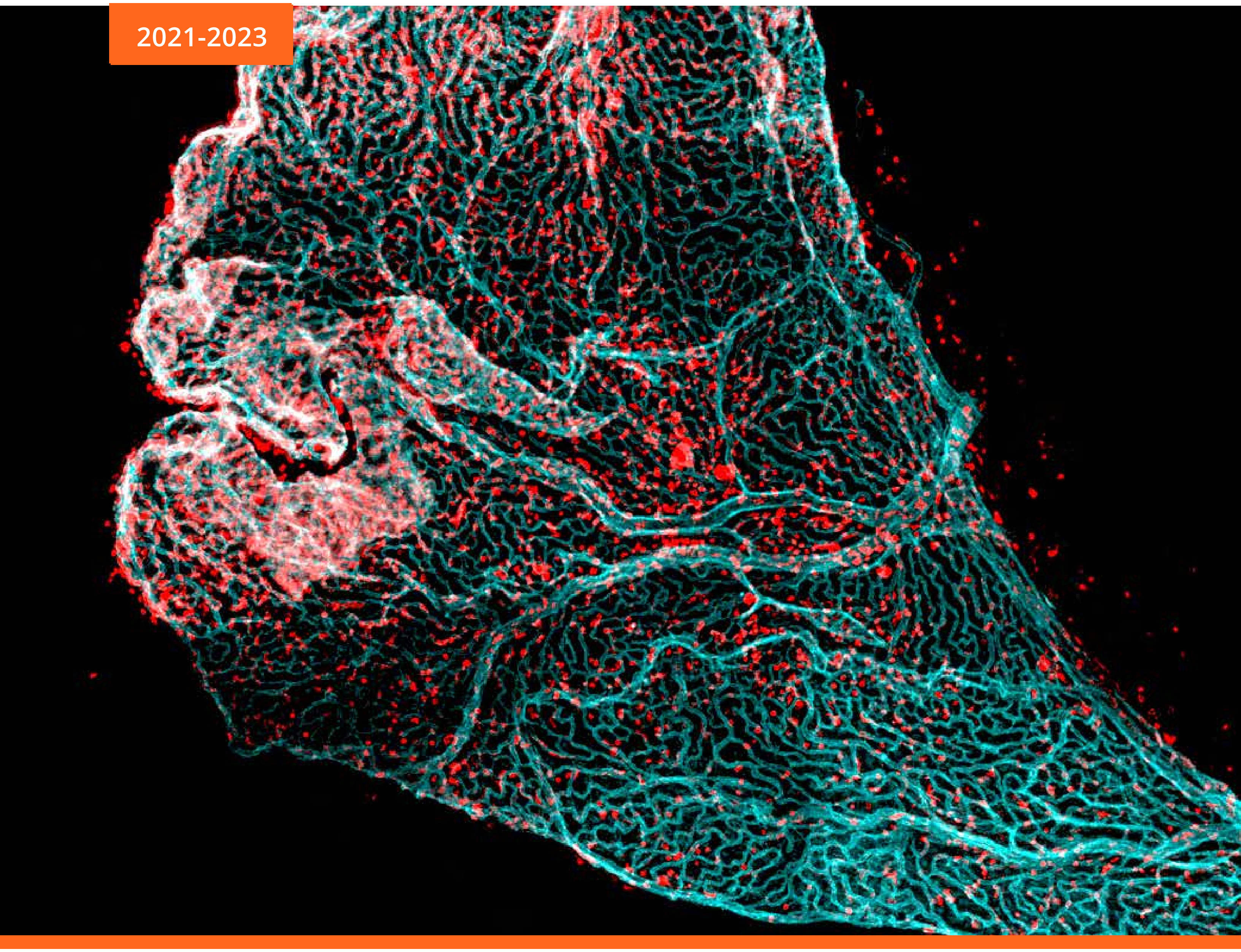
Elevating Research Impact

Research Initiative Report

2021-2023



Hydrocephalus Association

Letter From the CEO and Chair

Over the course of the last decade we have seen remarkable advances in technological innovation and in medical and scientific research.

Our partnerships with leading researchers and healthcare professionals have yielded tangible results, and we continue to push the boundaries of our understanding of hydrocephalus. Through your support, we have seeded pioneering studies which could grow into non-invasive treatments that substantially elevate the quality of life for those living with this condition.

As a result of this success, our dedication to advancing research in hydrocephalus grows stronger every year. It is through this critical program that we discover new and significant knowledge about the brain, about care, and about potential treatments for hydrocephalus.

Together, we have reached significant milestones that would not have been achievable without the commitment of our network of scientists, physicians, supporters, funders, and the community of people impacted by hydrocephalus.

We are thrilled to introduce our Community Research Priorities. This framework is the result of a collective endeavor, embodying both the voice of the patients and the aspirations of the community. These priorities guide our initiatives and ensure that we remain grounded in what matters most – improving the lives of those impacted by hydrocephalus.

These priorities reflect our commitment beyond the boundaries of our own organization as we work hard to bring together patients, scientists, medical professionals, and industry partners. By fostering collaboration, we are working to transform hydrocephalus research and care. This diversity of expertise is the best way to drive innovation, accelerate discoveries, and forge new solutions.

As always, we extend our heartfelt appreciation to every member, supporter, and partner who has played a part in making the Hydrocephalus Association a beacon of hope and support.

