAO-17-121



Alliance for
Headache
Disorders
Advocacy

Alliance for Patient Access
American Academy of Neurology
American Headache Society
CHAMP
Chronic Migraine Awareness
Clusterbusters
Cluster Headache Support Group

Headache Cooperative of New England
Headache Cooperative of the Pacific
Miles for Migraine
National Headache Foundation
Southern Headache Society
Spinal CSF Leak Foundation