# HYDROCEPHALUS ASSOCIATION & RUDI SCHULTE RESEARCH INSTITUTE

# RESEARCH WORKSHOP

Honoring the legacy of Dr. Michael Pollay

Developing Non-Invasive Hydrocephalus Therapies: Molecular and Cellular Targets



Le Méridien Dallas, Stoneleigh Hotel 2927 Maple Avenue Dallas, Texas, 75201

Wednesday, September 27, 2023 2:15 PM - 6:30 PM

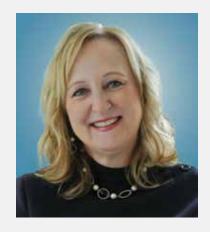
Thursday, September 28, 2023 7:00 AM - 5:00 PM

> Friday, September 29, 2023 7:00 AM - 2:00 PM



### **Welcome Letter:**

### From HA President and CEO, Diana Gray



Planning Committee
Bonnie Blazer-Yost, PhD
Indiana University

William Dawes, FRCS(SN) PhD Alder Hey Children's Hospital

**Ryann Fame, PhD** Stanford University

**Gabriel Haller, PhD**Washington University in St. Louis

Carolyn Harris, PhD Wayne State University

**Sheng Chih (Peter) Jin, PhD**Washington University in St. Louis

**Richard Keep, PhD** University of Michigan

**Kevin King, MD**Barrow Neurological Institute

**Abhay Moghekar, MBBS**Johns Hopkins University

Welcome to the Hydrocephalus Association (HA) & Rudi Schulte Research Institute (RSRI) 2023 Research Workshop dedicated to pursuing non-invasive treatments for hydrocephalus. We are delighted to have you here, and we extend our heartfelt gratitude to the RSRI for their generous support in making this important event possible. There is an urgent need for non-invasive therapies for hydrocephalus. For this reason, our workshop will focus on delving into targetable pathways for hydrocephalus therapy, with a focus on using -omics tools to identify potential molecular and cellular targets. Our primary focus during these two days is to collectively explore non-invasive targets of treatment that could lead us towards a future where patients no longer need shunts or other invasive therapies for managing hydrocephalus.

This workshop holds a special significance as it is dedicated to the legacy of Dr. Michael Pollay, a cherished friend of Rudi Schulte and a long-time RSRI board member. Dr. Pollay's passion for neuroscience, dedication to his patients, and commitment to mentorship have left a lasting impact on the field of neurosurgery. His numerous publications and recognition as an internationally renowned scientist underscore his contributions to understanding hydrocephalus better.

Our commitment to this research is fueled by the outcomes of HA's comprehensive, patient-centered Community Research Priorities study from last year, which identified the top 20 research priorities of the hydrocephalus community. This workshop addresses the following research priorities:

- Develop new treatments that do not require brain surgery to manage hydrocephalus.
- Develop new one-time treatments to manage hydrocephalus (i.e. permanent treatments that do not require additional interventions).
- Develop therapies (e.g. stems cells, cellular regeneration) to repair brain damage for people affected by hydrocephalus.

We encourage lively discussions and debates during the course of this workshop, and we envision the proceedings to culminate in a white paper and publication in a peer-reviewed journal. The insights gained from this workshop will significantly contribute to HA's mission of improving the lives of individuals affected by hydrocephalus at every stage of life.

Thank you for being an integral part of this collaborative effort. Your expertise and dedication to hydrocephalus research are invaluable as we strive towards the development of better solutions and non-invasive therapies.

Sincerely,

Diana Gray, MA

President and Chief Executive Officer
Hydrocephalus Association

# HA & RSRI Research Workshop Agenda

### Wednesday, September 27, 2023

Room: Grand Salon | Theme: Identifying Hydrocephalus Targets Using Big Data and Machine Learning

2:15 PM	Welcome and Introduction
	Speakers: Diana Gray, MA
	Caudan McCamb MD

Gordon McComb, MD Monica Chau, PhD

# SESSION 1: BIG DATA AND HYDROCEPHALUS TARGETS

MODERATOR: PAT MCALLISTER, PHD

2:55 PM The Choroid Plexus Secretome and its

Contributions to Myelination

Speaker: Alexandra Hochstetler, PhD

3:20 PM Leveraging Targeted and Untargeted

Metabolomics to Characterize Embryonic CSF

**During Inflammation** 

Speaker: Boryana Petrova, PhD

3:50 PM Break

### SESSION 2: MACHINE LEARNING AND HYDROCEPHALUS TARGETS

MODERATOR: PAT MCALLISTER, PHD

4:20 PM From Data to Decision: A Pragmatic Guide to Machine Learning in Hydrocephalus Research

Speaker: Daniel Harris, MS

4:45 PM Automated Identification of Normal Pressure

Hydrocephalus on Imaging: Current Research

Datasets

Speaker: Kevin King, MD

5:10 PM Machine Learning and RNAseq in NPH

Speaker: Maria Grazia Ruocco, PhD

5:40 PM Synthesis Discussion:

Moderator: Kevin King, MD

6:20 PM End of Program, Day 1

7:30 PM Welcome Reception at Hotel Venue

Room: Terrace Ballroom

### Thursday, September 28, 2023

Room: Grand Salon | Theme: Hydrocephalus Targets and Preclinical Testing

7:00 AM Breakfast, Music Room 7:45 AM Welcoming Remarks

Speaker: Monica Chau, PhD

### SESSION 3: CONGENITAL HYDROCEPHALUS

MODERATOR: RYANN FAME, PHD

8:00 AM Cell Reprogramming to Ependymal Lineage by

GemC1/Lynkeas and McIdas

Speaker: Stavros Taraviras, PhD

Genetic Targets in Hydrocephalus

Speaker: June Goto, PhD

8:50 AM Molecular Genetics and Complex Inheritance of

Congenital Hydrocephalus

Speaker: Sheng Chih (Peter) Jin, PhD

9:15 AM Break

8:25 AM

9:45 AM Genetic Drivers of Congenital Hydrocephalus:

Towards Precision Neurosurgery
Speaker: Kristopher Kahle, MD, PhD

10:10 AM Connecting Congenital Hydrocephalus and Neural Tube Closure Through Chromatin

Remodeling

Speaker: Ryann Fame, PhD

# SESSION 4: POSTHEMORRHAGIC HYDROCEPHALUS (PHH)

MODERATOR: RAMIN ESKANDARI, MD

10:35 AM Choroid Plexus-Targeted NKCC1 Overexpression

to Treat PHH

Speaker: Cameron Sadegh, MD, PhD

11:00 AM Electrolyte Transporters as Drug Targets in

**Preclinical Studies** 

Speaker: Bonnie Blazer-Yost, PhD

11:25 AM Choroid Plexus-Mediated Iron Clearance Prevents

Neonatal PHH

Speaker: Jennifer Strahle, MD

11:50 PM Lunch (Music Room)

