

Hydrocephalus Issues Summary

Increase funding for the National Institutes of Health

The National Institutes of Health (NIH) are responsible for conducting and facilitating life-saving research into hydrocephalus and its treatments. Currently, there is no known cure for hydrocephalus. Shunts—medical devices permanently implanted in the ventricles of the brain—have the highest failure rate of any implanted medical device. At NIH, the National Institute of Neurological Disorders and Stroke (NINDS) focuses on research to help scientists better understand the brain and associated illnesses. For instance, NINDS's Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative seeks to map the brain. This initiative could prove immensely helpful in better understanding hydrocephalus and developing new treatments.

Yet, even as NIH conducts vital research through the BRAIN Initiative and other programs, funding is regularly threatened. As part of the 2013 sequestration process, the NIH budget was cut by more than \$1.5 billion over the next 10 years. As a result, hundreds of long-term research projects have been abandoned. NIH and NINDS funding will continue to be impacted by long-term budget cuts unless Congress takes steps to protect these critical funds. This is why the Hydrocephalus Association supports increased funding for NIH, NINDS, and the BRAIN Initiative.

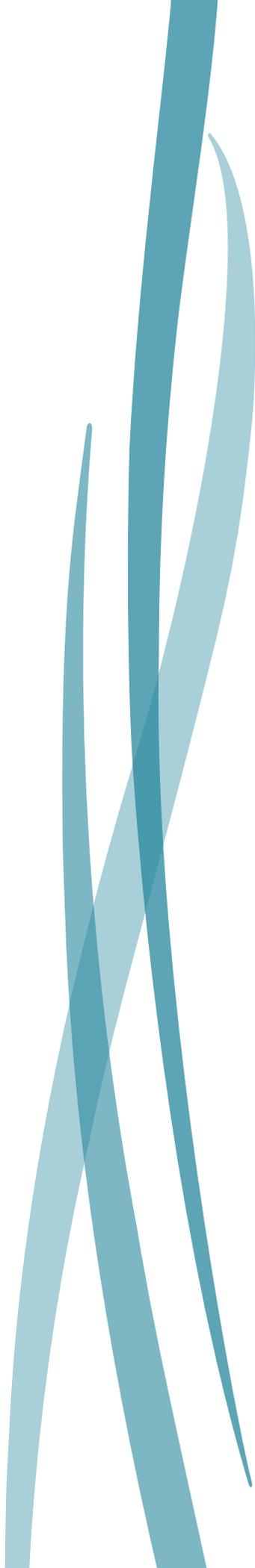
Continue to include hydrocephalus as a condition eligible for CDMRP funding at the Department of Defense

Hydrocephalus can be caused by traumatic brain injury. Active service members and veterans who have experienced traumatic brain injury are particularly vulnerable to developing hydrocephalus. Since 2000, more than 333,000 U.S. service members have sustained a traumatic brain injury. Over 35,000 are at risk of developing hydrocephalus. The Department of Defense does not currently track the development of hydrocephalus, so, while Normal Pressure Hydrocephalus (NPH) affects elderly adults, it is not known if previous injury, even mild injury, increases the risk of NPH. NPH may affect over 700,000 senior citizens in the United States. That includes over 180,000 veterans.

Within the Department of Defense, the Congressionally Directed Medical Research Program (CDMRP) seeks out and funds research proposals on various diseases related to military health. CDMRP currently lists a number of conditions that are eligible for research funding. Recently, as a result of the Association's advocacy efforts, hydrocephalus was added to this list. The Hydrocephalus Association supports the continued inclusion of Hydrocephalus as a condition eligible for funding through the CDMRP.

Include hydrocephalus as a condition to be tracked under the National Neurological Diseases Surveillance System

The 21st Century Cures Act (H.R. 6) seeks to improve the discovery, development, and delivery of cures for a wide variety of diseases. Among many other things, this bill would establish a program at the National Institutes of Health to track neurological diseases. The brain, in many ways, remains a mystery to scientists. Greater



understanding of the workings of the brain and diseases associated with it would help doctors better understand hydrocephalus, lead to earlier diagnosis, particularly for our adult populations, and hopefully lead to the development of new, more effective treatments, preventions, or cures. Because hydrocephalus is a neurological condition with wide-ranging impact across the country, the Hydrocephalus Association supports the very specific inclusion of hydrocephalus as one of the neurological diseases to be tracked through this program.

Co-Sponsor the Advancing Research for Hydrocephalus Act (H.R. 2313)

Congressman Chris Smith (R-NJ-04) introduced the Advancing Research for Hydrocephalus Act of 2016 in the House of Representatives. This bill aims to facilitate hydrocephalus research by requiring the collection of demographic information on the hydrocephalus community. Only by facilitating research and obtaining better data can scientists develop more effective treatments than shunts, which often fail and must be replaced.

Congressman Smith's bill establishes a National Hydrocephalus Surveillance System. This system would collect information on the incidence and prevalence of hydrocephalus among various populations in the United States. Such data would help researchers better understand hydrocephalus and hopefully lead to the development of new, more effective treatments. The Hydrocephalus Association asks members of the US House of Representatives to co-sponsor this important legislation. The Association asks Senators to introduce a companion to the one in the House.

Join the Congressional Pediatric and Adult Hydrocephalus Caucus and the Congressional Neuroscience Caucus

Legislators form congressional membership organizations (CMOs) to learn more about an issue or to become an advocate for an issue. By joining a hydrocephalus or neurological group, members of Congress will remain up-to-date on hydrocephalus-related policies and become more active advocates. Therefore, the Hydrocephalus Association urges members of Congress to join hydrocephalus-related CMOs, such as the Congressional Pediatric and Adult Hydrocephalus Caucus and the Congressional Neuroscience Caucus.

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To join the Hydrocephalus Action Network, email advocacy@hydroassoc.org. For additional resources about hydrocephalus and information about the services of the Hydrocephalus Association, please contact:



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