

[OPTIONAL: CREATE YOUR OWN PERSONAL LETTERHEAD]

[INSERT DATE]

[INSERT ADDRESS BLOCK]

Dear Congressman/Congresswoman/Senator:

On behalf of the Hydrocephalus Association and in conjunction with the 2015 Rally for Medical Research, I am writing today to urge you to:

- Support the robust increases in funding for the National Institutes of Health (NIH);
- Support the continued inclusion of hydrocephalus as a condition eligible for funding under the Congressionally Directed Medical Research Programs within the Department of Defense;
- Co-sponsor the Advancing Research for Hydrocephalus Act of 2015 and introduce a companion bill in the Senate.

Hydrocephalus is an abnormal accumulation of cerebrospinal fluid (CSF) within cavities in the brain called ventricles. As the CSF builds up, it causes the ventricles to enlarge and the pressure inside the head to increase. Hydrocephalus is a life-threatening condition that affects approximately 1 million Americans, and anyone can develop the condition as a result of a traumatic brain injury. Populations particularly at risk include premature babies, active duty service members, and veterans. Individuals can also be born with the condition, develop it as part of the aging process, or acquire it as a result of infections or brain tumors, among other causes.

NIH conducts critical research on hydrocephalus primarily through the National Institute of Neurological Disorders and Stroke (NINDS). In the past, NIH researchers have made groundbreaking discoveries critical to developing shunts—the only known treatment for hydrocephalus. Furthermore, NINDS's Brain Research through Advancing Innovative Technologies (BRAIN) Initiative promises significant insights into the intricate mysteries of the brain that still elude scientists. The BRAIN Initiative's plan to comprehensively map the human brain could help scientists better understand hydrocephalus and develop new tools and treatments.

In addition to NIH, the Department of Defense conducts medical research into military health conditions through the Congressionally Directed Medical Research Programs (CDMRP). Hydrocephalus can be caused by traumatic brain injury (TBI), which is prevalent among active service members and veterans. Since 2000, more than 333,000 U.S. service members have sustained a traumatic brain injury. Active or retired service members who have experienced severe traumatic brain injury are particularly vulnerable to developing hydrocephalus, with estimates showing that 14% of those individuals that suffered a severe TBI could develop the condition. The incidence of hydrocephalus for active service members is understated because it is likely that the onset is delayed from the initial trauma or not readily identified. Further, the aging Veteran population is not counted in these numbers yet many will develop Normal Pressure Hydrocephalus. Approximately 180,000 Veterans currently have NPH, many of which are probably undiagnosed or misdiagnosed with Alzheimer's, Parkinson's, or another related dementia. I ask you to ensure that hydrocephalus continues to be one of the conditions eligible for research funding through CDMRP.

Finally, I urge you to co-sponsor the Advancing Research for Hydrocephalus Act (H.R. 2313) in the House of Representatives and introduce a companion bill in the Senate. This piece of legislation, introduced by Rep. Chris Smith (R-NJ-04), aims to facilitate hydrocephalus research by requiring the collection of demographic information on the hydrocephalus community. It creates a National Hydrocephalus Surveillance System, which will collect information on the incidence and prevalence of hydrocephalus among various populations in the United States. Such data will help researchers better understand hydrocephalus and promises to lead to the development of new, more effective treatments.

[INSERT YOUR STORY]

As a member of the Hydrocephalus Association, I ask that you prioritize and increase funding for NIH in FY2016, include hydrocephalus as a 2016 CDMRP-eligible condition, and co-sponsor the Advancing Research for Hydrocephalus Act of 2015. I also urge you to join the Congressional Pediatric and Adult Hydrocephalus Caucus and the Congressional Neuroscience Caucus to stay up-to-date on the status of hydrocephalus research. Anyone can develop hydrocephalus resulting from a number of causes, and it is a life-threatening condition that affects approximately 1 million Americans. Medical research is critically important to reducing the impact of hydrocephalus nationwide.

Sincerely,

[INSERT YOUR SIGNATURE]