

Hydrocephalus Association



Research. A Reason for Hope.

Pediatric hydrocephalus alone represents 40,000 annual hospital admissions,² 433,000 hospital days and \$2B worth of hospital charges.³

Today's Reality

Hydrocephalus (hī'drō-sef'ă-lūs) is an abnormal accumulation of cerebrospinal fluid (CSF) within cavities of the brain called ventricles. It is a chronic condition that affects approximately one million individuals in the United States—from newborns to the elderly. Left untreated it is life-threatening. The predominant treatment is the surgical implantation of a shunt, a device developed more than 50 years ago.

Shunts are biomedical devices implanted into patients' brains to treat the symptoms of hydrocephalus. While instrumental in dramatically reducing the high death rates previously associated with hydrocephalus, shunting is not a cure, and as a treatment it is highly unreliable. Approximately 50 percent of shunts placed in children fail within the first two years.² This difficulty with shunting leads to additional brain scans, surgeries and risks of surgical infection. Many people with hydrocephalus have more than 10 brain surgeries to correct problems associated with shunting.

According to the National Institutes of Health (NIH), an estimated 1 in 500 children have hydrocephalus. Pediatric hydrocephalus alone accounts for 40,000 annual hospital admissions,² 433,000 hospital days and \$2 billion worth of hospital charges.³ Over 36,000 shunt surgeries are performed each year, and more than half of them represent life-and-death emergencies.



Without wide-scale research efforts to discover root causes, improve diagnostic capabilities and develop better treatments, people will continue to suffer.

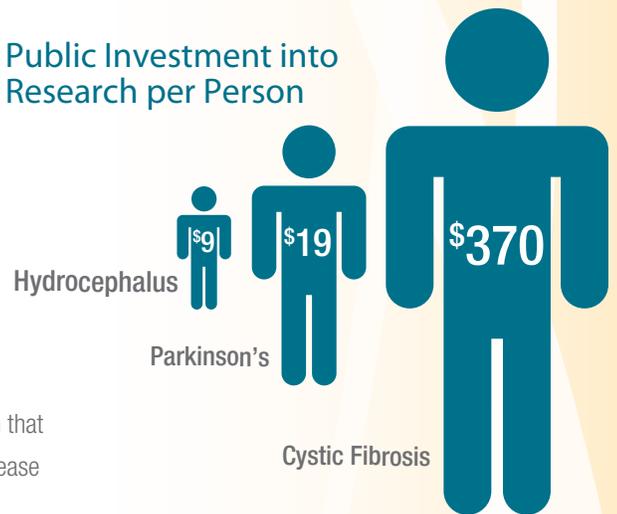
In fact, nearly half of those who acquire hydrocephalus as infants and children score below 80 on standardized intelligence tests,⁴ only half attend mainstream schools and nearly 60 percent are not independent in adulthood.⁵

For the health and financial burden hydrocephalus places on individuals and society, far too little is being invested in research.

Annual Public Investment into Research⁶



Public Investment into Research per Person



In fact, public dollar investment in hydrocephalus research is significantly lower than that for conditions with similar health or hospitalization burdens, such as Parkinson's disease and cystic fibrosis.

Creating Hope

HA Makes a Commitment to Research

To begin to address the research shortage, the Hydrocephalus Association (HA) has launched a **Strategic Research Initiative**. The Initiative identified the following interrelated research issues:

- The complexity of hydrocephalus makes it difficult to treat, understand and attack scientifically.
 - To date, hydrocephalus research activities have been scattered and uncoordinated, which—combined with its complexity—makes it difficult to forge a comprehensive research agenda.
- Shunting—the main treatment for the condition—is unacceptably problematic.
- There is far too much variation in clinical diagnoses and treatments, which leaves much room for improvement of patient safety and clinical outcomes, as well as lower costs of treatment.

The HA Strategic Research Initiative addresses issues through three priority investment areas:

Priority Area 1: Stimulate the research ecosystem

Hydrocephalus has been perceived as “solved” by the introduction of the shunt and is not considered a cutting-edge scientific research area. Injecting young talent into the field of hydrocephalus research and creating a supportive career development path are essential to generating enough scientific activity to advance the field of research. Funding mentored young investigators and research conferences are critical components to creating a vibrant research environment to cure hydrocephalus.

Priority Area 2: Improve clinical outcomes and quality of life for those with the condition

As with many conditions, variations in medical practice abound, with no evidence behind treatment options or scientific evaluation of outcomes. A focused and collaborative clinical research effort such as the Hydrocephalus Clinical Research Network can rapidly improve treatments and outcomes by reducing shunt infection rates, shunt failures and variations in clinical practice.

Priority Area 3: Advance the study of root causes

The basic mechanisms of brain injury and recovery as well as the function of cerebrospinal fluid (CSF) are poorly understood. Based on the work from two NIH workshops on hydrocephalus since 2005, there are a few basic research priorities that our expert advisors believe could lead to important advances. Studies in biomarkers, CSF physiology and genetics are the highest priority.

