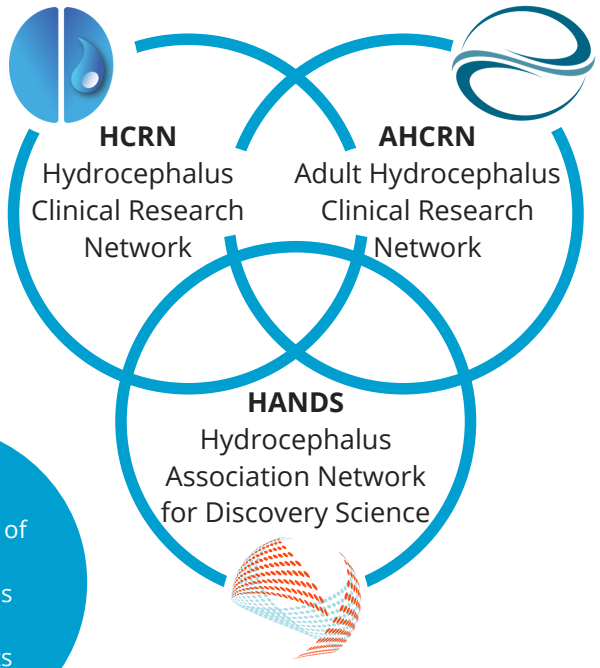
Hydrocephalus Association

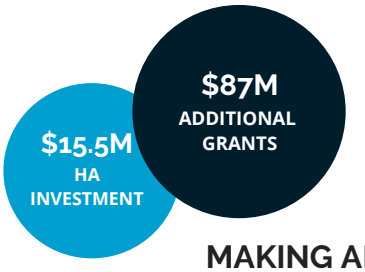
HYDROCEPHALUS IN **MASSACHUSETTS**

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



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



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

Medford, DCR Torbert MacDonald Park
September 29, 2024
hydroassoc.org/gnewalk





COMMUNITY SUPPORT GROUPS

Boston Community Network
State-wide Online Facebook Group
One-on-one Peer Support Volunteers

Hydrocephalus Association

CONTRIBUTIONS TOWARD A CURE

BOSTON CHILDREN'S HOSPITAL

2010 Hydrocephalus Association **$110,000**
Determine the role of pro-angiogenic factor VEGF in hydrocephalus. Principal Investigator: Shim, Joon

2018 Hydrocephalus Association **$297,000**
Determine how a brain bleed changes choroid plexus function and brain development. Lehtinen, Maria

2020 NIH NINDS **$472,004**
Improving the Safety and Efficacy of Intraventricular Neurosurgery via Robotics. Principal Investigator: Dupont, Pierre E

2021 NIH NICHD **$536,941**
Improving infant hydrocephalus outcomes in Uganda: Predicting developmental outcomes and identifying patients at risk for early treatment failure after ETV/CPC. Principal Investigator: Lin, Pei-Yi and Warf, Benjamin

2022 Hydrocephalus Association **$1,500**
Brain monitoring to predict surgical treatment outcome for neonatal hydrocephalus. Travel Award. Principal Investigator: Rajaram, Ajay

2022 Hydrocephalus Association Innovator Award
Principal Investigator: Lehtinen, Maria

2023 NIH NINDS **$2,979,352**
Targeting the Choroid Plexus-Cerebrospinal Fluid System to Treat Post-Hemorrhagic Hydrocephalus. Principal Investigator: Lehtinen, Maria

2023 Hydrocephalus Association **$50,000**
Principal Investigator: Lehtinen, Maria

2024 BCH-Cell Discovery Network **$48,000**
Manton Cell Discovery Lehtinen Accelerator Award: Generating a Cross-species Choroid/Plexus Atlas. Principal Investigator: Lehtinen, Maria

Beth Israel Deaconess Medical Center / Harvard Medical School

2017 Hydrocephalus Association $50,000
Identify markers of delayed hydrocephalus following subarachnoid hemorrhage (SAH). Principal Investigator: Fillippidis, Aristotelis

MASSACHUSETTS GENERAL HOSPITAL

2021 NIH NINDS $200,880
Apathy and Depression following Intracerebral Hemorrhage. Principal Investigator: Biffi, Alessandro

MASSACHUSETTS GENERAL HOSPITAL CON'T

2021 NIH NICHD **$510,303**
Portable MRI Technology for Neonatal Care. Principal Investigator: Cooley, Clarissa Zimmerman

2021 NIH NINDS **$462,000**
Development of a multi-modal MRI methodology to map paravascular clearance linked to astrocyte dysfunction in fetal-onset hydrocephalus. Principal Investigator: Yu, Xin

UNIV OF MASSACHUSETTS MED SCH WORCESTER

2020 NIH NINDS **$561,865**
Genetics of Adult Idiopathic Hydrocephalus. Principal Investigator: Johnson, Mark D.

2021 NIH NINDS **$31,969**
Genetics of Adult Idiopathic Hydrocephalus. Principal Investigator: Johnson, Mark D.

2021 NIH NINDS **$638,592**
Genetics of Adult Idiopathic Hydrocephalus. Principal Investigator: Johnson, Mark D.

2021 NIH NIGMS **$636,066**
Flagellar Motility and Assembly. Principal Investigator: Witman, George B.