# HA & RSRI Research Workshop Agenda (cont.)

1:00 PM	Anti-Inflammatory Targets for Treating Hydrocephalus Speaker: Brandon Miller, MD, PhD
1:25 PM	Cerebrospinal Fluid-Based Extracellular Vesicle Signaling and Related T-Cell Activation in Post-Hemorrhagic Hydrocephalus <b>Speaker: Maria Garcia-Bonilla, PhD</b>
1:50 PM	Anti-Complement Targets in Post-Hemorrhagic Hydrocephalus <b>Speaker: Ramin Eskandari, MD</b>
2:15 PM	Break

# SESSION 5: NORMAL PRESSURE HYDROCEPHALUS (NPH)

MODERATOR: ABHAY MOGHEKAR, MBBS, MD

2:45 PM Cerebrospinal Fluid and NPH

Speaker: Abhay Moghekar, MBBS

3:10 PM Genetic Underpinnings of NPH Speaker: Mark Johnson, MD, PhD

3:35 PM Activating Lymphatics to Reduce Abnormal Brain

Fluid Accumulation

Speaker: Young Kwon Hong, PhD

4:00 PM Preclinical Studies Synthesis Discussion

Moderator: Richard Keep, PhD

4:45 PM End of Program, Day 2

### Friday, September 29, 2023

Room: Grand Salon | Theme: Navigating Clinical Trials

7:00 AM Breakfast, Music Room

## SESSION 6: CLINICAL TRIALS PAST AND PRESENT

#### A. NAVIGATING THE CLINICAL TRIAL PROCESS

MODERATOR: BONNIE BLAZER-YOST, PHD

8:00 AM Bench to Bedside in 10 Years or Less: A Novel,

Non-Surgical Therapy for PHHP **Speaker: Lauren Jantzie, PhD** 

8:25 AM Initiating Clinical Trials

Speaker: Carolyn Harris, PhD

8:50 AM Trials in Neonatal Hydrocephalus: Intraventricular

Hemorrhage & PHH

Speaker: William Dawes, FRCS(SN), PhD

9:15 AM Break

# B. PARTNERING WITH OTHER SITES FOR CLINICAL TRIALS

MODERATOR: BONNIE BLAZER-YOST, PHD

9:45 AM PENS Trial

Speaker: Mark Luciano, MD, PhD

10:10 AM Hydrocephalus Research Network (HCRN)

Speaker: John Kestle, MD

#### **SESSION 7: PATIENT PERSPECTIVE**

10:35 AM Patient Perspective Panel: What Clinical Trial

Measures are Important to Patients?

Panelists: Jennifer Bechard, Janet Miller, MPA,

Daniela Vasquez, BS

Moderator: Lauren Jantzie, PhD

# SESSION 8: FUNDERS PANEL - FUNDING OPPORTUNITIES WITH Q&A

MODERATOR: CAROLYN HARRIS, PHD

11:25 AM **Lunchtime Session** *Grand Salon* 

Department of Defense (DoD) - Congressional Directed Medical Research Programs (CDMRP)

**Funding Opportunities** 

Speaker: Cecilia Dupecher, Program Manager of Peer Reviewed Medical Research Program

(PRMRP)

National Institutes of Health (NIH)- Division of Rare Diseases Research Innovation (DRDRI), National Center for Advancing Translational

Sciences (NCATS)

Speaker: Philip J. (P.J.) Brooks, Acting Director

National Institutes of Health (NIH)- National Institute of Neurological Disorders and Stroke

(NINDS), Division of Neuroscience

Speaker: Jill Morris, PhD, Program Manager

#### **SESSION 9: MODES OF TREATMENT DELIVERY**

MODERATOR: ALEXANDRA HOCHSTETLER, PHD

12:40 PM Ultrasonic CSF Flow Control to Enhance Drug

Delivery and Clear Pathogenic Waste

Speaker: Matine Azadian, MA

1:05 PM Canavan Disease as a Prototype for Gene Therapy

of Hydrocephalus advancing Translational Sciences

Speaker: Christopher Janson, MD

1:30 PM Synthesis Discussion

Moderator: Michael Williams, MD

2:00 PM End of Program, Day 3

### Clinical Research Networks

#### ABOUT

We support two multicenter clinical research networks, the pediatric-focused Hydrocephalus Clinical Research Network (HCRN) and the Adult Hydrocephalus Clinical Research Network (AHCRN).

These networks of highly skilled clinician-scientists are changing how hydrocephalus clinical research is conducted and producing high quality, high impact studies at an unprecedented pace.



A network of fourteen children's hospitals that conduct clinical research on hydrocephalus.

Learn more: HCRN.org



A network of eight hospitals that conduct clinical research focused on adults with hydrocephalus.

Learn more: AHCRN.org





2927 Maple Avenue Dallas, Texas, 75201

**Hydrocephalus Association & Rudi Schulte Research Institute** 

# RESEARCH WORKSHOP

Honoring the Legacy of Dr. Michael Pollay









# Workshop Attendees

Denotes Speaker

### Mohammed Alshareef, MD

### Pediatric Neurosurgeon

### Children's Hospital Colorado alsharemoh@gmail.com

Dr. Mohammed Alshareef is a pediatric neurosurgery fellow at the Children's Hospital Colorado Department of Neurosurgery. Prior to this position, he completed his neurosurgery training at the Medical University of South Carolina (MUSC). He also obtained a biomedical engineering degree at the University of South Carolina (USC) and a medical degree from MUSC. At USC, he studied cancer bio-microfluidics for diagnosis and isolation of circulating tumor cells. Currently, he focuses on complement activation in germinal matrix hemorrhage (GMH) and post-hemorrhagic hydrocephalus (PHH) in neonatal mice. He contributed to the development of a novel GMH model for testing of complement inhibitors and exploring the natural history of posthemorrhagic sequela, a project with a high translational potential.

# Matine Azadian, MA PhD Candidate, Neurosciences

### Stanford University matine@stanford.edu

Matine Azadian is a PhD Candidate in the Neurosciences Program at Stanford University School of Medicine. He joined the team of Dr. Raag Airan in 2019 and hopes to positively contribute toward the lab's mission of discovering non-invasive methods to interact with and modulate the central nervous system. He is a fellow of the Ford Foundation through the National Academies of Sciences, Engineering, and Medicine, and currently focuses on the development of ultrasonic interventions that can enhance drug delivery and waste clearance via cerebrospinal fluid flow pathways in

the brain. Matine enjoys scientific research as a fundamental source of innovation and hopes to make a tangible difference for patients with neurodegenerative diseases prior to retiring as a tea farmer in Kaua'i.

