

Hydrocephalus Association



4340 East West Highway
Suite 905
Bethesda, MD 20814
(301) 202-3811
www.hydroassoc.org



Mission

The mission of the Hydrocephalus Association is to eliminate the challenges of hydrocephalus. It provides support, education, and advocacy for people whose lives have been touched by hydrocephalus, an abnormal buildup of cerebrospinal fluid within cavities of the brain, and the professionals who work with them.

Strategy/Approach

The association focuses its efforts in three major areas:

- **Research** – Provides grants for promising hydrocephalus research and hosts a research conference.
- **Education and Support** – Offers a support group network and provides one-on-one support services, generates and disseminates educational materials, and provides scholarships to young adults with hydrocephalus.
- **Government Advocacy** – Manages a broad range of activities, from local grassroots awareness efforts to state-level efforts to federal efforts, which focus on research programs at the National Institutes of Health (NIH) and legislation with Congress. Its advocacy goal is to assure that the federal government is investing adequate funds in hydrocephalus research and resources.

Research Portfolio

In 2009, the association launched a research initiative with the goal of funding research that improves the quality of life for people living with hydrocephalus and finding ways to prevent or cure the disease. It is intended to support innovative scientists so that they go on to apply for further grant funding from the NIH and others. The initiative's initial grant mechanism aims to address the shortage of hydrocephalus-focused researchers while supporting seasoned investigators.

- **Opportunities in Hydrocephalus Research Grant** – Hydrocephalus Association partnered with the Rudi Schulte Research Institute to release a request for applications in conjunction with its 2012 research conference. Together they will fund the most promising research/science discussed at the conference.
 - *up to \$200,000 for 1-3 years (as approved)*
- **Hydrocephalus Clinical Research Network (HCRN)** – A collaboration of multiple research institutions whose mission is to overcome the obstacles that have stymied previous research efforts: too few patients to study in any one hospital,

uncoordinated research, and under-staffed/under-funded studies. HCRN's current organization consists of a central data coordinating center and seven research centers at high-patient-volume pediatric hospitals in North America. On June 4, 2012, the Hydrocephalus Association and HCRN announced their partnership to ensure the continuation of HCRN's research into treatments and outcomes in hydrocephalus that benefit the alliance's membership.

Partnership Practices

The association does not partner with biotech and pharmaceutical companies. Other than engaging in traditional sponsorship relationships with corporations (such as Medtronic) for the Hydrocephalus Association WALK and related events, *FasterCures* is not aware of any formal industry partnerships maintained by the organization.

Financials

Hydrocephalus Association is a 501(c)(3) charitable organization. The most recent financial information available is from 2011.¹

Year ending 12/31/2011:

- Revenue: \$1,603,636
- Net Assets: \$1,215,491
- Gifts received: \$1,689,904
- Expenditures: \$1,805,015
- Grants: \$483,327 for grants, \$4,500 for grants to individuals

Key Accomplishments

- Launched a \$3 million dollar campaign called "Reason for Hope" to fund its five-year Research Initiative plan.
- Founded in 1983 and incorporated as a nonprofit in 1986, the Hydrocephalus Association is the nation's largest and most widely respected advocacy group dedicated to hydrocephalus.
- Early returns on the alliance's research initiative show promise – several of the Mentored Young
- Investigators have gone on to apply for NIH grants (both career development and research grants).
- Alliance-funded research has resulted in 20 presentations at professional meetings and four publications in peer-reviewed journals, and an

¹ Information obtained from Foundation Center Directory, <http://fconline.foundationcenter.org>, May 2012.

additional three manuscripts have been submitted for publication.

- In August 2011, alliance Chairman Paul Gross was appointed to a four-year term for the Advisory Council of the National Institute of Neurological Disorders and Stroke.

Leadership

Hydrocephalus Association is governed by a **Board of Directors**, counseled by a **Medical Advisory Board**, and managed by a California-based staff.

- **CEO:** Dawn Mancuso, MAM, CAE, FASAE, dawn@hydroassoc.org
- **Director of Development:** Aisha Heath, CFRE, aisha@hydrosassoc.org
- **Communications and Marketing Manager:** Amanda Garzon, amanda@hydrosassoc.org
- **Support Group Liaison:** Jennifer Bechard, jennifer@hydroassoc.org