

2023 ANNUAL REPORT HIGHLIGHTS

Honoring Our Legacy and Shaping the Future

The Westin Anaheim Resort was ablaze with excitement and purpose on November 10, 2023, as the Hydrocephalus Association commemorated four decades of impact, dedication, and support for our community at our 40th Anniversary Gala.

The event brought together a diverse ensemble of researchers, physicians, industry partners, individuals living with hydrocephalus, their families, and esteemed supporters for an evening that blended celebration, gratitude, and a resounding call for progress.

In celebrating this milestone, the Hydrocephalus Association (HA) reaffirmed its pledge to persist in driving forward research, support, and advocacy, ensuring that every step brings us closer to a world where hydrocephalus is a thing of the past.



Announcing the 2023 Innovator Award Recipients

The Hydrocephalus Association Innovator Awards are a testament to the spirit of innovation within the scientific and medical community. In 2023, HA granted seven Innovator Awards to scientists so they could turn their groundbreaking ideas into reality, offering crucial seed funding and support. The Innovator Awards are for one year of support at a \$50,000 level. The Hydrocephalus Association would like to extend a thank you to Team Hydro and the Rudi Schulte Research Institute for their generous support.

Record-Breaking \$14 Million Grant for iNPH Clinical Trial in Full Swing

Groundbreaking research in idiopathic normal pressure hydrocephalus (iNPH) is underway with a \$14M grant from the National Institute of Neurological Disorders and Stroke (NINDS), the largest ever for adult



Mark Luciano

hydrocephalus. The Adult Hydrocephalus Clinical Research Network (AHCRN) received the grant to conduct the first large-scale, multi-center, randomized controlled trial evaluating the effectiveness of shunting patients with iNPH and improving diagnosis.

The "Placebo Controlled Efficacy in iNPH Shunting (PENS)" study is being conducted at 21 centers in the US, Canada, and Sweden, led by Dr. Mark Luciano at Johns Hopkins Cerebral Fluid Center. So far, 61 participants have been randomized, with a goal of 100 by March 2025. Results are expected by the end of 2026.



The AHCRN, comprising eight institutions, played a pivotal role in identifying the need for this study. The AHCRN is one of three research networks funded by the Hydrocephalus Association, dedicated to conducting clinical research to improve treatment for adult forms of hydrocephalus.

"Where we need to be is funding research so we can find better treatments. A million people in the US alone deserve better, and the Hydrocephalus Association is the only one that will do it."

 Emily Fudge, mother of Gerard and one of the founders of the Hydrocephalus Association



UnderPressure: A Campaign to Accelerate the Pace of Research

The majority of the promising research funded by HA is thanks to private donations from individuals, foundations, and corporate partners. These results have expanded hydrocephalus research into new disciplines, greatly increasing funding opportunities. With your continued support, we will accelerate

breakthroughs, transform lives, and bring hope to those affected by hydrocephalus. *Together, we can change the future of hydrocephalus!*

Please reach out to Linda Riley, National Director of Development at linda@hydroassoc.org. Or visit hydroassoc.org/underpressure

Join Us for World Hydrocephalus Day 2024!

After the success of our inaugural World Hydrocephalus Day last year, we aim to make an even bigger impact this year. World Hydrocephalus Day sheds light on this often-misunderstood condition and promotes global unity among patients, caregivers, healthcare professionals, and advocacy organizations. By fostering understanding and compassion, we strive to improve the lives of those affected by hydrocephalus.

Our goals are to raise awareness, support those affected, advocate for research, promote early diagnosis, and celebrate resilience.

Visit our newly created website: worldhydrocephalusday.org to meet our global partners and learn how you can participate in making this the biggest event yet!

JOIN US!

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\$14M INVESTED IN RESEARCH SINCE 2009

\$74M SECURED IN ADDITIONAL FUNDING BY HA RESEARCHERS

> 12 PRECLINICAL DRUGS TESTED

> > 63

TOTAL GRANTS AWARDED TO SCIENTISTS

1158 PEOPLE HAVE JOINED HAPPIER, OUR HYDROCEPHALUS PATIENT REGISTRY



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