JOIN THE CONGRESSIONAL PEDIATRIC AND ADULT HYDROCEPHALUS CAUCUS

Representative Lloyd Doggett (D-TX) and Representative Chris Smith (R-NJ) have formed the Congressional Pediatric and Adult Hydrocephalus Caucus, which seeks to raise awareness of this condition on Capitol Hill. The Hydrocephalus Association urges members of Congress to join this caucus as a means of learning more about the condition and the federal government’s role in improving quality-of-life for those living with hydrocephalus. To do so, please contact Mary Vigil in Representative Smith’s office, or Darcy Milburn in Representative Doggett’s office.

COSPONSOR H.RES.20, RECOGNIZING SEPTEMBER AS HYDROCEPHALUS AWARENESS MONTH

Representatives Lloyd Doggett and Chris Smith have introduced H.Res. 20, a bipartisan resolution supporting September as Hydrocephalus Awareness Month. The resolution points to the many challenges this condition poses for patients, their families, and the country as a whole. Among other things, the resolution references the following facts: over one-million Americans live with the condition; one in 770 babies develop hydrocephalus; a form of hydrocephalus develops in seniors for unknown reasons and is often undiagnosed or misdiagnosed as Alzheimer’s, Parkinson’s or a related dementia; and, the only treatment for the condition is brain surgery.

We urge members of Congress to demonstrate their support for hydrocephalus patients, families, and caregivers in their district by cosponsoring the resolution.

SUPPORT FUNDS FOR THE CONGRESSIONALLY DIRECTED MEDICAL RESEARCH PROGRAM (CDMRP) AND DIRECT FUNDING FOR HYDROCEPHALUS RESEARCH 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 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.

In addition, we urge legislators to support a proposed line item for $5 million in direct hydrocephalus funding.
CREATE AN FDA NEUROSCIENCE CENTER OF EXCELLENCE

The Hydrocephalus Association is part of a large coalition of brain health-oriented organizations in supporting the introduction of the Bringing Regulatory Advances Into Neuroscience (BRAIN) Act, to establish a Neuroscience Center of Excellence (NCOE) at the Food and Drug Administration (FDA). A NCOE will spur innovation and investment in the study, creation, and regulation of brain-focused therapies by creating an environment designed to achieve patient-centered regulatory decision making, with the goal of bringing the right treatments and cures to patients who desperately need them.

Therefore, we urge legislators to cosponsor the Bringing Regulatory Advances Into Neuroscience (BRAIN) Act (H.R. 5435) and to support similar provisions in the bipartisan Cures 2.0 Act (H.R. 6000).

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.

For 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.

COSPONSOR THE CONNECT FOR HEALTH ACT

The Hydrocephalus Association has joined dozens of other patient groups in supporting the Creating Opportunities Now for Necessary and Effective Care Technologies (CONNECT) for Health Act of 2021, which has been introduced in both the U.S. House of Representatives and Senate (S 1512/HR 2903). If passed, this bipartisan bill would expand coverage of telehealth services through Medicare, make permanent COVID-19 telehealth flexibilities, improve health outcomes, and make it easier for patients to safely connect with their doctors.

Improving access to care through telehealth opportunities would offer significant benefits to the hydrocephalus community. By removing geographic restrictions on health services, more patients would be able to receive care from their home and/or qualified sites from medical professionals experienced in hydrocephalus diagnosis, treatment and care. Therefore, we urge legislators to cosponsor S 1512/HR 2903, the bipartisan CONNECT for Health Act.