# Jennifer Bechard Education Manager

### **Hydrocephalus Association** support.liaison@hydroassoc.org

Jennifer Bechard is the Education Manager at the Hydrocephalus Association, overseeing all aspects of an ongoing education program. Her responsibilities include managing scholarships, conferences, and all educational events, while also developing educational materials for the community. With a personal connection to hydrocephalus, Jennifer began volunteering in 2007 and joined HA full-time in 2011. Diagnosed with communicating hydrocephalus at age 10, she has undergone 111 brain surgeries. Jennifer started the Detroit WALK and chaired it for five years. She established a support group in Detroit and has been a compelling speaker, championing hydrocephalus awareness and actively fundraising. Jennifer received the 2010 Cash Sweat and Tears Award and HA's Distinguished Volunteer of the Year Award.

### Teri Belecky-Adams, PhD

#### **Associate Professor**

## Indiana University-Purdue University Indianapolis

tbadams@iupui.edu

Dr. Teri Belecky-Adams is a vision biologist focused on retinal development and disease. In regards to hydrocephalus, her laboratory collaborates with the laboratories of Drs. Bonnie Blazer-Yost, Lauren Jantzie, and Shenandoah Robinson to study the effects of acquired hydrocephalus on the optic nerve and eye.

# Bonnie Blazer-Yost, PhD Professor, Biology Department

### Indiana University - Purdue

**University Indianapolis** 

bblazer@iupui.edu

Dr. Bonnie Blazer-Yost is a cell physiologist with an interest in fluid/electrolyte transporters and how they are regulated in normal homeostasis as well as pathophysiological states. Her laboratory studies the processes involved in the production of CSF with a view to determining the optimal sites in the biochemical regulatory pathways that can be targeted to alter CSF volume for the treatment of diseases such as hydrocephalus.

# Philip J. (P.J.) Brooks, PhD Acting Director

### NIH Division of Rare Diseases Research Innovation (DRDRI) and National Center for Advancing Translational Sciences (NCATS)

pj.brooks@nih.gov

Dr. Philip J. (P.J.) Brooks is the Acting Director of NCATS' Division of Rare Diseases Research Innovation. In May 2022, Brooks was selected as the recipient of the 2022 Sonia Skarlatos Public Service Award by the American Society of Gene & Cell Therapy for consistently fostering and enhancing the field of gene and cell therapy.

# Monica Chau, PhD National Director of Research

### Hydrocephalus Association

monica@hydroassoc.org

Dr. Monica Chau is responsible for planning, managing, and implementing the research program for the Hydrocephalus Association. She enjoys supporting scientists and advocating for patients. Dr. Chau is a neuroscientist with 17+ years of experience in research. She received

her PhD from Emory University. Prior to HA, she was conducting clinical research as a research assistant professor at the University of Kentucky. Dr. Chau's expertise is in the use of cell therapies for conditions such as stroke, peripheral nerve injury, and Parkinson's disease. She was awarded fellowships from the American Heart Association, the American Cancer Society, and funding for her clinical research. She has published numerous works on neurodegeneration and has received many scientific awards throughout her career.

### Tim Cherry, PhD

Assistant Professor, Department of Pediatrics, Division of Genetic Medicine

### University of Washington

timothy.cherry@seattlechildrens.org
Dr. Tim Cherry's research focuses on
how poorly understood genetic
variation in non-coding regions of the
genome shapes the development,
function and disorders of the central
nervous system. He aims to 1)
elucidate the genetic regulation of
neural development and function, 2)
to uncover genetic mechanisms that
contribute to disorders of the CNS,
and 3) to develop novel approaches to
diagnose and treat
neurodevelopmental disorders. To
achieve these goals the lab studies
non-coding genetic variation between
individuals and across species, using

non-coding genetic variation between individuals and across species, using high throughput genomic, epigenomic, and machine learning-based approaches to distinguish between deleterious and benign genetic variants. This strategy is revealing new insights into the genetic basis of developmental disorders including disorders of vision and congenital hydrocephalus and provides a blueprint for restoring function that has been lost to disease.

### **Adam Cunningham**

Research Assistant, Department of Biomedical Engineering

### **Marshall University**

cunningha219@marshall.edu

Adam Cunningham is pursuing a BS BME degree at Marshall University studying hydrocephalus of all ages under the research mentorship of Dr. Joon "Simon" Shim, who is one of the recipients of the inaugural MYI award winners from the Hydrocephalus Association. Mr. Cunningham is interested in choroid plexus and fluid exchange in the human brain.

### Sarah Daniel, PhD

Science Communication Consultant

#### In Scripto, LLC

sarahdaniel@inscriptoscience.com

Dr. Sarah Daniel is a science writer, editor, and communication consultant with a goal to help others communicate their ideas and research clearly and effectively. She received her Bachelor of Arts from Barnard College at Columbia University in 2009 and her PhD in neuroscience from Emory University in 2016. After graduating, she worked as an academic editor for a manuscript preparation service from 2016-2020, helping numerous researchers from around the world publish their work. In 2020, Sarah began working more closely with research scientists to develop grants, prepare manuscripts and more effectively communicate their research, ideas, and future plans. That is when she started In Scripto, where she aims to streamline the writing process, leaving you more time to pursue your goals.

### William Dawes, FRCS(SN), PhD

Consultant Academic Pediatric Neurosurgeon

### Alder Hey Children's Hospital william.dawes@alderhev.nhs.uk

Dr. William Dawes is a consultant in pediatric neurosurgery working at Alder Hey Children's Hospital in Liverpool, England and an honorary senior clinical lecturer and honorary associate professor at the University of Liverpool and University College London respectively. He has a special interest in the clinical management and pathophysiology of neonatal intraventricular hemorrhage / post hemorrhagic hydrocephalus and is co-investigator and lead for basic sciences on the DOLPHIN-UK trial, a randomized controlled trial investigating the impact of neuroendoscopic ventricular lavage on neurodevelopment.

### **Engin Deniz, MD**

Associate Professor, Pediatric Critical Care Medicine

### Yale University

engin.deniz@yale.edu

Dr. Engin Deniz is a physician-scientist trained in pediatric critical care medicine and developmental biology. His laboratory focuses on elucidating hydrocephalus' pathogenesis and utilizes mechanistic analyses of novel genes discovered in our patients presenting with congenital hydrocephalus (CH). Engin has developed a model system to study CH genes in frog Xenopus where he can realize "genes-to-functions screens" for the large number of candidate genes already identified in the literature. His lab aims to provide mechanistic studies to understand novel gene function at the molecular level and test drugs to reverse/recover

disease progression using Xenopus, for which high-throughput drug screens are amenable.

