

2021 Annual Report Highlights



2021 was an important year for our research program. We exceeded the \$13 million mark for our total research program spending. This investment helped advance hydrocephalus research in incredible ways. It allows us to support three research networks and award 47 grants to brilliant scientists exploring new treatments and pathways to a cure. Today, thanks to our generous supporters, we are the largest, private funder of hydrocephalus research in the country.

AHCRN Awarded \$14M NIH Grant to Study Shunt Treatment for NPH

A \$14 million grant from the National Institute of Neurological Disorders and Stroke (NINDS) will fund a study designed to prove conclusively whether shunt surgery for iNPH is beneficial. This is the largest grant ever awarded to study adult hydrocephalus and is being conducted in partnership with the Johns Hopkins Cerebral Fluid Center. The study will include the eight sites of the Adult Hydrocephalus Clinical Research Network (AHCRN), working with 13 other health centers.



Neurosurgeons on a new NPH clinical trial

“This study is important because right now some in the medical community are not convinced that shunts are an effective treatment for iNPH. Much of this uncertainty is due to the lack of a high-quality randomized controlled trial,” said Dr. Mark Luciano, Neurosurgeon, Director of the Cerebral Fluid Center at Johns Hopkins and Principal Investigator of the study.

Expanding our Online Learning Opportunities

With the COVID-19 pandemic still affecting the nation, we expanded our virtual offerings. We hosted 170 virtual Community Network gatherings and educational meetings. The gatherings gave adults and young people an opportunity to meet their peers and make new friendships.

We also offered 12 educational webinars, including our first-ever webinar in Spanish. Our webinars touched on a variety of topics—from shunt obstructions and hydrocephalus drugs currently in development to how to transition from pediatric to adult medical care.

WALKs Help Raise Over \$1.6M

Thanks to our passionate volunteers, we held 41 WALK to End Hydrocephalus events this year. Most of HA's WALKs were held live and in person. In total, the WALKs raised over \$1.6 million, with 734 teams participating and 6,500 registered participants and volunteers.



Hydrocephalus Once Again Receives Research Funding by the Department of Defense

Senator Patty Murray stood with our community again this year and hydrocephalus was included as an eligible condition under the Fiscal Year 2022 Defense Appropriations Act. To date, scientists have received \$14.4M in funding from the CDMRP to further their science and bring us closer to prevention and alternative treatment options.

HA Holds Virtual Hydrocephalus Day on Capitol Hill

Even though we couldn't travel to come together in Washington, DC, 180 advocates representing 30 states from across the country participated in a "Virtual Fly-In" on July 20, 2021. Hydrocephalus patients, along with caregivers, doctors, and others, participated in online meetings with staff and legislators in the U.S. House and Senate. 10 members of Congress personally joined the meetings. Advocates shared their personal experiences and urged legislators to become active in support and research funding.



New Members Join Congressional Hydrocephalus Caucus

In 2021, we were pleased to welcome several new members to the Congressional Pediatric and Adult Hydrocephalus Caucus.



Representative
Cindy Axne (D-IA)



Representative
Derek Kilmer (D-WA)



Representative
Mike Levin (D-CA)



Representative
Thomas Souzzi (D-NY)



Representative
Joe Wilson (R-SC)

The Congressional Pediatric and Adult Hydrocephalus Caucus informs Congress about the needs of those living with hydrocephalus, their families and caregivers, and is an important way for members of Congress to show their support for our issues and to elevate the discussion about our key legislative priorities.

Visit our website for the latest list of congressional offices that are on the Caucus www.hydroassoc.org/congressional-pediatric-and-adult-hydrocephalus-caucus/

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SINCE 2009

\$50M
SECURED IN ADDITIONAL
FUNDING BY HA
RESEARCHERS

11
PRECLINICAL
DRUGS TESTED

47
TOTAL GRANTS
AWARDED TO SCIENTISTS

810
PEOPLE HAVE JOINED
HAPPIER, OUR
HYDROCEPHALUS
PATIENT REGISTRY

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