

## HYDROCEPHALUS ISSUES SUMMARY FOR THE U.S. HOUSE OF REPRESENTATIVES

### JOIN THE CONGRESSIONAL PEDIATRIC AND ADULT HYDROCEPHALUS CAUCUS

Representative Chris Smith (R-NJ) and Representative Lloyd Doggett (D-TX) 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. Caucus issues include federal research, pediatric-to-adult healthcare transition, and healthcare access. To do so, please contact John McDonough ([john.mcdonough@mail.house.gov](mailto:john.mcdonough@mail.house.gov)) in Representative Smith's office, or Afton Cissell ([afton.cissell@mail.house.gov](mailto:afton.cissell@mail.house.gov)) in Representative Doggett's office.

### SUPPORT FUNDS FOR THE CONGRESSIONALLY DIRECTED MEDICAL RESEARCH PROGRAM (CDMRP)

Since 2000, more than 470,000 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 60,000 service members—could develop hydrocephalus. This does not include the approximately 180,000 veterans who have symptoms consistent with 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 \$1.561 billion in FY2024) seeks out and funds research proposals on various diseases related to military health, including hydrocephalus. Within the CDMRP, hydrocephalus competes with other conditions for research grant funding through the Peer Reviewed Medical Research Program (PRMRP) (funded at \$370 million in FY 2023). In the 2022 grant cycle, hydrocephalus was awarded a historical high of \$15 million in research funding. Hydrocephalus was awarded \$11.78 million in the 2023 grant cycle.

### 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 FY2024, the NIH budget was funded at \$47.3 billion, the first decrease since 2013. For FY2025, we urge lawmakers to increase this topline number to support scientific innovation across the country. The Hydrocephalus Association supports maintaining our strong commitment to finding new treatments and 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 2023, which has been introduced in both the U.S. House of Representatives and Senate (S. 2016 and HR 4189). 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.2016/HR.4189, the bipartisan CONNECT for Health Act.

## COSPONSOR THE ACCELERATING KIDS' ACCESS TO CARE

The Hydrocephalus Association has joined a large number of other patient groups in supporting the Accelerating Kids' Access to Care Act of 2023, which has been proposed in both the House of Representatives and Senate (S.2372 and HR.4758). If passed, this bipartisan bill would eliminate the unnecessary barriers that prevent kids from seeking out-of-state pediatric care. By streamlining the process for providers to enroll in another state's Medicaid program, it strengthens the ability for kids with complex medical issues to receive life-saving care from physicians that are experts in their field. Therefore, we urge legislators to cosponsor S.2372/HR.4758, the Accelerating Kids' Access to Care Act of 2023.

## COSPONSOR THE SSI SAVINGS PENALTY ELIMINATION ACT

The Hydrocephalus Association has joined others in the disability community in supporting the SSI Savings Penalty Elimination Act, which has been introduced in both the House of Representatives and Senate (S.2767/H.R.5408). If passed, the bipartisan bill would raise the SSI (Supplemental Security Income) asset limit from \$2,000 to \$10,000 for individuals and \$3,000 to \$20,000 for married couples. The bill will also index the limits with inflation. The limit, which was established in 1974, has not been raised since 1989. By increasing the limits, it will give elderly Americans and those with disabilities a better change to achieve financial independence. Therefore, we urge legislators to cosponsor S.2767/H.R.5408, the SSI Savings Penalty Elimination Act.



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