Hydrocephalus Association

HYDROCEPHALUS IN **MARYLAND**

HYDROCEPHALUS IS A CHRONIC NEUROLOGICAL CONDITION THAT HAS NO CURE. ANYONE AT ANY TIME CAN DEVELOP HYDROCEPHALUS, FROM INFANTS TO SENIORS. THE ONLY TREATMENT REQUIRES BRAIN SURGERY.

TOGETHER TOWARDS A CURE

HCRN
Hydrocephalus Clinical Research Network

AHCRN
Adult Hydrocephalus Clinical Research Network

HANDS
Hydrocephalus Association Network for Discovery Science

PAGE 2
for a full listing of funded hydrocephalus research in Maryland

$15.5M
HA INVESTMENT

$87M
ADDITIONAL GRANTS

MAKING AN IMPACT

The Big Picture

2 Clinical Research Networks

1 Basic & Translational Research Network

2 Biobanks

1 Hydrocephalus Patient-Powered Registry

36% Decrease in Shunt Infection Rates

12 Preclinical Drug Therapies in testing

2 New Patent for a Drug Target

1 FDA Investigational New Drug Application

WALK TO END HYDROCEPHALUS

Baltimore, UMBC, October 19, 2024
hydroassoc.org/baltimorewalk

Washington, DC, National Mall, September 21, 2024
hydroassoc.org/nationalcapitalwalk



COMMUNITY SUPPORT GROUPS

Baltimore Community Network
DC Metro Community Network
State-wide Online Facebook Group
One-on-one Peer Support Volunteers

Hydrocephalus Association



CONTRIBUTIONS TOWARD A CURE

EUNICE KENNEDY SHRIVER NATIONAL INSTITUTE OF CHILD HEALTH & HUMAN DEVELOPMENT, NIH

2020 NIH NICHD **$46,288**
Genetic Factors in Birth Defects. Principal Investigator: Mills, James

HYDROCEPHALUS ASSOCIATION

2015 PCORI **$49,827**
Translation to Transform. Principal Investigator: Koschnitzky, Jenna

JOHNS HOPKINS UNIVERSITY

2016 Hydrocephalus Association **$50,000**
Mechanisms of post-hemorrhagic hydrocephalus of prematurity. Principal Investigators: Robinson, Shanandoah and Jantzie, Lauren

2017 DOD CDMRP **$2,320,750**
Mechanisms and Nonsurgical Treatment of Acquired Symptomatic Hydrocephalus. Principal Investigators: Robinson, Shanandoah and Jantzie, Lauren (follow on from HA funding)

2019 Hydrocephalus Assoc/Rudi Schulte Research Institute **$50,000**
Motile cilia dysfunction in neonatal post-infectious hydrocephalus. Principal Investigators: Robinson, Shanandoah and Jantzie, Lauren

2020 NIH NINDS **$453,891**
Determine protocol for labeling the subarachnoid space and dura on MR images, develop automated algorithm to do so, and carry out pilot studies with NPH and MS patients. Principal Investigator: Prince, Jerry L

2021 NIH NINDS $204,688
A study of paravascular and interstitial flow in Hydrocephalus and shunting. Principal Investigator: Luciano, Mark

2020 Hydrocephalus Association $1,500
Evaluating the effects of CSF proteins on valves and anti-siphoning devices in a benchtop shunt system. Travel Award. Principal Investigator: Serra, Riccardo

JOHNS HOPKINS UNIVERSITY CON'T

2021 NIH NICHD **$318,709**
Stem cell-based biomaterials for spinal regeneration in neural tube defects. Principal Investigator: Kunisaki, Shaun Michael

2021 Department of Defense **$2,289,370**
2023 Continuation Grant ---
Novel Non-Surgical Neuro-Immunomodulatory Treatment for Acquired Hydrocephalus. Principal Investigators: Robinson, Shanandoah and Jantzie, Lauren (follow on from HA funding)

2021-2026 NIH NINDS **$14,000,000**
A Placebo-Controlled Effectiveness in INPH Shunting (PENS) Trial. Principal Investigators: Luciano, Mark Gregory and Holubkov, Richard

2022 DOD CDMRP **$7,800,000**
Development of Pharmacotherapies for the Treatment of Hydrocephalus. Principal Investigators: Robinson, Shenandoah, Jantzie, Lauren, and Blazer-Yost, Bonnie (IN)

2022-2023 NIH NICHD **$2,580,803**
Safety of Combinatorial Therapy with Erythropoietin and Melatonin for Preterm Infants with Intraventricular Hemorrhage. Principal Investigators: Robinson, Shenandoah and Jantzie, Lauren.

MEMBER

Hydrocephalus Clinical Research Network
Johns Hopkins University, Johns Hopkins Hospital

MEMBER

Adult Hydrocephalus Clinical Research Network
Johns Hopkins Hospital