With gratitude and determination,

Diana Gray

Diana Gray, MA

President & CEO
Hydrocephalus Association

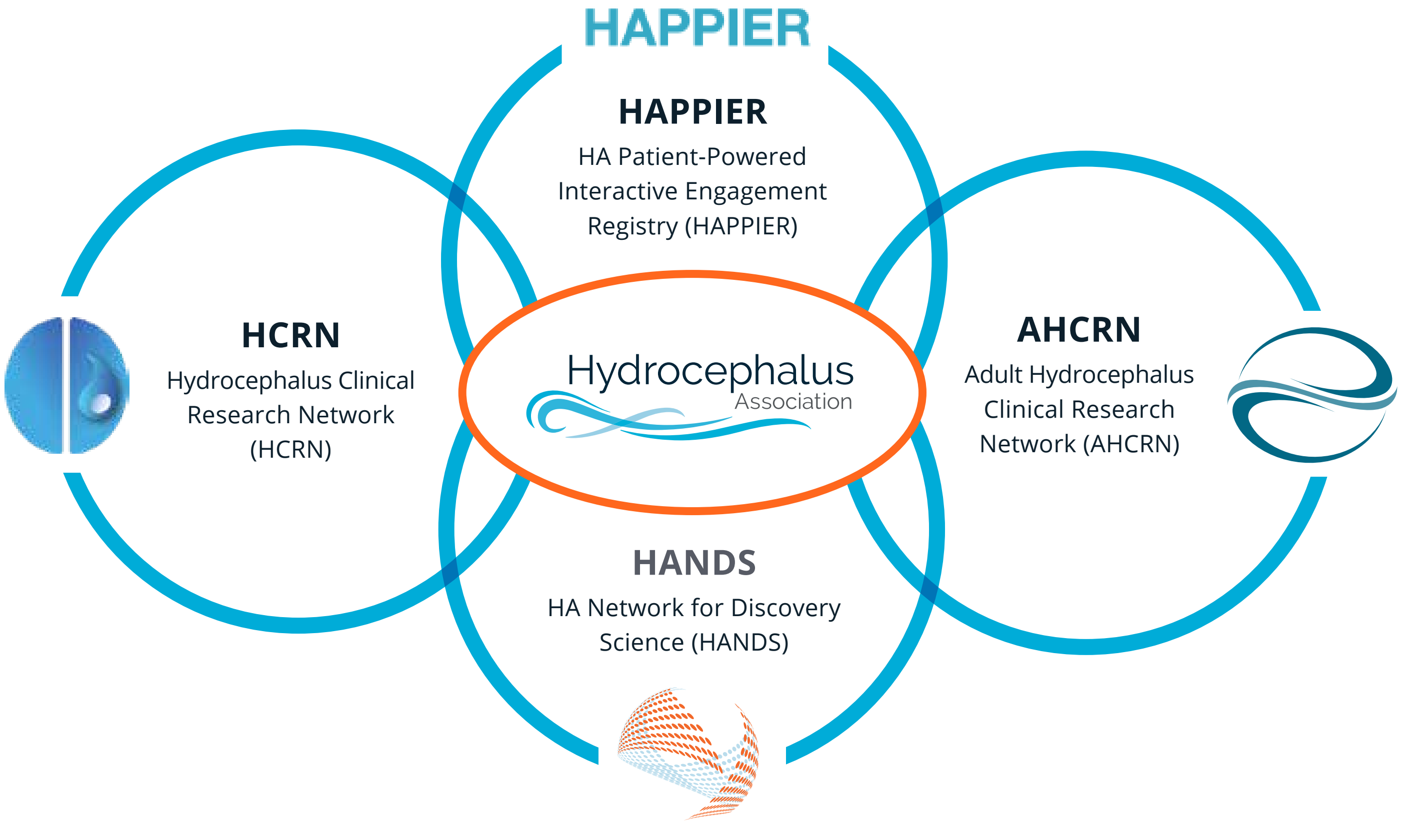
Jason Preston

Chair, Board of Directors
Hydrocephalus Association

COVER IMAGE: Choroid plexus explant from mouse lateral ventricle: stained for CD45 (immune cells) and Collagen IV (blood vessels) following injection of Group B Strep into the lateral ventricle to create CNS infection. **Photo credit:** Alexandra Hochstetler, PhD, Laboratory of Maria Lehtinen, PhD

Our Research Program and Networks

The drivers of our research program are our patient registry and three research networks. Collectively, these programs cover a broad spectrum of research, including the exploration of new causes of hydrocephalus, the evaluation of innovative treatments, the enhancement of current therapies, and the advancement of long-term outcomes and quality of life.



HAPPIER

HA Patient-Powered Interactive Engagement Registry (HAPPIER) is an online survey-based registry created to bring the patient's perspective to hydrocephalus research.

HANDS

HA Network for Discovery Science (HANDS) is an online platform for basic, translational, and clinical scientists to interact, collaborate, and apply for grants.

HCRN

Hydrocephalus Clinical Research Network (HCRN) is a network of fourteen children's hospitals focused on improving outcomes for children with hydrocephalus.

