



The Stats

How can we, as a community, raise awareness about hydrocephalus? We can begin by getting out the facts:

Hydrocephalus Is Common

- Hydrocephalus affects hundreds of thousands of Americans, in every stage of life, from infants to the elderly. It affects people in all walks of life, from every socioeconomic background.
- One to two of every 1,000 babies are born with hydrocephalus, making it as common as Down's syndrome and more common than spina bifida or brain tumors.
- Hydrocephalus is the most common reason for brain surgery in children.

There Is No Cure

- There is no medical therapy to treat hydrocephalus. The only effective treatments are surgical.
- While many people are helped by surgery, many more need further operations to stay well. Of the over 40,000 hydrocephalus operations performed annually (one every 15 minutes), only 30% are the patient's first surgery to treat hydrocephalus.
- The medical costs of treating hydrocephalus are over \$1 billion per year, yet the National Institutes of Health (NIH) invests less than \$1 million per year in hydrocephalus treatment.

There Is a Crisis in Diagnosis

- An estimated 375,000 older Americans have normal pressure hydrocephalus (NPH). This disorder often goes undiagnosed and untreated.
- Research suggests that treating hydrocephalus in the elderly population would reduce U.S. health care expenditures by \$25,000 per patient, or \$184 million, over five years. Mistaken placement in an extended care facility or nursing home, for example, costs considerably more than the minimal extra care someone might need to stay at home after appropriate treatment for NPH.
- Hydrocephalus also often goes undiagnosed and untreated in younger adults, leading to substantial workforce losses and health care costs.

There Is a Crisis in Access to Care

- Doctors are sometimes understandably reticent to take on complicated hydrocephalus cases, particularly in adults, because little is known about the disorder. We don't always know what causes it, and we don't know yet how to make these people well.
- There are fewer than ten centers in the U.S. specializing in treating adults with hydrocephalus.

More Effective Treatment Is Needed Now

- Over the last 50 years, there has been no significant improvement in hydrocephalus treatment and no progress toward prevention or cure.
- Research is essential. At the very least, we need better treatments, with more positive long-term outcomes, and diagnostic tests that are accurate, cost-effective, and noninvasive.