

# Hydrocephalus



Hydrocephalus comes from the Greek words **hydro** meaning water and **cephalus** meaning head.

Hydrocephalus is an abnormal accumulation of cerebrospinal fluid (CSF) within cavities in the brain called ventricles. Cerebrospinal fluid is produced in the ventricles and in the choroid plexus. It circulates through the ventricular system in the brain and is absorbed into the bloodstream. This fluid is in constant circulation and has many functions, including to surround the brain and spinal cord and act as a protective cushion against injury. It contains nutrients and proteins necessary for the nourishment and normal function of the brain, and carries waste products away from surrounding tissues.

Hydrocephalus occurs when there is an imbalance between the amount of CSF that is produced and the rate at which it is absorbed. As the CSF builds up, it causes the ventricles to enlarge and the pressure inside the head to increase.

## Who develops hydrocephalus?

Hydrocephalus affects a wide range of people, from infants and older children to young, middle-aged and older adults.

- Over 1,000,000 people in the United States currently live with hydrocephalus.
- For every 1,000 babies born in this country, one to two will have hydrocephalus.
- Hydrocephalus is the most common reason for brain surgery in children.
- It is estimated that more than 700,000 Americans have NPH, but less than 20% receive an appropriate diagnosis.

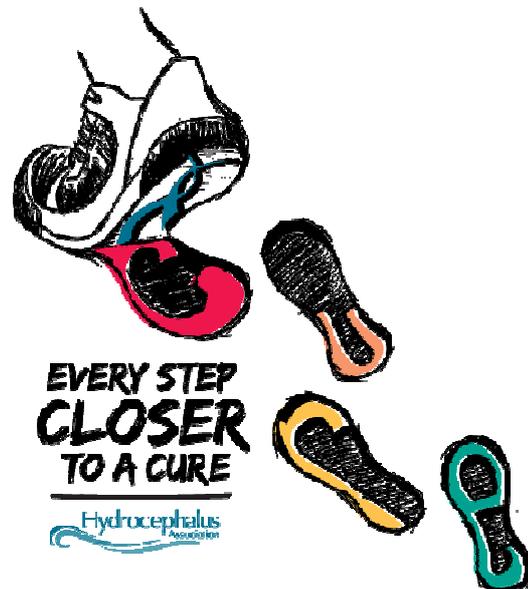
## HA WALKS

The first Hydrocephalus Association (HA) WALK was held in 1993 in San Francisco. Since then, the WALK program has grown tremendously and now accounts for **30% of HA's annual revenue**. More than *12,000 people participate across the US* to connect the local hydrocephalus community and increase awareness of hydrocephalus and the Hydrocephalus Association.

***The HA WALKS are a 100% volunteer effort.***

Dedicated Chairs generously donate their time and energy to recruit local volunteers to assist with event planning and coordination.

Western NY HA Walk  
September 19<sup>th</sup>  
Beaver Island State Park  
Grand Island NY



# Who We Are



## Community. Clarity. Cure.

### Seeking an end to hydrocephalus.

The Hydrocephalus Association serves as the primary nexus for research on hydrocephalus, a condition defined by an abnormal, excessive accumulation of cerebrospinal fluid (CSF) within the cavities of the brain. Hydrocephalus affects over 1 million people in the U.S. alone. Approximately 1-2 babies for every 1000 births are born with hydrocephalus, but anyone can get hydrocephalus at any time through a brain injury or infection, among other reasons, or as part of the aging process.

In our effort to find a cure, HA pursues a **three-pronged strategy**.

**COMMUNITY.** Hydrocephalus means a lifetime of uncertainty for the families and individuals who are confronted with a diagnosis or who are affected by the condition. Naturally, they want to learn more, to understand what the condition entails, what treatments are available, and they want to know they're not doing this on their own. We understand this, because many of us have stood in those same shoes. To help, HA gathers together valuable resources and connects individuals to larger communities that can provide support and understanding. By providing an online library and common space for those dealing with hydrocephalus, HA works to reduce uncertainty, advance the overall hydrocephalus community, and provide as much insight as possible into what remains an often challenging and bewildering condition.

**CLARITY.** Despite its broad prevalence, hydrocephalus remains a misunderstood and often hidden condition, and the general population largely remains unaware of the breadth and depth of the impact of hydrocephalus. This lack of clarity complicates diagnosis, and not surprisingly, it also results in limited funding. For example, while hydrocephalus is 30x more common than Cystic Fibrosis, it receives only 1/13<sup>th</sup> of the federal research money.

HA works to educate national and state policymakers, the medical community, and the general population about the nature and extent of hydrocephalus, and to focus attention on the condition and the legislation/attention needed for individuals to overcome challenges. Our Medical Advisory Board contains leading neurosurgeons, neurologists and other medical professionals and scientists to ensure that we are providing the most current and reliable information. We work to help others see the condition for what it is, so that it can receive the consideration it deserves.

**CURE.** Today, no cure for hydrocephalus exists, and the primary treatment – the insertion of a shunt into the brain – was developed fifty years ago and suffers from one of the highest failure rates of any surgical treatment. By focusing attention and research monies, HA works toward the ultimate end: a final cure to hydrocephalus. Little is known about the causes of hydrocephalus, but recent research offers hope that a cure is indeed possible. Already we are seeing improved diagnostic techniques. New valve designs are improving the efficacy of the shunts used to treat patients. New treatment options have opened up the possibility of a life without a shunt for some individuals. Studies in biomarkers and genetics are providing promising insights into how we might prevent the condition from occurring. This is the power that research has, and every dollar matters. The more research we can fund now, the better the scientific foundation upon which future research will build. HA supports a Strategic Research Initiative that focuses on work that will truly advance our understanding of the condition, and with that, discover its causes, improve its treatment, and help us see an end to hydrocephalus.