

# Hydrocephalus Association Plays Key Role in Rare Disease Week

*Hydrocephalus advocates unite with 800 fellow advocates from the Rare Disease community to champion critical life-saving legislation on Capitol Hill today.*

WASHINGTON, DC, UNITED STATES, February 27, 2024 /EINPresswire.com/ -- Hydrocephalus advocates unite with 800 fellow advocates from the Rare Disease community to champion critical life-saving legislation on Capitol Hill today. Patients and loved ones from across the country have come together in Washington, DC, to participate in Rare Disease Week, taking place from February 25 – 28, 2024. Hosted by the [Everylife Foundation for Rare Diseases](#), this annual event brings awareness to the need to prioritize and accelerate access

to treatments and timely diagnosis for rare disease patients to save lives and address a significant public health crisis in cost, which is estimated to have reached a staggering \$1 trillion dollars in 2019. The [Hydrocephalus Association](#) (HA) first participated in Everylife's event in 2016.

The theme for Rare Disease Week is Every Voice Matters. The events on Capitol Hill serve as a pivotal platform for hundreds of individuals and families within the rare disease community to share their stories directly with Congress to punctuate how current or needed legislation could benefit the patient community. Members of the Hydrocephalus Association Action Network, the advocacy program of the association, will be at the forefront throughout the event, actively engaging to drive policy change and raise awareness for hydrocephalus and related rare conditions. They will also participate in two events on Capitol Hill on Wednesday, February 28: the Rare Disease Week 2024 DEIA Discussion and the Rare Disease Congressional Caucus Briefing.



Hydrocephalus Association at Rare Disease Week

"The Hydrocephalus Association is excited to bring our advocates together at Rare Disease Advocacy Week," said Amanda Garzon, HA Chief Operations Officer. "Our participation underscores our commitment to raising awareness and advocating for individuals affected by hydrocephalus and related rare conditions."

As a part of this week, Rare Disease Day at NIH ([National Institutes of Health](https://www.nih.gov/rare-disease-day)) takes place worldwide on Thursday, February 29, 2024. This global observance aims to raise awareness about rare diseases, the people they affect, and NIH collaborations that address scientific challenges and advance research for new treatments.

While hydrocephalus itself is not considered a rare disease, given the over 1 million individuals affected by the condition, certain medical classifications (etiologies) of hydrocephalus are indeed rare.

Examples include hydrocephalus caused by a brain bleed (post-hemorrhagic hydrocephalus) or X-Link Hydrocephalus.



Hydrocephalus Association Advocates

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HA is excited to bring our advocates together at Rare Disease Week, highlighting our dedication to raising awareness and advocating for those affected by hydrocephalus and related rare conditions.”

*Amanda Garzon, HA Chief  
Operations Officer*

For more information about the Hydrocephalus Association's participation in Rare Disease Advocacy Week, please contact Davis Kaderli at 240-483-4884 or [advocacy@hydroassoc.org](mailto:advocacy@hydroassoc.org).

About the Hydrocephalus Association:

Founded in 1983 by parents of children with hydrocephalus, the Hydrocephalus Association has grown to become the nation's largest and most widely respected organization dedicated to hydrocephalus. The Hydrocephalus Association began funding research in 2009. Since then, HA has committed over \$13 million to research, making it the largest nonprofit, non-

governmental funder of hydrocephalus research in the U.S. For more information, visit [www.hydroassoc.org](https://www.hydroassoc.org).

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