Our organizational mission is bold: to ***eliminate the challenges of hydrocephalus***. Implementation of our Strategic Research Initiative will catalyze a national effort to improve treatments and outcomes—and eventually find a cure for hydrocephalus.



Our first step forward is to raise \$3 million in major gifts by December 2013 to fund hydrocephalus research.

Priority Investments

Funds raised for the Strategic Research Initiative will support three priority areas of investment.

Priority Area	Investment	Yr1	Yr2	Yr3	Total
1	Scientific Conferences & Career Awards	\$270,000	\$270,000	\$270,000	\$810,000
2	Hydrocephalus Clinical Research Network	\$500,000	\$500,000	\$500,000	\$1,500,000
3	Basic Science Investments to understand root causes	\$230,000	\$230,000	\$230,000	\$690,000
		\$1,000,000	\$1,000,000	\$1,000,000	\$3,000,000

Progress

Progress is already under way: as of 2011, we have raised \$1.7 million.

We have invested \$770,000 in mentored young investigator awards and \$400,000 in CSF research.

We also have developed an exciting partnership with the Hydrocephalus Clinical Research Network (HCRN). A gift of \$500,000 has been directed to this first-ever pediatric clinical research network consisting of seven participating children's hospitals across North America. The HCRN has already published some important discoveries that can help patients today.

Outcomes

Your contribution toward our goal will:

- have near-term positive results on patients living or being diagnosed with hydrocephalus today.
- increase the number of scientists trying to unlock the mysteries of hydrocephalus.
- fund studies that can stimulate significant public investment in hydrocephalus research.

HCRN

Coordinating Center: Primary Children's Medical Center

Data Coordinating Center: University of Utah

Participating Centers: Children's Hospital of Alabama, Children's Hospital of Pittsburgh, Children's Hospital of St. Louis, Seattle Children's Hospital, SickKids, Texas Children's Hospital



The Hydrocephalus Association is Working for a Better Future

- Imagine that by 2020, the landscape of hydrocephalus research and treatment has dramatically improved. An influx of new researchers and the collaborative environment of the prior decade has produced promising findings in basic science that have immediate and direct impact for people with hydrocephalus.
- Imagine that the development of standardized treatments, through the process of evidence-based medicine, has led to better outcomes for patients. For example, the infection rate for shunt surgeries (currently approximately 10 percent) has dropped by 50 percent nationwide as neurosurgeons adopt proven techniques.
- Imagine that a deep understanding of the complex brain dynamics of hydrocephalus has led to research that translates directly into improved treatments and cures.
- Imagine having the confidence that you are receiving medical advice and treatment that conforms to a standard of care based on the highest understanding of hydrocephalus.
- And finally, imagine that we have a way to reduce or eliminate the need for shunt revisions . . . Or that we have a pill that alleviates intracranial pressure, memory loss and imbalance . . . Or even that shunts are unnecessary because hydrocephalus can be detected, cured at its onset or even prevented.

The Hydrocephalus Association is committed to making all of this a reality.



You Can Help

We have donor opportunities at many financial levels. Each investment will make a direct impact on moving us toward the day when we can say we've eliminated the challenges of hydrocephalus!

To learn more about how you can help, contact our development office at 888-598-3789.



About the Hydrocephalus Association

Started in 1983 to provide support to a handful of families, the Hydrocephalus Association has developed into the nation's largest and most respected organization devoted exclusively to hydrocephalus, providing education and support services to individuals with hydrocephalus and their families.

Several years ago, the Association's leadership, concerned with the paucity of research around clinical outcomes of hydrocephalus and its underlying causes, began planning to expand HA's mission to go beyond education and support. In 2009 we formally adopted a new mission:

The Hydrocephalus Association's mission is to eliminate the challenges of hydrocephalus by stimulating innovative research and providing support and education for individuals, families and professionals dealing with the condition.



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¹ John R Kestle, MD et al., "Lack of Benefit of Endoscopic Ventriculoperitoneal Shunt Insertion: A Multicenter Randomized Trial," *J Neurosurgery* 98: 284–290; (February 2003)

² Ravish V. Patwardhan, MD and Anil Nanda, MD, "Implanted Ventricular Shunts in the United States: The Billion-Dollar-a-Year Cost of Hydrocephalus Treatment," *Neurosurgery* 56: 139–145; (2005)

³ Tamara D. Simon, MD et al., "Hospital Care for Children with Hydrocephalus in the United States: Utilization, Charges, Comorbidities and Deaths," *J Neurosurgery Pediatrics* 1(2):131-137; (February 2008)

⁴ Paul Chumas, MD, Atul Tyagi, MD and J. Livingston, MD "Hydrocephalus—What's New?" *Archives of Disease in Childhood: Fetal and Neonatal Issue*, 85(3): F149–154; (November 2001)

⁵ M. Mataro, C. Junque, M. Poca and J. Sahuquillo "Neuropsychological Findings in Congenital and Acquired Childhood Hydrocephalus," *Neuropsychology Review*, 11(4): 169–178; (December 2001)

⁶ NIH RePORTER, <http://report.nih.gov>, 2010