FUND THE CONGRESSIONALLY DIRECTED MEDICAL RESEARCH PROGRAM (CDMRP) AT THE DEPARTMENT OF DEFENSE

Since 2000, more than 370,000 U.S. service members have sustained a traumatic brain injury, one cause of hydrocephalus, and it is estimated that 14% of those individuals who suffer a from a severe TBI—over 50,000 service members—could develop hydrocephalus. This does not include the approximately 180,000 veterans who currently have Normal Pressure Hydrocephalus (NPH), a number that grows every year as the population ages. Unfortunately, many of these cases are often undiagnosed or misdiagnosed as Alzheimer’s, Parkinson’s, or another related dementia. Within the Department of Defense, the Congressionally Directed Medical Research Program (CDMRP) (funded at $1.518 billion in FY2022) seeks out and funds research proposals on various diseases related to military health, including hydrocephalus.

CREATE AN FDA NEUROSCIENCE CENTER OF EXCELLENCE

The Hydrocephalus Association has joined over 85 organizations in supporting the 21st Century Cures 2.0 proposal to authorize a new Center of Excellence at the Food and Drug Administration (FDA). The center would focus on high prevalence and burdensome diseases, like those affecting the brain and central nervous system (CNS). Hydrocephalus patients continue to lack access to less invasive and reliable treatments as well as non-surgical treatment options. We believe such a center will allow the FDA to create a faster path for the review and approval of safe, effective, and non-surgical treatments.

Therefore, we urge legislators to support the creation of a Neuroscience Center of Excellence at the FDA as part of the 21st Century Cures 2.0 discussion in Congress. Such a center will encourage innovation in the study, creation, and regulation of brain-focused devices and therapeutics with the goal of delivering cures and better treatments to patients quickly.

SUPPORT 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.

In FY2022, Congress recognized the need for additional funding for NIH, approving a 3% increase to bring the budget to $45 million. For FY2023, the Hydrocephalus Association supports maintaining our strong commitment to finding new treatments and possibly even a cure for hydrocephalus through research at the NIH, NINDS, the BRAIN Initiative, and the Precision Medicine Initiative.
SUPPORT CRITICAL RESEARCH PROGRAMS

The Hydrocephalus Association is part of a large coalition of groups supporting critical research programs at the National Institutes of Health, the Department of Veterans Affairs, and the National Science Foundation. We have joined with our partners in urging Congress to support the following levels of funding for FY2023: $47.5 billion for the National Institutes of Health; $2.75 billion for the Advanced Research Projects Agency for Health (ARPA-H, which seeks to speed investment in and action on biomedical research; $926 million for the VA Medical and Prosthetic Research Progra; and, $9.63 billion for the National Science Foundation.

SUPPORT SEPTEMBER AS HYDROCEPHALUS AWARENESS MONTH

September is Hydrocephalus Awareness Month, which provides an opportunity to raise awareness of the many challenges this condition poses for patients, their families, and the country as a whole. The Hydrocephalus Association urges Senators to demonstrate their support by making a statement on the Senate floor highlighting the important work being done across the country to both raise awareness of this condition as well as to find potential treatments and possibly a cure.