# Cecilia Dupecher, PhD Program Manager

### Department of Defense (DoD), Peer Reviewed Medical Research Programs (PRMRP)

mariacecilia.f.dupecher.civ@health.mil

Dr. Cecilia Dupecher currently serves as the Program Manager for the Peer Reviewed Medical Research Program (PRMRP), within the Congressionally Directed Medical Research Programs (CDMRP), U.S. Army Medical Research and Development Command. She is responsible for executing the PRMRP's entire program life cycle, including investment strategy, development of funding opportunities, overseeing review of research proposals, and analysis of PRMRP's accomplishments. She joined CDMRP in 2017 as science officer, providing scientific management and oversight to a portfolio of research awards focused on Infectious Diseases. Dr. Dupecher holds a PhD in Microbiology and Immunology from University of Sao Paulo, Brazil. She conducted her thesis research on invasion pathways and intracellular trafficking exploited by various pathogens, focusing on Trypanosoma cruzi and Coxiella hrunetii.

### Michael Edwards, MD

### Professor of Neurological Surgery and Pediatrics

### UC Davis School of Medicine

msbedwards@me.com

Dr. Michael S. B. Edwards, is a distinguished professor specializing in pediatric neurological surgery, focusing on pediatric brain tumors, fetal anomalies, hydrocephalus, and Al applications. With a career spanning UCSF, Stanford, and UC Davis Medical Center, he's known for pioneering

hydrocephalus techniques, creating a Pediatric Brain Tumor Research Lab, initiating a Family Support Group for hydrocephalus, which evolved into the Hydrocephalus Association, and leading innovations like 3D Printing for separating craniopagus twins. His education initiatives include a Post-Doctoral Pediatric Neurosurgery Fellowship program and multiple teaching awards.

### Ramin Eskandari, MD

#### **Associate Professor**

### Medical University of South Carolina

eskandar@musc.edu

Dr. Ramin Eskandari grew up in Ann Arbor, MI, where he received his BS in Biology/Neurobiology. He continued his education at Wayne State University in Detroit, MI, receiving his master's and medical degree, followed by neurosurgical training in Salt Lake City, UT. Dr. Eskandari joined the Medical University of South Carolina (MUSC) in 2014 after his pediatric neurosurgery fellowship at Stanford University. With 24 years of research, Dr. Eskandari founded the Pediatric Brain Injury and Hydrocephalus Laboratory at the Darby Children's Research Institute (DCRI) at MUSC focusing on novel medical treatment for pediatric hydrocephalus and brain injury. He serves on the Medical Advisory Board of the HA and has a strong passion for education and academics.

### Ryann Fame, PhD

### Assistant Professor of Neurosurgery

#### Stanford University

fame@stanford.edu

Dr. Ryann Fame joined the faculty of Stanford University in 2022. Early neural progenitors respond to extrinsic cues that maintain and support their potency. These stem/ progenitor cells are in direct contact with the cerebrospinal fluid (CSF), which acts as part of their niche. Her research program encompasses the early neural stem cell niche, neural tube closure, CSF, hydrocephalus, metabolism, and cortical neuronal development. She is dedicated to broad collaboration focused on translating an understanding of neurodevelopment and CSF biology into therapeutic strategies.

# Maria Garcia Bonilla, PhD Postdoctoral Researcher

### Washington University in St. Louis

mariag@wustl.edu

Dr. Maria Garcia Bonilla has a PhD in Cell and Molecular Biology in Neuroscience from the University of Malaga (Spain). She focused on developing a stem cell therapy for congenital hydrocephalus. Now, at Washington University in St. Louis along with Drs. McAllister and Limbrick, she has developed a large animal model of hydrocephalus for evaluating emerging CSF shunt technologies and ETV-CPC. Also, she is investigating the role of neuroinflammation on the molecular pathogenesis of pediatric hydrocephalus.

### Amanda Garzon, MA Chief Operations Officer

# **Hydrocephalus Association** amanda@hydroassoc.org

As the Hydrocephalus Association's (HA's) Chief Operations Officer, Amanda is responsible for developing and implementing operations strategies that allow HA to meet its strategic goals and vision. She works in partnership with the CEO and management team to find innovative ways to grow revenue that support the diverse research and patient-focused programs of the association.

She oversees the development and oversight of education and advocacy initiatives, patient-centered support services as well as the management and implementation of an aggressive communications and marketing strategy. Amanda's passion for the mission of the association stem from a personal connection to the condition as the mother of an adult daughter with hydrocephalus.

### June Goto, PhD

# Assistant Professor of Neurosurgery

#### **CCHMC**

june.goto@cchmc.org

Dr. June Goto is a neuroscientist researching the molecular and cellular mechanisms of perinatal brain development and how their maladaptation causes developmental brain disorders. Her lab is using rodent models to investigate neonatal hydrocephalus' genetic and cellular etiologies to find possible new therapeutic targets to improve neurocognitive outcomes. One of her discoveries is that the loss of motile cilia gene in rodent brains reduces cerebrospinal fluid flow and neonatal hydrocephalus with delayed neural cell maturation and neuroinflammation. Her pre-clinical trials in these animals suggest that medical treatment to suppress neuroinflammation via microglia can improve brain function, neuronal maturation and myelination in neonatal hydrocephalus.

# Diana Gray, MA President and CEO

### **Hydrocephalus Association**

diana@hydroassoc.org

Diana Gray is the President and CEO of the Hydrocephalus Association (HA). She has been working in the public health and nonprofit sectors for more than 30 years and began her tenure with HA in November 2015. In December 2017, Diana was elected to the National Health Council (NHC) Board of Directors and in 2021 served in the capacity of Board Chair. In addition, Diana was honored to join the Board of Directors for the Rudi Schulte Research Institute in May 2019. Diana has a Bachelor of Arts degree from Anderson University and a Master's degree in Counseling Psychology from Ball State University.

#### **Paul Gross, BS**

### President, CEO, & Co-Founder

#### Cerebral Palsy Research Network

paul@cprn.org

Paul Gross is a driving force in accelerating clinical and translational research in neuroscience for cerebral palsy and hydrocephalus. He is the President, CEO and Co-Founder of the Cerebral Palsy Clinical Research Network – a thirty center effort in North American to conduct high quality clinical research for CP. He is the co-founder of the Hydrocephalus Clinical Research Network and the former Board Chair of the Hydrocephalus Association. He spent four years as an advisor to the National Institute of Neurological Disorders and Stroke. He was a Senior Vice President with Microsoft and with Borland. In his personal life, he is married and the father of two children, one of whom has hydrocephalus and cerebral palsy. He is also an avid mountain biker.

