

Strategic Plan 2023-2025

November 2022





STRATEGIC PLAN 2023-25

Mission/Vision

Mission – Find a cure for hydrocephalus and improve the lives of those impacted by the condition.

Vision – A world without hydrocephalus.

PILLAR 1 – FIND AND ENGAGE THE HYDROCEPHALUS COMMUNITY

The Hydrocephalus Association still remains relatively unknown by the majority of individuals in this country living with hydrocephalus. It is estimated that there are approximately 1 million Americans living with hydrocephalus, yet our core community membership reflects only a very small portion of that number. Increasing the awareness of hydrocephalus in the general population and with medical professionals in all fields of medicine is critical. Additionally, we have individuals who have used our services or participated in our programs at one point in time but are not currently active. We must find ways to rejuvenate their interest and keep them involved. We must also find ways to connect with the community of individuals who are diagnosed with hydrocephalus but have fewer complications impacting their lives and therefore do not connect with us. All of these groups of individuals can help us move the needle forward.

1. Increasing Awareness of HA by the Patient Community. Increasing our visibility is imperative to individuals finding and engaging, and re-engaging, with the association.

We will achieve this:

- through a digital marketing strategy to help connect and engage with patients and caregivers.
- through traditional media including print, radio, television, and targeted outreach to major markets.
- by enlisting volunteers to assist in referrals and outreach activities.

2. Serving as the referral for patient support and education by medical professionals. Most medical professionals, particularly neurosurgeons, neurologists, and their advanced practice providers, do not refer patients to HA upon diagnosis or as part of routine management and care.

We will achieve this:

- by enlisting medical professionals who provide diagnosis and/or direct care of hydrocephalus patients in the distribution of information about HA.
- by expanding engagements with medical specialties outside of the neurosciences, including obstetrics, gerontology, primary care, pediatrics, rehab specialists, among others, through a direct marketing and awareness campaign.
- by leveraging new website portal for medical professionals as set forth in Pillar 4.

3. Increasing Engagement of the Patient Community with HA. Once patients and caregivers are aware of HA, we must show the value of connection to the association in order to move them through the pipeline toward active engagement.

We will achieve this:

- by increasing the usefulness and appeal of our website and social media channels.
- through a product-driven marketing strategy that market us as a provider of value to the patient community.
- by engaging the community of individuals who are diagnosed with hydrocephalus but have fewer complications impacting their lives and therefore do not connect with us.
- by implementing campaigns to highlight needed services to improve the lives of those impacted by hydrocephalus at every age and every stage of life, as set out in Pillar 3.

PILLAR 2 – FUND AND PROMOTE HIGH IMPACT RESEARCH TO ADVANCE CARE, TREATMENTS, PREVENTION, AND ULTIMATELY A CURE FOR HYDROCEPHALUS

Our vision for the medium term is of treatments for hydrocephalus that are non-invasive and do not fail, of diagnostics that are non-invasive and accurate, and of treatments and interventions that support patients' quality of life. To get from here to there, we need a large and thriving ecosystem of researchers including all relevant disciplines, with the infrastructure and financial support they need, focused on the issues patients care most about.

1. Promoting innovation in treatment and prevention. As we know from our recent study of community research priorities, our patients are desperate for better treatments and prevention, including non-invasive and/or one-off treatments and shunts that do not fail. In addition, many patients continue to experience struggles and delays in the process of diagnosing and treating Normal Pressure Hydrocephalus (NPH). Our research networks, both clinical and scientific, are well-positioned to advance research in these areas, and our grants have proved themselves effective in moving research forward.

We will achieve this:

- by promoting innovation and discovery science for prevention and treatments, including improvements in existing devices and druggable targets
- by promoting improvements in NPH diagnosis and decisions to treatment

2. Growing the hydrocephalus research ecosystem. HA has been instrumental in growing the bench-to-bedside research ecosystem in hydrocephalus over the last decade. We need to continue our efforts to bring more researchers into the area, support collaboration among them, ensure that their research is targeted to patients' most pressing concerns, and support their efforts to secure funding.