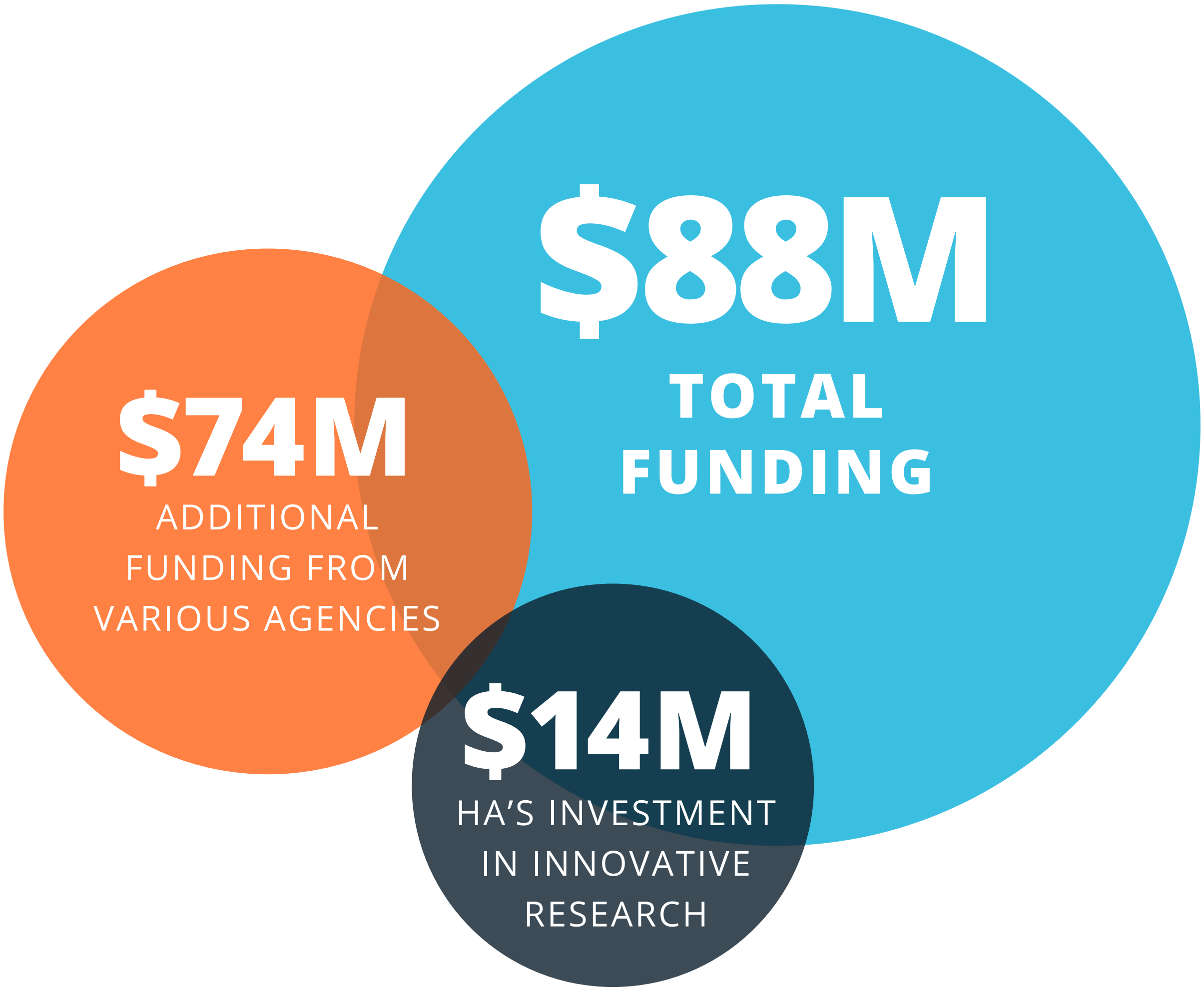
AHCRN

Adult Hydrocephalus Clinical Research Network (AHCRN) is a network of eight hospitals focused on improving the lives of adults with hydrocephalus.

Research Amplified

HA is focused on funding high-quality, high-impact research and building the hydrocephalus research community. Our impact can be seen far and wide throughout the hydrocephalus research field.

Since the inception of our research program in 2009, HA has **invested $14 million** into research and our **return on investment has been $74 million** as our funded scientists and clinical networks have gone on to secure even greater funding amounts through the National Institutes of Health (NIH), the Department of Defense (DOD), and other foundations.



$88M
TOTAL FUNDING

$74M
ADDITIONAL FUNDING FROM VARIOUS AGENCIES

$14M
HA'S INVESTMENT IN INNOVATIVE RESEARCH

Highlighting Research Success

Our network of scientists play a pivotal role in driving hydrocephalus research forward. These are two examples of remarkable research success.

Kidney scientist turned hydrocephalus researcher has been awarded multi-million dollar grants from the Department of Defense.

Medical research is painstaking, methodical, and not often a straightforward process. Dr. Bonnie Blazer-Yost, Ph.D., did not set out to cure hydrocephalus. As Professor of Biology at Indiana University-Purdue University Indianapolis, her specialty was renal (kidney) physiology and studying how the body moves salt and water around for its needs.

In 2014, she and her colleagues were testing a diabetes drug to find its potential impact on polycystic kidney disease. The drug was ineffective in animal testing and, unexpectedly, caused the heads of rats to get bigger from severe hydrocephalus. With these unexpected results, Dr. Blazer-Yost and her team decided to test an antagonist of the drug—which would have its opposite effect on the rats. “We found that the head size decreased; the hydrocephalus decreased,” Dr. Blazer-Yost observed.