# Mark Hamilton, MDCM, FRCSC

#### Professor of Neurosurgery

#### **University of Calgary**

mghamilton.hydro@gmail.com

Dr. Mark G. Hamilton, MDCM, FRCSC, FAANS, is from the University of

Calgary, Cumming School of Medicine, Department of Clinical Neurosciences, Division of Neurosurgery. He is currently a professor of neurosurgery with additional appointments in the Department of Surgery and the Department of Pediatrics. He is head of the University of Calgary Adult Hydrocephalus Program, the Chair of the Adult Hydrocephalus Clinical Research Network (AHCRN), Past-President of the Hydrocephalus Society (International Society for Hydrocephalus and Cerebrospinal Fluid Disorders (ISHCSF), a member of the Board of Directors of the Hydrocephalus Association (HA), Vice Chair of the Medical Advisory Board (MAB) of HA. He is Co-Editor-in-Chief of Fluids and Barriers of the CNS.

### Carolyn Harris, PhD

Associate Professor, Department of Chemical Engineering and Materials Science

#### Wayne State University

caharris@wayne.edu

Dr. Carolyn Harris is currently an Associate Professor at Wayne State University in Detroit, Michigan. She is broadly interested in understanding neuroinflammation and cellbiomaterial interactions in neurological conditions. Using translational research, bench top 3D culture models, and high-throughput microfluidic models, Dr. Harris works to understand variable degrees of neuroinflammation and CSF dynamics and how they contribute to shunt failure. Dr. Harris received her bachelor's degree from Purdue University and her PhD from the University of Utah. She then completed a postdoctoral fellowship at Seattle Children's Research Institute's Center for Integrative Brain Research.

### → Daniel Harris, MS Principal Software Engineer

#### Amazon.com Inc

danimal@amazon.com

Daniel Harris is a Principal Software Engineer at Amazon with 16 years of experience in the fields of software engineering and machine learning (ML). Dan led the launch of the Amazon Selling Partner APIs, used by 800,000 Amazon Sellers to manage their business. Dan has expertise in networking, security, evolvable architecture, code quality, and language design, and has applied ML to domains spanning privacy, risk, negotiation, and business optimization. He has also standardized ML best practices across the company. Prior to Amazon, Dan worked in the video game industry, notably leading the networking team for Bungie's Destiny. Dan holds a BSE in Computer Science from the University of Michigan and a MS in Computer Science from Purdue University, specializing in ML, both Summa Cum Laude.

# Christine Hehnly, PhD Postdoctoral Research Fellow

### **Boston Children's Hospital**

christine.hehnly@childrens.harvard.edu

Dr. Christine Hehnly's overall research interests are the molecular pathology of how neuroinflammation and infection during development contribute to the development of post infectious hydrocephalus (PIH). Her research goals are twofold 1) precision diagnostics for hydrocephalus before its development and 2) choroid plexus regulation of neuroinflammation.

### Alexandra Hochstetler, PhD

### Postdoctoral Research Fellow, Pathology, Neurobiology

### Boston Children's Hospital

alexandra.hochstetler@childrens. harvard.edu

Dr. Alexandra Hochstetler is a postdoctoral fellow in the laboratory of Dr. Maria Lehtinen, where she is working on a number of projects involving white matter injury and demyelination. Her primary research interest is white matter injury in post-hemorrhagic and post-infectious hydrocephalus of prematurity. Her current project investigates the role of the choroid plexus in instructing myelination of the central nervous system in mouse models. She is also helping to establish a greater understanding of the pig and human choroid plexus transcriptomes. As a part of this work, she is training in piglet neurosurgical techniques, with a specific focus to test the laboratory's ChP-targeted therapies in a piglet model of intraventricular hemorrhage.

# Young-Kwon Hong, PhD

#### Professor

### University of Southern California

Young.hong@usc.edu

Dr. Young-Kwon Hong is a professor of surgery, Keck School of Medicine, at the University of Southern California (USC). He currently serves as the Chief of Division of Basic Sciences for Department of Surgery and Director of Basic and Translational Sciences. Dr. Hong completed his doctoral studies at the University of California, Davis, where he obtained his doctoral degree. He furthered his training as a post-doctoral fellow at the Harvard Institute of Human Genetics. Following this, he

was appointed as an Instructor at Harvard Medical School and Massachusetts General Hospital until 2005. In 2005, he joined the Keck School of Medicine at USC. His primary focus of research revolves around the molecular mechanisms that regulate lymphatic development and diseases.

### Christopher Janson, MD

Associate Professor, Neuroscience & Cell Biology

### Rowan University and NJ Institute for Successful Aging

janson@memorymatters.org

Dr. Christopher Janson's research laboratory focuses on vascular factors in neurodegeneration, including the role of the physiological brain barriers. Dr. Janson completed his undergraduate training in biological sciences at Stanford University and medical school at Yale University, followed by a postdoctoral fellowship in gene therapy at Thomas Jefferson University. He received additional clinical research training at UMDNJ-Robert Wood Johnson Medical School, where he was recipient of the NORD Roscoe Brady Fellowship and a principal co-investigator on the first NIH sponsored human gene therapy for a neurodegenerative disease. Dr. Janson completed residency training in the clinical neurosciences at the University of Minnesota.

# Lauren Jantzie, PhD Associate Professor

#### Johns Hopkins University

ljantzie@jhmi.edu

Dr. Lauren Jantzie is a neuroscientist whose independent research program serves a medically disadvantaged patient population that includes infants and children with early brain injury living in metro, rural and economically depressed communities.

The Jantzie lab is dedicated to understanding the pathophysiology, diagnosis and treatment of central nervous system insults that result in cerebral palsy, hydrocephalus, pain, and neuropsychiatric disorders. The goal of Dr. Jantzie's laboratory is to identify novel drug targets, agents, biologics and cell-based therapeutics to facilitate neurological recovery and brain repair. Through diverse, expansive and translational mechanistic studies and preclinical modeling, she is able to connect her research program to clinical practice on a daily basis.

# Sheng Chih (Peter) Jin, PhD Assistant Professor of Genetics

# Washington University in St. Louis jin810@wustl.edu

The Sheng Chih (Peter) lab has a mission to provide meaningful and interpretable insight into disease biology, and define new targets for risk determination, prevention, and therapy. Dr. Jin currently focuses on the formation, development, and application of genetic, genomic, and bioinformatics methods to better analyze and integrate genome sequencing, single-cell RNA-sequencing, epigenomic, spatial genomic, and proteomic data. Through integration of diverse types of omics data and epigenetic functional annotations, the integrated analysis will provide a better understanding of the molecular and cellular basis of cardiovascular diseases and neurological disorders. Following integrative genomic analyses, he uses zebrafish and massively parallel reporter assays to precisely model human mutations.