We will achieve this:

- by continuing to increase HANDS membership
- by continuing to expand HAPPIER and making it more diverse
- by promoting collaboration from bench to bedside, including between inventors/tech companies/basic scientists and clinicians
- by promoting our community priorities to align scientists and the clinical research networks (A/HCRN) to patient concerns.
- by maintaining CDMRP status and increase government support of hydrocephalus research

- by exploring opportunities to connect innovators and investors

3. Broadening the research ecosystem to disciplines not previously targeted by HA, specifically engineering and data science. To complement our success in growing the bench-to-bedside research ecosystem, we must leverage the potential of disciplines that are currently underrepresented in hydrocephalus research. Engineers have important contributions to make to improving devices, and we need to explore the potential for the newer fields of data science and machine learning to contribute to major outstanding research questions.

We will achieve this:

- by raising interest in problems in current treatments among engineers
- by determining the potential of big data/machine learning to address key open questions in hydrocephalus and develop a plan
- by ensuring public availability and usability of HA-owned and HA-funded data

4. Bringing research approaches to the Quality of Life (QOL) aspects of hydrocephalus across the lifespan. Improving quality of life, including neuropsychological outcomes, was amongst our top community research priorities and an often-overlooked need in those with hydrocephalus. QOL needs more attention as an outcome of treatment, and better understanding the natural history of QOL outcomes will not only help reduce the distressing uncertainties faced by patients and families, but also provide a basis for early preventive or mitigative interventions

We will achieve this:

- by promoting a focus on QOL outcomes in clinical and pre-clinical research
- by promoting research on the QOL outcomes of hydrocephalus, especially with a view to early intervention

5. Developing reliable data on the epidemiology and health economics of hydrocephalus. There is an urgent need for updated hydrocephalus prevalence numbers as well as understanding the cost of hydrocephalus. Understanding this is needed for advocacy, research funding (both public and commercial), provision of care, and insurance reimbursement, and for moving hydrocephalus out of the “rare disease” category.

We will achieve this:

- by ensuring publication of an analysis of the epidemiology and costs of hydrocephalus, and promoting its use by researchers and tech companies, notably for purposes of raising funding

PILLAR 3 – SUPPORT AND ADVOCATE FOR THOSE IMPACTED BY HYDROCEPHALUS AT EVERY AGE AND EVERY STAGE OF LIFE

The provision of services to those impacted by hydrocephalus is a critical part of HA’s mission, and does much to connect the patient community to the association. These services include acting as a source of

trusted information and social and emotional support. There are important opportunities to improve the services offered by HA, to ensure *all* patients get what they need. These opportunities relate importantly to the increasing role of online information and connection in everyone's lives, as well as the power to connect across organizations and institutions.

1. Providing Access to Information and Support. Patients across the entire age spectrum must have access to current and comprehensive information in order to make informed decisions. Further, they must have the tools and knowledge to effectively find and use the support services and programs they need. Such information and knowledge also serves those working to support the patient, be it in the school, workplace, or home setting. As the trusted provider of information outside of medical institutions, and with an array of support programs and partnerships with other organizations, the Hydrocephalus Association, with the Medical Advisory Board, are uniquely positioned to meet this responsibility.

We will achieve this:

- through provision of information online to patients and those who care for them
- through the development of hydrocephalus toolkits and tip sheets for patients, reflective of all ages and stages of accessing and/or transitioning care
- by reducing barriers to access to information and support by underserved communities
- by expanding our support capabilities through the participation in an online social services referral network
- by piloting a virtual mini HA CONNECT

2. Supporting Personal Connections. The journey with hydrocephalus can feel isolating, particularly in moments of crisis. Connecting to HA support staff and to other individuals can provide invaluable sharing and emotional support, while also developing long-term sustaining affinity with the association as a steadfast partner in the patient and family's life journey.