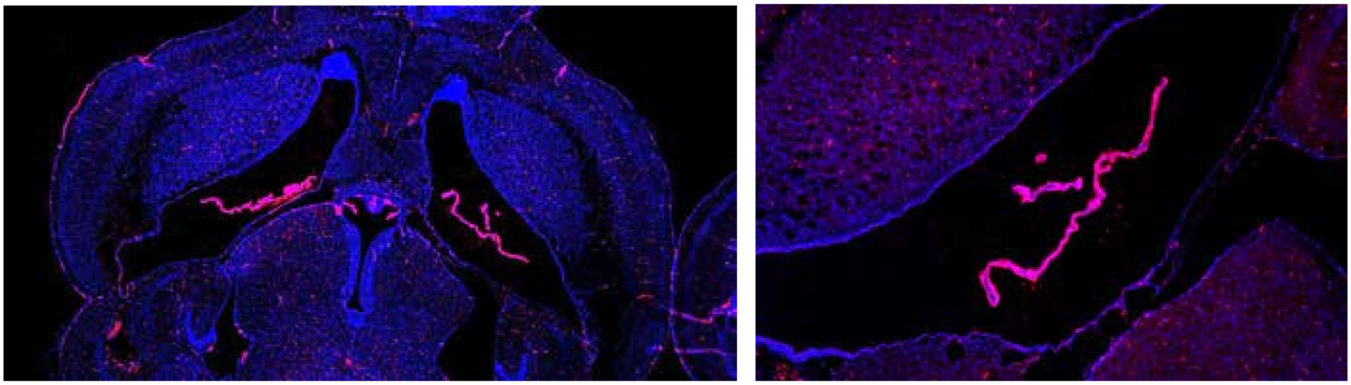
Thanks to her funding through the 2015 HA Innovator Award, generously supported by Team Hydro, Dr. Blazer-Yost and her lab were able to obtain the compelling preliminary data they required to apply for Department of Defense (DOD) funding to continue their ground-breaking work on hydrocephalus. In 2022, they were awarded two multimillion dollar DOD grants to conduct research on this potential drug treatment. With this funding, they will also test potential treatments developed by Johns Hopkins University investigators (erythropoietin + melatonin) and Indiana University – Purdue University Indianapolis investigators (TRPV4 antagonists) in genetic, posthemorrhagic, and post-traumatic hydrocephalus rat models. Furthermore, this funding has allowed her and her colleagues to create a Hydrocephalus Research Center to foster collaboration locally and globally, and to train members of the next generation of hydrocephalus scientists.

> “The Hydrocephalus Association Innovator Award award was a pivotal turning point in my journey, drawing my research focus towards hydrocephalus. With immense gratitude, it paved the way for two multimillion-dollar DOD awards and collaboration with remarkable minds. This award led to the patenting of a potential breakthrough drug.”
>
> — Dr. Blazer-Yost

Record-Breaking $14 Million Grant Fuels Landmark iNPH Clinical Trial in Adult Hydrocephalus Research

Dr. Mark Luciano at Johns Hopkins University is leading the charge in NPH research. He was funded to conduct the first large scale, multi-center, blinded, randomized controlled trial to evaluate the true response of shunting in patients with iNPH and to evaluate factors improving diagnosis. The clinical trial is entitled, "A Placebo-Controlled Efficacy in idiopathic Normal Pressure Hydrocephalus Shunting (PENS)", and funded by the National Institute of Neurological Disorders and Stroke (NINDS) of the National Institutes of Health (NIH).

The study is conducted at the lead site at the Johns Hopkins Cerebral Fluid Center, and it includes 21 centers located in the US, Canada, and Sweden. The Adult Hydrocephalus Clinical Research Network (AHCRN) is comprised of eight member institutions, where the need for the study was initially identified, discussed, and ultimately pursued. The AHCRN is one of three research networks funded by the Hydrocephalus Association that conducts clinical research to improve treatment for adult forms of hydrocephalus.



Neonatal hydrocephalus mouse brain with choroid plexus stained (red). Photo credit: June Goto, PhD

> "The Hydrocephalus Association has been with us through all our ups and downs, as this condition affects our daughter, which in turn affects our family. Over a million people in the U.S. alone have hydrocephalus, and yet many people have never heard of hydrocephalus. More research needs to be done to learn about this condition, eliminate an overabundance of surgeries, and find a cure. We all know that surgery is not a cure for hydrocephalus."
>
> — Pam and Jamie Crouthamel. HA Supporters

Stats At a Glance

Since the inception of our research program, HA has fostered achievements & milestones contributing to advancements in the overall care of hydrocephalus.

63
RESEARCH GRANTS
FUNDED

7
YOUNG INVESTIGATORS
MENTORED

11
WORKSHOPS
SUPPORTED

35+
COLLABORATIONS
FACILITATED

1ST
PATIENT-POWERED REGISTRY
CREATED

36%
SHUNT INFECTION RATE
DECREASED

1
NEW FDA DRUG APPLICATION
SUPPORTED

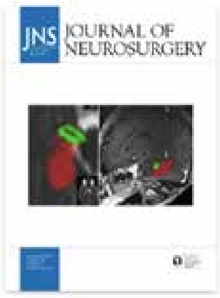
7 & 2
BIO BANKS & DATABASES
DEVELOPED

12
PRECLINICAL DRUG THERAPIES
FUNDED

1
NEW DRUG TARGET
PATENTED

1
NEW DRUG APPLICATION
INVESTIGATED

Community Research Priorities



We listened to the needs of our community by conducting a formal study using the James Lind Alliance (JLA). Our methodology included patients and their families, scientists & HCP's. This study has been published in the Journal of Neurosurgery.

With input from almost 1,500 people over the course of two surveys and a workshop, we have developed our Top 20 Community Research Priorities.

