RESEARCH UPDATE

HANDS
Hydrocephalus Association Network for Discovery Science
Collaboration • Innovation • Impact




# HA CONNECT 2024

July 25-27 | Tampa, FL

Over the course of three days, hundreds of individuals and families from all walks of life convened with medical professionals, scientists, and experts from top hospitals and research facilities at the 18th National Conference on Hydrocephalus, HA CONNECT, in Tampa, Florida. This conference not only provided insightful information for those affected by hydrocephalus, but also fostered a unique dialogue beyond the typical patient-physician environment.




***SUMMER 2024***

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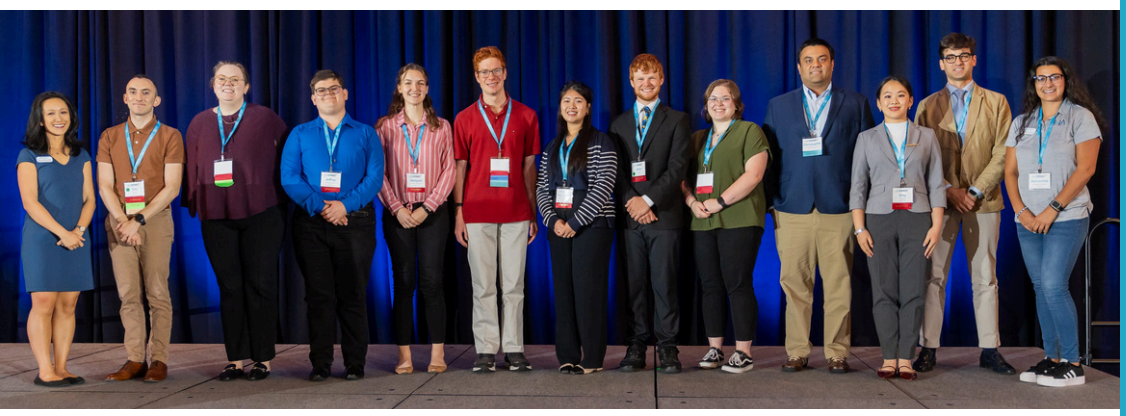
*HIGHLIGHTING RECENT PUBLICATIONS*

*Written by Edgar Xiong*

# Next Generation Scientists Travel Award

Ushering in fresh ideas and new minds in research for hydrocephalus, the Next Generation Scientists Travel Award provides the funding necessary to attend the National Conference on Hydrocephalus. Doing so gives these new researchers an excellent opportunity to further connect with individuals with hydrocephalus and other medical professionals. From a patient perspective, it is extremely invigorating to see the innovative new ideas that are being explored.

The 2024 Next Generation Travel Award rewarded a total of twelve early-career hydrocephalus researchers. They were carefully selected for this coveted award, providing them the opportunity to connect face-to-face with those impacted by hydrocephalus and network with established medical professionals. Their presentations took on varied approaches towards hydrocephalus, ranging from the development and dynamics of the condition to new and improved methods for reducing the impact of shunt malfunctions. These twelve researchers bring hope to the horizon for hydrocephalus research, showcasing their creativity and ingenuity. **Check out their posters by clicking their titles on the right.**



**Patient Perspective:** “In the limited amount of time we had for the session, I was able to mingle, query, and pick their brains (pun intended). My only regret was the inability to spend even more time with them. I sincerely appreciated that they all had such innovative yet different ideas. The experience was very much a two way street. On one hand, the attendees were exposed to the researchers’ new ideas and were elated to see the trajectory of current and future research. On the other hand, these young researchers were able to learn from us. From a scholastic standpoint, the lived experiences of those affected is invaluable learning material beyond the textbook.” - Edgar Xiong

## 2024 Next Generation Scientists Travel Award Projects

**Bianka Valecruz** - *Developing a Testing System to Improve Shunt Blockages*

**Riccardo Serra, MD** - *Novel Ventricular Catheter for Drainage of Intraventricular Hemorrhage*

**Gwen Sebring, BS** - *Developing a genetic tool to treat infant hydrocephalus*

**Chris Roberts, MS** - *Modeling Brain Fluid Dynamics with Shunts*

**Brady Rivkin** - *Noninvasive Measurement of CSF flow*

**Elizabeth Ricci, BS** - *Modeling Congenital Hydrocephalus in Tadpoles*

**Leah Pendl-Robinson, BS** - *Modeling Candidate Congenital Hydrocephalus Genes in Frogs*

**Verayna Newland, BS** - *The movement of molecules when cerebrospinal fluid is produced*

**Amy Huang, BASc** - *Design of Non-obstructive Self-cleaning Ventricular Shunt*

**Jeff Horbatiuk, BS** - *Predicting CSF Production Using Blood Pressure: A Rat Model*

**Tim Heck, MD** - *Long Term Benefits with a Novel Drug Treatment in a Rat Model of Post-Hemorrhagic Hydrocephalus of Prematurity*

**Hawley Helmbrecht, PhD** - *Posthemorrhagic Hydrocephalus Slows Cerebrospinal Fluid (CSF) Movement in Rats*

# Engineering in Hydrocephalus Prize









Complementing the Travel Award, the Engineering in Hydrocephalus Prize has been inaugurated to challenge undergraduate and graduate researchers to think outside the box. The goal is to brainstorm creative, unique methods and technologies to address the many facets of hydrocephalus. The first batch of awardees for this year all went above and beyond to integrate up and coming technology to improve treatment outcomes.