# Mark Johnson, MD, PhD Chair and Professor, Neurological Surgery

### **UMass Chan Medical School**

mark.johnson3@umassmemorial.org

Dr. Mark Johnson is a widely-known expert in the management of brain

tumors and is the director of programs for adult hydrocephalus and neurosurgical pain management. Dr. Johnson is also a senior consulting vice provost for mentorship, leadership and transformation of UMass Medical School and directs the UMass Medical School residency program in neurological surgery. In addition to his clinical practice, Dr. Johnson leads a translational research lab focused on adult hydrocephalus and on the genomics, cell biology and treatment of brain tumors. Prior to his role at UMass, Dr. Johnson was an associate neurosurgeon at Brigham and Women's Hospital and an Associate Professor of Neurosurgery at Harvard Medical School.

### Davis Kaderli, BA

# Advocacy Engagement Manager Hydrocephalus Association

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As the Advocacy Engagement Manager, Davis is responsible for overseeing the advocacy initiative and strengthening HA's relationship with federal, state, and local lawmakers. He oversees policy research, works to maintain the Congressional Pediatric and Adult Hydrocephalus Caucus, and tracks relevant legislation that is crucial to the hydrocephalus community.

### Kristopher Kahle, MD, PhD

Director of Pediatric Neurosurgery, Director of Harvard Center for Hydrocephalus and Neurodevelopmental Disorders

#### Massachusetts General Brigham Hospital

kahle.kristopher@mgh.harvard.edu

Dr. Kristopher T. Kahle, is the Nicholas T. Zervas Associate Professor of Neurosurgery at Harvard Medical School (HMS), Chief of Pediatric Neurosurgery at the Massachusetts General Hospital (MGH), and Director of the MGH Hydrocephalus & Neurodevelopmental Disorders Program. He is an Investigator in the Division of Genetics & Genomics at Boston Children's Hospital (BCH) and Associate Member of the Broad Institute. He is a board-certified pediatric neurosurgeon specializing in treatment of congenital anomalies of the nervous system in patients across the age spectrum. He is a fellow of the American Association of Neurological Surgeons, Congress of Neurological Surgeons, American Society of Pediatric Neurosurgeons, and the International Society of Pediatric Neurosurgeons.

# Richard Keep, PhD Professor

### University of Michigan

rkeep@umich.edu

Dr. Richard Keep's work primarily is preclinical, focusing on hemorrhagic stroke (including intraventricular hemorrhage), the blood-brain barrier and the CSF system (choroid plexus). He also conducts clinical MRI studies focusing on hemorrhagic stroke.

### John Kestle, MD

### Professor of Neurosurgery/Vice Chair of Clinical Research

#### University of Utah

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Dr. John R.W. Kestle, is a professor of neurosurgery and Vice Chair of Clinical Research at the University of Utah. His clinical practice has been exclusively in pediatric neurosurgery, with a specific interest in hydrocephalus. His research is centered on clinical trials in hydrocephalus as Co-Founder and Chair of the Hydrocephalus Clinical Research Network.

# Kevin King, MD Professor of Neuroradiology

# Barrow Neurological Institute kking@sniweb.net

Dr. Kevin King is a neuroradiologist with an interest in learning more about neurologic disease and brain aging through automated image analysis. Currently he is developing tools for automated identification of normal pressure hydrocephalus and utilization of advanced imaging to better diagnose shunt responsiveness.

### Pengfei Liang, PhD Postdoctoral Associate

# **Duke University Medical Center** pengfei.liang@duke.edu

Dr. Pengfei Liang's research interests are ion channels and their roles in both physiological and pathological processes. Dr. Pengfei is currently affiliated with Huanghe Yang Lab at Duke University. Their primary research interests lie in understanding the physiological and pathological significance of ion channels in post-hemorrhage-induced hydrocephalus. By exploring the involvement of ion channels in this condition, they aim to unravel their contributions to the development and progression of hydrocephalus, potentially leading to the identification of novel therapeutic targets.

### David D. Limbrick, Jr., MD, PhD

Executive Vice Chair, Department of Neurosurgery; Chief, Division of Pediatric Neurosurgery

### Washington University in St. Louis

limbrickd@wustl.edu

Dr. David D. Limbrick, Jr., is the T.S. Park Chair and Chief of Pediatric Neurosurgery and Executive Vice Chair of Neurological Surgery at Washington University. He also serves as Neurosurgeon-in-Chief at St. Louis Children's Hospital. Dr. Limbrick received his MD and PhD from the Medical College of Virginia and completed his residency in neurosurgery and fellowship in pediatric neurosurgery at Washington University/BJH/SLCH. He is certified by both the American Board of Neurological Surgery and the American Board of Pediatric Neurosurgery. Dr. Limbrick's research focuses on pediatric cerebrospinal disorders and is funded through NIH/ NINDS and PCORI. He has published 180 peerreviewed articles and has led several federally funded clinical trials.

# Mark Luciano, MD, PhD Professor of Neurosurgery Johns Hopkins University

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Dr. Mark Luciano is the Director of the Johns Hopkins Hydrocephalus and Cerebral Fluid Center. A renowned leader in treating hydrocephalus, Dr. Luciano is distinguished both nationally and internationally for his research and educational and clinical work in neuroendoscopy. Dr. Luciano treats adults with hydrocephalus, pseudotumor cerebri, intracranial hypotension, Chiari malformations, and cerebral and spinal cysts. He has significant expertise treating children and adults with cerebrospinal fluid leaks and congenital disorders.

### Francesco Mangano, DO

### Chief, Division of Pediatric Neurosurgery

### Cincinnati Children's Hospital Medical Center

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Research in the Francesco Mangano Lab is directed at understanding pathogenesis of pediatric hydrocephalus, which will lead Dr. Mangano to develop new surgical and medical treatment options and to improve patient outcomes and quality of life. To establish these goals, he studies essential brain anatomy, neural cell types, and genes involved in pediatric hydrocephalus utilizing advanced MR imaging methods (diffusion tensor imaging), mouse genetic models, and several surgical techniques.

### Heidi Mayer, BBA

#### **Executive Director**

### Theodore W. Batterman Family Foundation

bffgiving@gmail.com

As Executive Director, Heidi is honored to be representing the Theodore W. Batterman Family Foundation. They are interested in learning more about hydrocephalus accelerated research projects and non-invasive targets for hydrocephalus for potential future funding support of the Hydrocephalus Association.

### Pat McAllister, PhD

Professor, Neurosurgery

### Washington University in St. Louis

pat.mcallister@wustl.edu

Dr. Pat McAllister is an experimental neuroscientist, his research involves interdisciplinary, translational approaches that advance understanding of the pathophysiology of hydrocephalus in order to improve treatments for this disorder. These efforts began in 1983 and continue with Drs. Dave Limbrick, Maria Garcia Bonilla, and Carolyn Harris, amongst others. Pat received his PhD from Purdue University in 1976 and the Robert H. Pudenz Prize for Excellence in Cerebrospinal Fluid Physiology and Hydrocephalus in 2005, and he

currently serves on the Medical Advisory Board of the Hydrocephalus Association. He remains dedicated to the training of students and colleagues, and has mentored numerous clinicians and neuroscientists who treat and investigate hydrocephalus.