These priorities have been condensed into five areas of focus where the Hydrocephalus Association is best poised for highest impact. These are the guiding beacons for HA's actions influencing our actions in research, advocacy, education, fundraising, and awareness.

Five Areas of Focus

1

DEVELOP NON-INVASIVE AND ONE-TIME THERAPIES

Rank 1: Develop new treatments that do not require brain surgery to manage hydrocephalus

Rank 2: Develop new one-time treatments to manage hydrocephalus (i.e. permanent treatments that do not require additional interventions)

Rank 8: Develop ways to prevent the development of hydrocephalus

Rank 12: Develop therapies (e.g. stems cells, cellular regeneration) to repair brain damage for people affected by hydrocephalus

2

IMPROVE THE SCREENING AND DIAGNOSIS OF HYDROCEPHALUS

Rank 3: Identify the causes and processes that lead to hydrocephalus (e.g. genetic influences, inflammation)

Rank 10: Improve ways of diagnosing and screening for hydrocephalus to allow for earlier detection of the condition

Rank 20: Develop ways to accurately determine if a patient would benefit from hydrocephalus treatment, such as shunt, prior to surgery

3

IMPROVE QUALITY OF LIFE

Rank 14: Improve our understanding and develop ways to reduce the emotional and psychological challenges (e.g. stress, anxiety, and depression) of living with hydrocephalus

Rank 15: Improve our understanding and develop ways to reduce headaches and migraines related to hydrocephalus and hydrocephalus treatments

Rank 16: Improve our understanding and develop ways to reduce impairments in attention, learning, memory, and problem solving related to hydrocephalus

Rank 17: Improve our understanding and develop ways to restore physical function and motor control (e.g. walking, balance, and urinary continence) in people with hydrocephalus

4

REDUCE THE BURDEN OF CURRENT TREATMENTS

Rank 4: Develop ways to monitor shunt function and detect shunt malfunction non-invasively and/or outside of the hospital

Rank 5: Improve shunt components and surgical techniques to prevent shunt blockages and mechanical failure (e.g. broken valve, disconnected tubing, broken tubing)

Rank 6: Develop methods to non-invasively or less-invasively unblock shunts

Rank 7: Improve shunt designs and surgical techniques to enable less or non-invasive shunt placement and shunt revisions

Rank 9: Develop a better understanding of the symptoms patients experience when their shunt is failing

Rank 11: Determine which treatment strategy will be most effective for each patient by comparing clinical protocols and treatment options (e.g. shunt vs. ETV, programmable vs. non-programmable shunts)

5

IMPROVE ACCESS TO CARE

Rank 13: Determine how to improve patient access to doctors and hospitals that have expertise in hydrocephalus

Rank 18: Determine how to improve coordinated care across medical specialties (e.g. neurosurgery, neurology, cognitive therapy, physical therapy, etc.) for people with hydrocephalus

Rank 19: Determine how to improve a patient's transition from pediatric to adult medical specialists (doctors)

Research Strategic Plan

Fund and promote high impact research to advance care, treatments, prevention, and ultimately a cure for hydrocephalus.

Our vision 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.

PROMOTING INNOVATION

Promoting innovation in treatment and prevention

GROWING THE ECOSYSTEM

Growing the hydrocephalus research ecosystem

BRINGING APPROACHES

Bringing research approaches to the Quality of Life (QOL) aspects of hydrocephalus across the lifespan

DEVELOPING DATA

Developing reliable data on the epidemiology and health economics of hydrocephalus

BROADENING THE ECOSYSTEM

Broadening the research ecosystem to disciplines not previously targeted by HA, specifically engineering and data science

HONORING THE LEGACY OF DR. MICHAEL POLLAY

HA and Rudi Schulte Research Institute (RSRI) Workshops

Over the past two years, our research endeavors have received invaluable support from our community of researchers, physicians, those impacted by hydrocephalus, and funders. This support has been crucial to moving the research forward in these areas. The first workshop centered on improving cognitive and neuropsychological outcomes in hydrocephalus, while the second focused on the development of non-invasive hydrocephalus therapies with a particular emphasis on molecular and cellular targets.

These initiatives were made possible through the generous sponsorship of the Rudi Schulte Research Institute (RSRI). We successfully brought together leading hydrocephalus scientists, physicians, and experts from diverse fields, fostering a remarkable sense of collaboration and shared purpose. The collective efforts and knowledge exchange in these workshops not only gave rise to new collaborations within and beyond the realm of hydrocephalus research but also increased attention to these critical areas within our network and the broader community.


Dr. Michael Pollay

These workshops were dedicated to the legacy of Dr. Michael Pollay, a friend of Rudi Schulte and long-time RSRI board member until he passed away in February 2021. At the beginning of the workshops, attendees heard more about Dr. Pollay's legacy through his dedication to patients, growing the field of neurosurgery through mentorship of medical students and residents, and his passion for making the world a better place through neuroscience. With nearly 100 publications, Dr. Pollay was an internationally recognized scientist and was funded multiple times by the National Institutes of Health and the Department of Veterans Affairs. "Michael would have been so touched by this recognition and pleased by this valuable sharing of information between many great minds. It makes me hopeful for the future of hydrocephalus research," said Peggy Pollay.

The HA and RSRI express their gratitude to all participants, speakers, and the scientific planning committees who contributed to the success of these events. The knowledge shared, and the connections forged at the workshops will undoubtedly have a lasting impact on the hydrocephalus research landscape.

