



2019 ANNUAL REPORT HIGHLIGHTS



2019 was truly monumental for the Hydrocephalus Association (HA) for so many reasons. Not only did we celebrate the 10th anniversary of our Research Initiative, we also had an amazing WALK to End Hydrocephalus season with over 15,000 people participating in 44 locations across the country. None of it would have been possible without the support of our community. Thanks to YOU, we were able to vastly expand the hydrocephalus research landscape and to continue helping people living with hydrocephalus by providing one-on-one support and educational resources. Here's a look at what made 2019 a great year:



Celebrating 10 Years of HA's Research Initiative

Families and researchers from across the country came together on Nov. 3, 2019 in St. Louis, MO to celebrate the 10th Anniversary of HA's Research Initiative. The event highlighted the successes of our research investments and honored the trailblazers who started it all. 10 years ago, HA began investing in high-impact research because we wanted a different future for people living with hydrocephalus. Now, we are the largest, private funder of hydrocephalus research in the U.S., investing over \$11 million in research and awarding 40 grants to brilliant scientists. Our grantees and clinical networks have gone on to secure an additional \$32 million in additional funding.

4 Scientists Awarded Grants for Hydrocephalus Research

We awarded four scientists with Innovator Award grants totaling \$1.3 million. These scientists are exploring new ideas to identify why hydrocephalus develops and testing new treatments to improve long-term outcomes for people living with hydrocephalus.

Scientists From Around the World Come Together for HA Research Workshop

In November 2019, we hosted a Research Workshop at Washington University in St. Louis, MO, bringing together scientists from across the United States and five countries. The workshop delved deeper into the research around posthemorrhagic hydrocephalus (PHH.)

"I'm so proud to be part of an organization that helps individuals and families throughout their journey with hydrocephalus. Even when faced with a global pandemic, we've been able to continue serving our community with valuable and timely resources. And I know we'll continue to do what we've always done – to innovate and succeed and to be on the front lines for families who have always leaned on us for support."

-Brett Weitz, Chair of HA's Board of Directors

Helping People Impacted by Hydrocephalus

In 2019, we continued to be the place to turn to for individuals and families impacted by hydrocephalus, providing one-on-one support to 5,000 individuals through our free HelpLine. We also connected local families through our 44 Community Networks around the country, and provided educational resources about hydrocephalus at 18 events.



WALKs Help Raise Over \$2 Million

Thanks to our volunteers, 44 WALKs to End Hydrocephalus were held across the U.S., with more than 15,000 people participating. For the first time, the WALKs raised over \$2 million for HA's mission!



"In Stitches" Event Features Conan O'Brien

On April 11, 2019, over 400 people joined us in Los Angeles for our 2nd annual In Stitches comedy fundraiser featuring Emmy Award-winning comedian and host, Conan O'Brien. The event raised

much-needed awareness of our cause and over \$300K for hydrocephalus research, support and education programs.



Caucus Briefing Educates Members of Congress About Hydrocephalus

On Oct. 17, 2019, the Hydrocephalus Association hosted a Hydrocephalus Caucus Briefing in Washington, D.C. More than 60 Congressional offices participated, along with members

of the hydrocephalus patient community. The briefing explored the impact hydrocephalus has on families and members of the military, and how Congress can support families impacted by this condition.

Our Advocacy Efforts Worked!

We continued to advocate for hydrocephalus patients and caregivers. With the help of our community, we were able to work with Congress to ensure several major wins for our community, such as preserving funding for the Congressionally Directed Medical Research Program (CDMRP), which funds research on hydrocephalus; extending funding for the Patient-Centered Outcomes Research Institute (PCORI); and repealing the Medical Device Excise Tax.

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2019 Annual Report
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\$1.3M
INVESTED IN NEW
RESEARCH GRANTS

\$11M
INVESTED IN RESEARCH
SINCE 2009

15,000
PEOPLE TOOK PART IN
A HYDROCEPHALUS WALK

5,000
PEOPLE RECEIVED
SUPPORT FROM HA

44
COMMUNITY NETWORKS
AROUND THE COUNTRY

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