We will achieve this:

- through online connections for individuals of all ages and stages of life
- through in-person events
- through phone and other support to individuals seeking out the association

3. Improving and expanding the Public Policy Framework. Protecting federal and state laws, policies, and programs is critical to sustaining and improving quality of care and quality of life - from the provision of healthcare, to educational programs, to protections in the workplace. The Hydrocephalus Association has a responsibility to advocate on behalf of the hydrocephalus community on public policies and legislation that will impact the lives of all people living with the daily challenges of hydrocephalus. Further, by training and empowering grassroots advocates to effectively speak directly about their experiences and the effect of policies and programs, we create a cadre of advocates and a self-sustaining strategy from both the top down and bottom up to influence policy-makers.

We will achieve this:

- by growing the number of Congressional champions for hydrocephalus through the Congressional Pediatric and Adult Hydrocephalus Caucus
- through direct advocacy in the areas of healthcare, education, and workforce legislation, by trained grassroots advocacy volunteers around the country

- through our partnerships with other organizations and coalitions to amplify the voice of the hydrocephalus community

PILLAR 4 – IMPROVE THE CARE AND MANAGEMENT OF HYDROCEPHALUS PATIENTS BY THE MEDICAL COMMUNITY

A significant gap in health care services exists for adults with hydrocephalus, underpinned by both a dearth of neurosurgeons who are willing and able to provide comprehensive longitudinal care and an unfamiliarity of neurologists, primary care physicians, and other health care professionals with the principles of care for patients with hydrocephalus. Opportunities exist to improve the care and management of hydrocephalus patients by facilitating collaboration and learning among *all* medical professionals, including advanced practice providers and other relevant medical specialties, that will make it easier to care for these patients. However, improving care ultimately needs an increase in the number of willing providers to treat and manage hydrocephalus patients, from the surgical suite to routine clinic appointments. Ultimately, we envision a healthcare system where hydrocephalus patients are able to easily find and receive the medical and rehabilitative care they need to thrive, not just survive, with hydrocephalus.

1. Increasing Access to Expertise in Hydrocephalus Diagnosis and Care.

Many patients report difficulty finding neurosurgeons to care for them as adults, leaving some without local access to care. Doctors themselves have admitted to a lack of knowledge or experience needed to manage pediatric and adult patients with complex hydrocephalus. Both patients and medical practitioners need access to expertise in the diagnosis and care of hydrocephalus patients that ultimately make it easier to diagnose and to provide quality care.

We will achieve this:

- through the provision of information online via a dedicated portal/hub relevant for a variety of medical professionals serving the hydrocephalus patient population
- through the development of educational programs for medical professionals that further their professional development through continuing medical education (CME) credits
- by actively engaging with Advanced Practice Providers and partnering with their respective Societies
- by advocating for legislation to allow greater access to experts in the field of hydrocephalus

2. Improving Quality of Longitudinal Care for Adults with Hydrocephalus.

All adult patients with hydrocephalus need a neurosurgeon. Additionally, other medical specialties that can play an integral role in the management of patients need to be engaged in diagnosis and care in a meaningful way. We must promote practices that can provide the longitudinal care and range of services that many of these patients need by addressing the barriers of adequate training, compensation, availability, and willingness of adult neurosurgeons and neurologists to care for these patients.

We will achieve this:

- by moving the neurosurgical and neurological professional societies, both in the U.S. and internationally, to improve education in the management of hydrocephalus
- by advocating for more medical professionals to accept hydrocephalus patients into their practices

- by advocating with partners for appropriate valuation of longitudinal care for hydrocephalus in new payment models

3. Improving the Transition from Pediatric to Adult Care. Reflecting the early focus of hydrocephalus care on pediatric populations, young adult hydrocephalus patients face special challenges in accessing and managing care. To close the gaps, the association needs to support providers on both the pediatric and adult side in adopting best practices and helpful models of care, and make it easier for adult patients to access the information they need to be effective partners in their own care.

We will achieve this:

- by expanding the use of HydroAssist among providers to assist with management of care
- through the provision of information online specific to transition for use by medical professionals and their clinical care teams
- by promoting the adoption of best practices for pediatric-to-adult transition
- by supporting the development of a hydrocephalus transition toolkit for providers
- through leadership in National Partnership for Pediatric to Adult Care Transition (NPPACT) to advocate for relevant legislative policies