> "Michael would have been so touched by this recognition and pleased by this valuable sharing of information between many great minds. It makes me hopeful for the future of hydrocephalus research..."
>
> — Peggy Pollay

Research Workshops

Our research workshops serve as a catalyst for knowledge exchange and collaboration during the presentations of cutting-edge scientific findings.

2022 RESEARCH WORKSHOP

Improving Cognitive and Psychological Outcomes in Hydrocephalus

In October 2022, we hosted 53 neuropsychologists, scientists, engineers, neurologists, neurosurgeons, and patients to the HA & RSRI Research Workshop in Houston, TX.

The workshop delved into the underlying neuropathology of the cognitive and psychological challenges individuals with hydrocephalus face across the age spectrum.

One of the ongoing frustrations for so many of those living with hydrocephalus, their caregivers, and healthcare providers is the hardship of the cognitive and psychological manifestations that too often negatively impact mental and physical health, relationships, education, and employment. From our Community Research Priorities, we learned that patients care deeply about the complications of living with hydrocephalus that are caused by cognitive challenges with memory,

KEY SCIENTIFIC THEMES AT THE 2022 RESEARCH WORKSHOP

- **BASIC AND TRANSLATIONAL SCIENCE:** The correlation between biomarkers and imaging in tandem with cognitive function, and the use of animal models for cognitive and psychological assessments.
- **PSYCHOLOGICAL AND COGNITIVE PHENOTYPES:** Understanding ways to assess adult and pediatric hydrocephalus patients. Insights include the need for early detection of cognitive and motor impairments across the lifespan.
- **TRANSITIONS, TREATMENT, AND QUALITY OF LIFE:** Considerations of psychometric assessment during the time of developmental transitions in youth with hydrocephalus, and a focus on post-traumatic stress in pediatric hydrocephalus.
- **SYNTHESIS DISCUSSION ON MOVING THE FIELD FORWARD:** Insights from the patient panels, scientists, physicians, and neuropsychologists. The collective aim was to collaboratively propel the field forward, identifying gaps in knowledge and determining actionable steps to address them.

attention, and executive function, as well as the mental health challenges that often go hand in hand with hydrocephalus and its related symptomatology. The hydrocephalus community is craving recognition and better solutions to these often-disabling psychological impacts on their lives.

The workshop was a success with positive feedback about the quality of the scientific presentations, venue, discussions, and the connections made during this meeting. The presentations encompassed a wide range of key topics related to improving the neuropsychological and cognitive outcomes of those living with hydrocephalus.

Discussions focused on moving the field forward - insights were given from patient panels, scientists, physicians, and neuropsychologists. The collective aim was to collaboratively propel the field forward, identifying gaps in knowledge and determining actionable steps to address them.

During the first day of the conference, attendees listened to sessions on basic and translational science, and cognitive and psychological phenotypes. They were also treated to a performance of spoken word by Dani Lucchese, a member of our hydrocephalus community, reading her poem about life with hydrocephalus. On the second day of the conference, attendees listened to sessions on transitions, treatment, and quality of life, and moving the field forward. Robin Ennis then shared her performance of spoken word followed by a Patient Perspective Panel that included Robin Ennis, Dani Lucchese, Amanda Garzon, and Gary Chaffee.

2022 workshop attendees

2023 RESEARCH WORKSHOP

Non-Invasive Hydrocephalus Therapies: Molecular and Cellular Targets

The 2023 research workshop took place in Dallas, TX in September, with more than 60 distinguished professionals.

This included scientists, educators, engineers, neurologists, neurosurgeons, and patients who came together to explore advancements in non-invasive hydrocephalus treatment research.

The need for non-invasive, non-shunt therapies for hydrocephalus is urgent. The most common surgical treatment for hydrocephalus is shunting the excess cerebrospinal fluid from the brain, which has one of the highest failure rates of any medical device on the market. With so many affected, the top priority of HA is to find non-invasive treatments for hydrocephalus. These are treatments that do not require brain surgery, like shunting.

The workshop served as a catalyst for collaboration and knowledge exchange during the presentations of cutting-edge scientific findings. Understanding the root causes of hydrocephalus and identifying molecular and cellular targets for therapy will bring us closer to new treatments. Attendees engaged in robust discussions on the critical aspects of hydrocephalus research.

"We are immensely proud of the strides made during this research workshop," remarked Monica Chau, PhD, National Director of Research at the Hydrocephalus Association. "The synergy of minds from various disciplines fuels our progress in hydrocephalus research and patient care. There aren't many hydrocephalus treatment research groups out there, and we are leading the charge in non-invasive therapies."

KEY SCIENTIFIC THEMES AT THE 2023 RESEARCH WORKSHOP

- **ARTIFICIAL INTELLIGENCE (AI), MACHINE LEARNING, AND BIG DATA:** Ongoing research endeavors in AI, machine learning, and big data were prominent as scientists learned more about the possibilities of these emerging technologies to enhance diagnosis, treatment, and management strategies for hydrocephalus.
- **EMERGING TARGETS IN DRUG AND GENE THERAPIES:** Advances in the preclinical and clinical arenas of drug and gene therapies for hydrocephalus. Presentations highlighted promising targets at various stages of development for the different etiologies of hydrocephalus.
- **HOW TO ADVANCE INTO CLINICAL TRIALS:** Scientists currently conducting clinical trials shared their process in navigating the many steps required in initiating and conducting clinical research. Presentations on clinical trials past and present in hydrocephalus clarified the context and highlighted the remaining work needed.
- **FUNDERS PANEL:** Representatives from governmental agencies including Jill Morris (NIH, NINDS), PJ Brooks (NIH, NCATS), and Cecilia Dupecher (DOD, CDMRP) spoke.