### Gordon McComb, MD

#### Professor of Neurological Surgery, **Pediatrics**

### Children's Hospital Los Angeles gmccomb@chla.usc.edu

Dr. Gordon McComb's accomplishments in neuroscience research and biomedical engineering are his investigation of the cerebrovascular response to hydrocephalus and the invention of a unique device for control of intracranial pressure (ICP) pulsatility to increase blood flow. His National Institutes of Healthfunded studies have explored prolonged compression and hypoxia in the brain as a result of hydrocephalus, as well as the interaction between cerebrospinal fluid and vascular systems.

### Brandon Miller, MD, PhD **Associate Professor**

#### **UTHealth Houston**

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Dr. Brandon Miller is an avid researcher and the principal investigator on a NIH Clinical Investigator Award focused on developing new treatments for IVH and hydrocephalus. Dr. Miller received his PhD in neuroscience and MD from The Ohio State University. He completed his residency in neurosurgery at Emory University School of Medicine, followed by a fellowship in pediatric neurosurgery at Washington University in St. Louis and St. Louis Children's Hospital. He joined UTHealth Houston Neurosciences and Children's Memorial Hermann Hospital from the University of Kentucky Departments of Neurosurgery and Neuroscience, where he was the director

of the Pediatric Brain Injury Laboratory at the Spinal Cord and Brain Injury Research Center and co-director of the MD/PhD program.

### Janet Miller, MPA Retired

### Johns Hopkins University Baltimore, MD

janetathome200@comcast.net

Janet attended California State Teacher's College in California, PA from 1968-1972. In 1973, she relocated to Southern California and worked in various industries before becoming the Consumer Affairs Specialist for the City of Santa Monica during which time she also was a talk show host for KCRW, the local NPR affiliate. In 1979, Janet moved to CA's Central Valley to work for Stanislaus County and ran their Alternative Sentencing Program and later their self-funded and self-insured health plans. In 1989, Janet obtained a Master's in Public Administration, qualified as a Presidential Management Fellow, and returned to the east coast for a job with the Centers for Medicare & Medicaid Services (CMS). At CMS, Janet initially recovered trust fund money (MSP) from fraudulent entities. She later focused on education and outreach about Medicare programs, targeting organizations that represent beneficiaries with disabilities and/or chronic illnesses. Janet now spends time cooking, traveling, and being grateful for successful surgeries and second chances

### Abhay Moghekar, MBBSA Associate Professor of Neurology Johns Hopkins University am@jhmi.edu

Dr. Abhay Moghekar is the Research Director of the Center for CSF Disorders at Johns Hopkins Hospital. Clinically he focuses on seeing patients with disorders of cerebrospinal fluid physiology like

normal pressure hydrocephalus, obstructive hydrocephalus, congenital hydrocephalus, pseudotumor cerebri, csf otorrhea, CSF rhinorrhea, intracranial hypotension due to spinal CSF leaks and peri-operative management of patients undergoing repair of CSF otorrhea and rhinorrhea. His research interests include identifying biomarkers and pathway analysis of neurodegenerative disorders including Alzheimer's disease and Normal Pressure Hydrocephalus. An additional area of interest includes understanding the epidemiology of CSF disorders.

### Jill Morris, PhD Program Manager

### NIH, National Institute of Neurological Disorders and Stroke (NINDS)

jill.morris@nih.gov

Dr. Jill Morris joined NINDS in 2011 and is a Program Director in the Division of Neuroscience at NINDS. She oversees basic grants in technology development for gene-targeted therapies, glia biology and neural tube development. She is also responsible for disease grants in hydrocephalus, neural tube defects, Tourette syndrome and multiple rare neurological disorders. Furthermore, Dr. Morris is the NINDS liaison for the Rare Disease Clinical Research Network (RDCRN) an initiative of the Office of Rare Disease Research (ORDR), NCATS in collaboration with NINDS. Prior to coming to the NIH, Dr. Morris was an assistant professor at Northwestern University. Her laboratory studied the function of DISC1, a schizophrenia susceptibility gene.

### Ronald Parchem, PhD

Assistant Professor, Department of Molecular and Cellular Biology

### **Baylor College of Medicine**

ronald.parchem@bcm.edu

The Parchem lab studies human disease using a combination of in vivo and in vitro

development and disease modeling. This work includes research on embryopathies, with a specific focus on neurodevelopmental defects. The Parchem lab's neurodevelopmental defect studies have been primarily dedicated to the neural tube, where they have found that neural tube differentiation, morphogenesis and metabolism are regulated by the microRNA family miR-302. The lab has further shown that miR-302 controls the developmental potential and chromatin accessibility of cranial neural crest cells by regulating the expression of transcription factors and chromatin modifiers using a single-cell approach. Their current work has identified a role for post-transcriptional regulation by microRNA in the pathogenesis of congenital hydrocephalus.

# Boryana Petrova, PhD Instructor, HMS

### Boston Children's Hospital

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Dr. Boryana Petrova is a broadly trained research scientist, with experience in cell and molecular biology, genetics, imaging, diverse model organisms, and LC-MS and metabolomics. She currently holds a position of instructor at Harvard Medical School and staff scientist in the lab of Dr. Naama Kanarek at Boston Children's Hospital. Dr. Boryana has dedicated herself to establishing a world-class metabolomics platform, focusing on methos development and diverse metabolism studies within the lab and with many collaborators. Dr. Boryana has broad expertise in metabolomics from vitamin and cofactor metabolism through redox metabolism, cancer and neuro metabolism etc., as well as in multiple systems such as model organisms, tissues and tissue culture, bio specimens from patient cohorts (such

as plasma or CSF).

### Arjun Rajan, BSE

# Graduate Student in Developmental Biology

### **Stanford University**

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Arjun Rajan is a graduate student in the department of developmental biology conducting research in Dr. Ryann Fame's lab at Stanford University. The Fame group studies how the chromatin state changes during neural tube closure and the role of chromatin remodelers, some of which are known congenital hydrocephalus risk genes, in neural tube closure. Arjun is interested in brain development and genomics, and hopes to understand how dynamic gene expression controls neural tube closure as well as how cerebrospinal fluid influences early brain development. The Fame group research applies genomics techniques such as single-cell RNA-seq and assays such as CUT&RUN and ATAC-seq to understand the at the chromatin level how genes are regulated during neural tube closure.

### Makenna Reed, BA

## PhD candidate Biology Department

#### **Indiana University**

reedmak@iu.edu

Makenna Reed's current project focuses on elucidating common cell and molecular mechanisms between different hydrocephalic animal models with the goal of developing drug candidates that target channels, transporters, or kinases with the hope of moving this research towards clinical trials.

