

Advocates to Rally on Capitol Hill for Hydrocephalus Awareness and Research Funding

On Friday, January 31, 2025, 50 key leaders in the hydrocephalus community from 18 states will convene in Washington, D.C., for Hydrocephalus Capitol Hill Day.



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/EINPresswire.com/ -- On Friday, January 31, 2025, 50 key leaders in the [hydrocephalus](#) community from 18 states will convene in Washington, D.C., for Hydrocephalus Capitol Hill Day. Organized by the [Hydrocephalus Association](#) (HA), this annual event connects patients, caregivers, and medical professionals with lawmakers to advocate for policies that support the

one million Americans living with hydrocephalus.

Participants will hold over 60 meetings with House and Senate offices, sharing personal stories and urging action on critical legislative priorities.



By uniting on Capitol Hill, we are making it clear that the hydrocephalus community needs action—research funding, better healthcare access, and policies that support those impacted by this condition.”

Diana Gray, President and CEO, Hydrocephalus Association

Hydrocephalus is a lifelong neurological condition with no cure, [affecting over 1 million Americans](#). It can develop in anyone at any age and often requires multiple brain surgeries to manage excess cerebrospinal fluid in the brain. As the nation’s leading nonprofit dedicated to hydrocephalus, HA has invested over \$16.4 million in groundbreaking research and continues to advocate for legislative action to advance treatment options and improve patient care.

Key Issues for Hydrocephalus Capitol Hill Day 2025:

1. Maintaining FY25/26 Funding for the Congressionally Directed Medical Research Program (CDMRP)

With over 470,000 U.S. service members sustaining traumatic brain injuries (TBIs) since 2000, many are at risk of developing hydrocephalus. Advocates will push to preserve funding for the

Peer Reviewed Medical Research Program (PRMRP), which supports vital research into military health issues, including hydrocephalus.

2. Increasing National Institutes of Health (NIH) Funding for Hydrocephalus Research

Hydrocephalus patients rely on medical implants with one of the highest failure rates of any device, leading to frequent brain surgeries. Funding for the National Institute of Neurological Disorders and Stroke (NINDS) and programs like the BRAIN Initiative is crucial to advancing treatment options and finding a cure.

3. Protecting Medicaid Coverage for Hydrocephalus Patients

Approximately one-third of hydrocephalus patients requiring brain surgeries depend on Medicaid. Proposed funding cuts could jeopardize access to life-saving care, including neurosurgeries, follow-up visits, and treatment for related conditions like epilepsy.

4. Extending Medicare Telehealth Flexibilities Before March 2025 Expiration

Telehealth access is essential for older Americans with Normal Pressure Hydrocephalus (NPH) and other hydrocephalus patients relying on Medicare. Advocates will call on Congress to extend telehealth provisions that allow continued virtual care, particularly for those in rural and underserved communities.

“Hydrocephalus is a complex condition that demands greater attention from our policymakers. Every day, families face the uncertainty of multiple brain surgeries and limited treatment options,” said Diana Gray, President and CEO, Hydrocephalus Association. “By coming together on Capitol Hill, we are making it clear that the hydrocephalus community needs action—sustained research funding, improved healthcare access, and policies that support those living with this condition. We urge Congress to stand with us and be a part of the solution.”

Hydrocephalus Capitol Hill Day 2025 is a crucial step toward securing federal support for research, patient care, and healthcare policies that directly impact those living with this condition. Advocates hope their voices will lead to meaningful legislative action to improve outcomes for individuals with hydrocephalus nationwide.

About the Hydrocephalus Association

Founded in 1983 by parents of children with hydrocephalus, the Hydrocephalus Association (HA) is the largest organization in the U.S. dedicated to hydrocephalus research, education, and advocacy. HA has invested over \$16.4 million in research since 2009, with a mission to find a cure and improve the lives of those impacted by hydrocephalus.

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