2023 workshop attendees

Innovator Awards

An unprecedented 21 Innovator Awards in the last three years go out to scientists for their exciting research.

The Hydrocephalus Association Innovator Awards are a testament to the spirit of innovation within the scientific and medical community. They provide a platform for visionaries to turn their groundbreaking ideas into reality, offering the crucial seed funding and support. This year, we received a multitude of exceptional submissions from across the globe. These submissions were rigorously reviewed by a panel of experts who evaluated alignment with the Hydrocephalus Community Research Priorities, potential for transformative impact, and the promise of improving the lives of those affected by hydrocephalus. The Innovator Awards are for one year of support at a $50,000 level. The Hydrocephalus Association would like to extend a thank you to Team Hydro and the Rudi Schulte Research Institute for their generous support.

2023 Award Recipients

Tim Cherry, PhD

University of Washington

The MicroMRNA, MIR9 as a Network Regulator in Hydrocephalus

Mercedeh Movassagh, PhD

Yale University

Improving Neonatal Hydrocephalus Diagnosis, Treatment, and Prevention Through Metagenomics and Genetic Characterization in Ugandan Cohorts

Andreas Rauschecker, MD, PhD

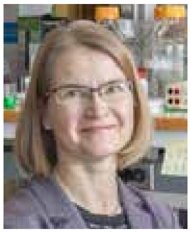
University of California , San Francisco

Automated Volumetric Measurements for Early Diagnosis and Identification of Fetal Hydrocephalus Requiring Intervention

Johnathan R. Sukovich, PhD

University of Michigan

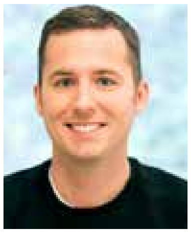
Histotripsy for the Treatment of Hydrocephalus



Maria Lehtinen, PhD

Boston Children's Hospital

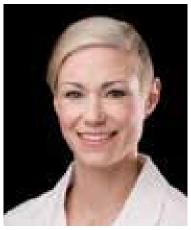
Cellular and Molecular Characterization of Human and Porcine Choroid Plexus to Study Post-Hemorrhagic Hydrocephalus (PHH)



Ronald Parchem, PhD

Baylor College of Medicine

MicroRNA Regulation of Neural Fate Specification in Congenital Hydrocephalus



Jennifer Strahle, PhD

Washington University in St. Louis

Amniotic Fluid and CSF Factors Responsible for Hydrocephalus and Altered Brain Development in Myelomeningocele

2022 Award Recipients

Ramin Eskandari, MD

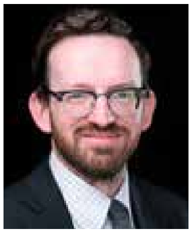
Medical University of South Carolina

Complement Inhibition in Hydrocephalus Therapy

Ryann Fame, PhD

Stanford University

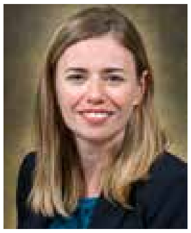
Hydrocephalus Associated Chromatin Remodelers Control Fluid Balance During Neural the Closure



Gabriel Haller, PhD

Washington University in St. Louis

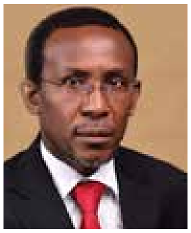
A Zebrafish Screen for Compounds that Prevent Post-hemorrhagic Hydrocephalus



Carolyn Harris, PhD

Wayne State University

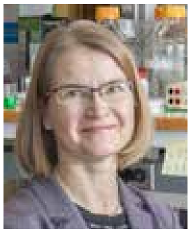
A Human Choroid Plexus-on-a-chip to Study Cerebrospinal Fluid Secretion and Pharmaceutical Treatment of Hydrocephalus, the Effects of Topographical Changes to Reduce Ventricular Catheter Obstruction,Ventricular Catheter Design Optimization With a Novel Manufacturing Process



Olufemi Idowu MBBS, FWACS, FACS

Lagos State University

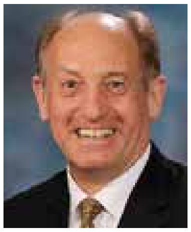
A Quantitative and Qualitative Analysis of the Barriers to Patients Early Presentation, Diagnosis and Treatment in Childhood Hydrocephalus



Maria Lehtinen, PhD

Boston Children's Hospital

Choroid Plexus Contributions to Myelimantion in Post Hemorrhagic Hydrocephalus



James (Pat) McAllister, PhD

Washington University in St. Louis

Cerebrospinal Fluid Profiling in Infants with Hydrocephalus: Defining a Novel Pathophysiological Pathway

Join HANDS

Join our online network of 400+ scientists who study hydrocephalus in the Hydrocephalus Association Network for Discovery (HANDS). Don't miss out on opportunities to collaborate and funding announcements. ***It is free to join HANDS.***

JOIN NOW

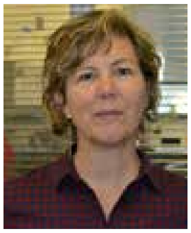
hands.hydroassoc.org

2021 Award Recipients

Bonnie Blazer-Yost, PhD

Indiana University-Purdue University

Pharmacokinetic and Pharmacodynamic Characterization of a Novel Pharmacotherapy for the Treatment of Hydrocephalus



