

## ABOUT US

The Pediatric Hydrocephalus Foundation, Inc. (PHF) was founded by Michael & Kimberly Illions, parents of Cole Illions, who was diagnosed with hydrocephalus at birth. Their personal journey navigating Cole's condition inspired them to create the PHF, a volunteer-driven organization dedicated to raising awareness, funding research, and supporting families affected by hydrocephalus.

Since its inception in 2009, the PHF has focused on funding research, providing support, and raising awareness for hydrocephalus. With close to \$900,000 granted to hydrocephalus research projects, the PHF has pioneered efforts that were previously missing, including the establishment of National Hydrocephalus Awareness Month and the creation of the first-ever Pediatric and Adult Hydrocephalus Congressional Caucus. These milestones have helped bring much-needed attention and support to the hydrocephalus community.

## OUR MISSION

The mission of the PHF is to educate the community by raising the level of awareness about this incurable brain condition. The PHF also provides support to the families, friends and children who are diagnosed with Hydrocephalus. The PHF advocates on behalf of the members of the Hydrocephalus community and works with the policy makers at the State and Federal level to raise awareness and push for more research and support in the fight against Hydrocephalus.

## OUR VISION

Funding a Cure for Hydrocephalus!

## WHAT IS HYDROCEPHALUS?

Hydrocephalus is a neurological condition caused by an abnormal buildup of cerebrospinal fluid (CSF) in the brain's ventricles (cavities). This excess fluid increases pressure inside the skull, which can lead to brain damage and a range of symptoms, including headaches, vision problems, cognitive difficulties, and developmental delays. Hydrocephalus can be congenital (present at birth) or acquired due to injury, infection, or other medical conditions. It is typically treated with surgical interventions, such as the placement of a shunt system or an endoscopic third ventriculostomy (ETV) to help drain and regulate CSF flow.

## TYPES OF HYDROCEPHALUS

**Congenital Hydrocephalus** – Present at birth, often due to genetic factors or developmental issues during pregnancy, such as:

- Spina bifida
- Aqueductal stenosis (narrowing of the cerebral aqueduct)
- Brain malformations

**Acquired Hydrocephalus conditions:**

- Traumatic brain injury (TBI)
- Brain tumors
- Infections like meningitis
- Brain hemorrhage or stroke

**Normal Pressure Hydrocephalus (NPH)** –

Typically affects older adults and is characterized by slowly developing symptoms, such as walking difficulties, memory problems, and urinary incontinence.

## GET INVOLVED!

The Pediatric Hydrocephalus Foundation (PHF) is a volunteer-driven organization, and its ability to fund research, awareness campaigns, and support for families depends on community fundraising efforts. There are many ways to get involved and make a difference!

## WAYS TO FUNDRAISE

Host a Fundraising Event:

- \*Organize a walk, run, or bike event in your community.
- \*Host a pasta dinner, bake sale, or restaurant fundraiser where a portion of proceeds go to PHF.
- \*Plan a cornhole tournament, trivia night, or bowling event for a fun and interactive way to raise money.
- \*Set up a charity auction or raffle with donated items from local businesses.

Join an Existing PHF Event

- \*Participate in major PHF Walks held across the country
- \*Volunteer to help organize or promote a local PHF event.

Online Fundraising & Social Media Campaigns

- \*Start a Facebook or GoFundMe fundraiser in honor of a loved one with hydrocephalus.
- \*Share PHF's mission on social media and encourage friends and family to donate.
- \*Host a virtual event, such as a livestream gaming marathon, online auction, or social media challenge.

Corporate & Community Partnerships

- \*Encourage local businesses to sponsor an event or donate a portion of sales to PHF.
- \*Work with your employer to see if they offer matching gifts for donations.
- \*Connect with schools, churches, and community groups to support fundraising efforts.
- \*Personal Giving & Peer-to-Peer Fundraising  
Make a one-time or recurring donation to PHF.
- \*Ask family and friends to donate in lieu of birthday or holiday gifts.