**Haritosh Patel, BASc and Amy Huang, BASc**

*Under the mentorship of Dr. Joanna Aizenberg*

Their project titled "Bioinspired Antifouling Ventricular Catheter Material and Design" focused on the physical design of the proximal catheter. They integrated curved flaps for increased fluid flow and decreased blockage, as well as SLIPS material to decrease the risk of bacterial adhesion and infections.
Learn more about their project here.

**Bianka Valecruz**

*Under the mentorship of Dr. Enrique Alvarez*

Her project titled "Test Bench Development for Enhancing Sensor and Catheter Design to Prevent Hydrocephalus Shunt Blockages" developed a system to mimic the pressures, flow, and conditions within the brain. This aimed to provide a platform for researchers to test shunts in a controlled environment, identifying blockages and fluid flow.
Learn more about her project here.

**Yuli Wang, MS**

*Under the mentorship of Dr. Harrison Bai*

His project titled "Artificial Intelligence for Monitoring and Predicting Disease in Patients with Idiopathic Normal Pressure Hydrocephalus (iNPH) using Imaging and Clinical Data" developed an artificial intelligence-based deep learning model to help more accurately detect and iNPH in medical imaging.
Read more about his project here.

# *Neuropsychology and Cognition Efforts*

While finding a cure for hydrocephalus is the ultimate goal, bettering the lives of those with the condition remains equally a critical focus of the Hydrocephalus Association's strategic plan. Not only is improving the quality of life for patients and caregivers a top community research priority, but it is also a frequently overlooked need for those impacted by hydrocephalus. HA is involved in various efforts focused on improving neuropsychological outcomes in hydrocephalus.

The **Neuropsychology and Cognition Award** has been created to understand hydrocephalus phenotypes across the lifespan, assess indicators/outcomes related to surgical intervention, develop novel and translational applications in preclinical and animal/cellular models, and guide improvements in patient care and transitions across the life course. Postdoctoral and faculty-level researchers are welcome to apply. The winner of the award will be granted $50,000 towards their project funding. **Apply here by the deadline!**




This year's **American Academy of Clinical Neuropsychology (AACN) Conference** highlighted the importance of neuropsychological efforts in hydrocephalus research in a special section titled, "Hydrocephalus: A Lifespan Disorder". Drs. Cynthia Smith Seidel, PhD, ABPP, Andrew Zabel, PhD, ABPP, Nickolas Dasher, PhD, ABPP, and Ramin Eskandari, MS, MD. discussed the neurological causes of various forms of hydrocephalus across the lifespan, the impact of treatment on cognitive functioning, and areas requiring further research on rehabilitative interventions to enhance quality of life.

The Hydrocephalus Association is particularly excited as these talks highlight the need for more research and advancement of neuropsychological outcomes for hydrocephalus patients.

# *Epidemiology Efforts*

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. HA’s strategic plan highlights a need to develop reliable data on the epidemiology and health economics of hydrocephalus.




One of the many ways this is being achieved is through the Epidemiology Challenge Award. This award will support an advanced trainee or scientist with strong methods expertise in epidemiology and/or biostatistics to conduct a focused project on the incidence and/or prevalence of hydrocephalus using a pre-existing dataset. One award of $50,000 will be rewarded. The deadline for applications is Monday, September 9. **Apply here!**

# *Open Faculty Position*

**Indiana University Faculty Position Opening**

The Department of Biology at Indiana University-Indianapolis invites applications for a tenured faculty position at the rank of Associate or Full Professor to begin March 1, 2025. Competitive salary and start-up funds are available. Learn more here.




Contact Teri Belecky-Adams (tbadams@iu.edu) with any questions.

# *Recent Publications in Hydrocephalus*

## Evaluating Shunting for Idiopathic Normal Pressure Hydrocephalus (iNPH)

Pearce et al. analyzed data from 4 randomized controlled trials on CSF shunting in 140 iNPH patients, which indicated with moderate certainty that, within six months of surgery, shunting increases gait speed and decreases disability. The analysis pointed out **important gaps** in the available data, though; it is still unknown how CSF shunting affects adverse events and cognitive performance.

In order to properly evaluate the long-term benefits and dangers related with CSF-shunting, the study recommends bigger sample numbers, longer follow-up periods, and more comprehensive methods. This highlights the need for more randomized clinical trials, such as the the Placebo-Controlled Effectiveness in iNPH Shunting (PENS) Trial. This trial will evaluate the response of shunting in patients with iNPH and improve diagnosis. Read more about this publication and the PENS trial.

## Largest GWAS on NPH To Date

Dr. Ville Leinonen and his team from the University of Eastern Finland have conducted the largest genome-wide association study (GWAS) on NPH to date. The study, which analyzed data from over 450,000 Finnish individuals, identified six genetic regions linked to NPH, which are implicated in the function of the blood-brain barrier and blood-CSF barrier, as well as increased lateral brain ventricle volume. These findings offer insights into the genetic factors contributing to NPH and identify potential risk factors for iNPH. The Hydrocephalus Association is excited to feature this groundbreaking research at the 2024 Research Workshop on iNPH in Falls Church, VA. Learn more about the study here.

## Hydrocephalus Dashboard for EPIC System

Nemours Children's Hospital Delaware has developed a hydrocephalus dashboard to enhance its EPIC medical system. The dashboard provides detailed data on all children with hydrocephalus treated at the hospital, including patient follow-up, emergency department visits, imaging, new patient statistics, hospital days, and revision surgery rates. This could benefit other medical institutions seeking to improve their EPIC systems or collaborate on hydrocephalus patient management. Read more here.