Joanne Conover, PhD

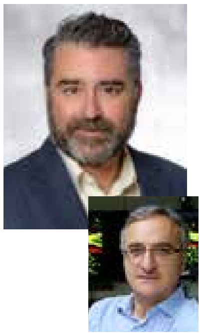
University of Connecticut

Single Cell Multiplex Characterization of Inflammatory Response in Congenital Post-Infectious Hydrocephalus

Sheng Chih (Peter) Jin, PhD

Washington University School of Medicine

A Genome Wide Assessment of Noncoding Risk Variants in Congenital Hydrocephalus



Justin Cetas, MD, PhD/ Nabil Alkayed MD, PhD

University of Arizona

The Role of the P450 Eicosanoids in the Development of Hydrocephalus

Dr. Nabil Alkayed undertook leadership of the research award after the passing of Dr. Justin Cetas in 2022.

Mats Tullberg, MD, PhD

University of Gothenburg

Utility of 3D Gait Analysis in Reference to Clinical Assessments to Detect Significant Change After a CSF Tap Test in Patients Investigated for iNPH

Your Story Matters!

Join HAPPIER

The Hydrocephalus Patient Registry

How many brain surgeries do most people with hydrocephalus have? How does hydrocephalus impact you at different stages of your life? There is so much we don't know about living with hydrocephalus. Help us solve the mystery by being part of HAPPIER – our Hydrocephalus Patient-Powered Registry – so you can share your experience of living, or caring for someone, with hydrocephalus.

By joining our patient registry, you're helping scientists understand the complexities of living with this condition and where to focus their research. Our registry will allow us to track long-term outcomes in a way that traditional research can't. It's time to see the bigger picture!

JOIN NOW

www.hydroassoc.org/happier

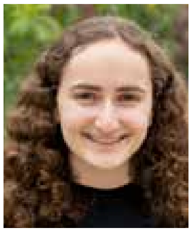
Ralph Kistler Interns 2021-2023

Bringing in the next generation of researchers.

The HA Ralph Kistler Research Internship is designed for undergraduate college students who are interested in the sciences, public health, and non-profit operations.

Ralph Kistler was a Hydrocephalus Association Board Member and a longtime friend of the Association. The Ralph Kistler Research Internship commemorates Ralph's spirit and the impact he had on the hydrocephalus community.

Under the guidance of the Hydrocephalus Association National Director of Research, the intern is involved with specific research projects and activities that advance the mission of the Association. In addition, the intern is involved with developing blogs and other research communications geared toward the hydrocephalus community, interacting with community members, clinicians, and scientists who support the Association, and aiding in running a research grant cycle.



2023

Melissa Sloan

American University

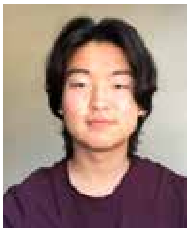
Melissa successfully completed her internship and is co-authoring two upcoming publications analyzing data from the HA patient-powered registry (HAPPIER). During her internship, her main focus was analyzing measures of independence in those living with hydrocephalus.

2022

Kevin Miller, BS

Florida State University

As of February 2022, Kevin is a semi-finalist for the Fulbright Scholarship. He is also first-author of a soon-to-be published paper about access to care in hydrocephalus.



2021

Elliot Myong, BS

University of Southern California

Elliot has been recently published in the Journal of Neurosurgery for the work he did during his time at HA, helping to establish the research priorities of hydrocephalus through a scientifically validated method.

Whats New at HA

Introducing HA's National Director of Research, Dr. Monica Chau.

Dr. Monica Chau joined HA in 2022 as a neuroscientist with experience in basic, translational, and clinical research. She received her PhD from Emory University in neuroscience, and most recently served as Research Assistant Professor of Neurosurgery at University of Kentucky. Dr. Chau's scientific expertise is in the use of cell therapy for neurodegenerative conditions such as ischemic stroke, peripheral nerve injury, and Parkinson's Disease. As Research Assistant Professor, she conducted clinical research on a cell therapy for Parkinson's Disease. Dr. Chau's expertise in neurodegenerative conditions, coupled with her leadership in scientific and community organizations, led her to HA where she is dedicated to advancing medical treatments and advocating for patients and families impacted by hydrocephalus.

With a focus on advancing hydrocephalus research, she supports scientists and research that aligns with the patient voice and the Community Research Priorities. This includes research in non-invasive treatments, reducing the burden of current shunt treatments, improving diagnosis of hydrocephalus, improving the quality of life for those living with hydrocephalus, and improving access to care.

In her first year at HA, Dr. Chau has already played a pivotal role in steering the new strategic plan by advancing research initiatives. She directed two research workshops by assembling scientific experts to identify and close the gaps in the field. She is a valuable addition to HA and strong leader in the scientific community.

UNDER PRESSURE

Campaign to accelerate the
pace of hydrocephalus research

Inspired by all the advances in research, you can be a part of supporting these great initiatives. Join us on this journey and take action today.

You may contact Linda Riley, National Director of Development, at (240) 483-4475, or linda@hydroassoc.org, to make an appointment with our leadership team to learn more.

> "Where we need to be is funding research. So we can find better treatments. So that Mary doesn't have to get up every morning wondering if today's headache is the one that will land her in the hospital. It's a crazy way to live. We have to do better than this, and the Hydrocephalus Association is the one who is going to do it."
>
> — Betsy Conyard, Seattle WALK Chair, HA supporter, and mother of Mary

Hydrocephalus
Association

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