### Daniela Robles, BS

### Atlanta WALK Chair, Hydro Mom

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Daniela Robles is the mother of a 2-year-old child with acquired hydrocephalus shunted at 21 days old. Her background in biochemistry and molecular biology provided her with a foundation to understand how precarious her child's day to day status really is. Daniela states "It's astounding that the treatment and diagnostic options are so invasive and often unreliable - that's why I'm thrilled to see the advances in noninvasive wearables and treatments in development. I hope to use my scientific understanding, experience as a Hydro mom, and connections in the VC funding space to help."

### Liudmila Romanova, PhD

# Assistant Professor, Department of Neurological Sciences

### **Rush University**

liudmila\_romanova@rush.edu

Dr. Liudmila Romanova's research focus is on the role of endothelial and epithelial tissues of the brain in health and neurological disorders. She received PhD in biochemistry from Lomonosov Moscow State University (Russia) followed by postdoctoral training in University of Pennsylvania and University of Minnesota. She started as an assistant professor and K01 scholar at RUMC in 2019 in the Department of Neurological Sciences under mentorship of Dr. Jeffrey Kordower. Current projects in the lab explore contribution of CSF-blood barrier to development of age-related neurodegeneration in Alzheimer's and Parkinson's. Specific emphasis in research is put on application and development of advanced imaging using confocal and electron microscopy for rodent, non-human primate and human tissues.

# Maria Grazia Ruocco, PhD Project Manager, Neuroscience

#### **Brown University**

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Dr. Maria Ruocco is overseeing a multidisciplinary normal pressure hydrocephalus (NPH) research study at Brown University to understand the molecular basis of NPH using omics approaches and machine learning models. Dr. Ruocco began her academic career by earning her master's degree from Universita' Federico II in Naples. She pursued her graduate studies at UCSD jointly with the University of Vienna, and was a postdoc at NYU. She was awarded by Marie Curie Actions to relocate to Paris and earned an MBA from Hult. Back to the U.S., Dr. Ruocco co-founded Adelle Diagnostics Inc., a startup company affiliated with Brown. Throughout her career, Dr. Ruocco has engaged in human and non-human research, published peer-reviewed research articles, and worked for the biotech industry, blending her multidisciplinary experiences and interests.

# Cameron Sadegh, MD, PhD Assistant Professor

#### University of California

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Dr. Cameron Sadegh completed his MD and PhD degrees in the Harvard/MIT Medical Scientist Training Program, building expertise in stem cell biology, neurodevelopment, and neuroanatomy. Midway through his residency, he worked as a lab instructor in neuroanatomy at Harvard Medical School and completed a research fellowship at Boston Children's Hospital, studying the cellular mechanisms of hydrocephalus and potential CSF-based therapies.

### Simon Shim, PhD

### Assistant Professor of Biomedical Engineering

#### **Marshall University**

shim@marshall.edu

Dr. Simon Shim is a biomedical engineer with interests in genetics and epigenetic instruction contributing to hydrocephalus of all ages. He currently studies human postmortem tissues to better understand gene expressions and DNA methylations in the brain tissues donated from patients with hydrocephalus and other age-related conditions.

# Associate Professor of Neurosurgery

# Washington University in St. Louis strahlej@wustl.edu

Dr. Jennifer M. Strahle is a neurosurgeonscientist at St. Louis Children's Hospital. She is an associate professor of neurosurgery at Washington University in St. Louis. Her laboratory investigates developmental CSF-brain interactions. Her lab also studies the mechanisms of neonatal intraventricular hemorrhageinduced hydrocephalus, including the role of iron and hemoglobin. Her research is (and has been) supported by an NIH R01, NRCDP K12, Doris Duke Foundation, and multiple foundation grants. She is the Co-PI of the multicenter Synostosis Research Group, a member of the Hydrocephalus Clinical Research Network. and on the scientific education and advisory board of the Chiari and Syringomyelia Foundation.

# Stavros Taraviras, PhD Professor

### Medical School, University of Patras

taraviras@med.upatras.gr

Dr. Stavros Taraviras is a professor in the department of physiology at the Medical School, University of Patras, Greece. He holds a PhD from the University of Heidelberg, Germany and postdoctoral research appointments at the German Cancer Research Center in Heidelberg and the MRC/National Institute for Medical Research (The Francis Crick Institute), London, UK.

His research group focuses on how extrinsic and intracellular signalling cues regulate stem/progenitor cell differentiation decisions and organogenesis and how these mechanisms participate in the pathogenetic mechanisms of human disease. Currently the main focus of his lab is the characterization of signaling cues governing ependymal cell determination and the identification of novel therapies for hydrocephalus in humans.

### **Bradley Weprin, MD**

Professor in the Division of Pediatric Neurosurgery in the Department of Neurological Surgery

# **UT Southwestern Medical Center** bradley.weprin@utsouthwestern.edu

Dr. Bradley Weprin is a professor in the Division of Pediatric Neurosurgery in the Department of Neurological Surgery at UT Southwestern. At Children's Health, he serves as Director of Pediatric Neurosurgery and Director of Neurooncology. His current research projects include long-term follow-along care for children with acquired brain injuries, radiographic features following Gamma Knife radiosurgery for AVMs in children, treatment of diffuse intrinsic pontine gliomas, radiographic findings of spinal cord injury in inflicted head injury of infants, neurobehavioral and social outcomes of head injuries in adolescents, and determination of infection rates for a particular type of catheter when used in shunt systems for the treatment of hydrocephalus.

### Tessa van der Willigen, MPhil, MAPP

**Visiting Scholar** 

#### **Georgetown University**

tessavanderwilligen@gmail.com

Tessa van der Willigen has trained successively in zoology, economics, psychology, and mindfulness teaching. She had a long career at the International Monetary Fund, culminating in the position of Chief of Staff. Tessa is currently a visiting scholar in the Psychology Department at Georgetown University, conducting research focused on autonomy, authenticity, and well-being. She has an adult son with hydrocephalus, and is a Co-Chair of HA's Research Committee and Chair of its Finance Committee.

### Michael Williams, MD

### Professor of Neurology and Neurological Surgery

### University of Washington

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Dr. Michael Williams is Chair of the Hydrocephalus Association Medical Advisory Board. He has career expertise in adult hydrocephalus and has actively promoted and participated in research in hydrocephalus for more than 30 years. His background also includes biomedical ethics. Dr. Williams was Co-Chair of the Ethics Committee at Johns Hopkins Hospital, and Chair of the American Academy of Neurology Ethics, Law and Humanities Committee.

### Miriam Zamorano, PhD

Research Scientist

### UT Health Science Center Houston

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Dr. Miriam Zamorano is completing research on the inflammatory profile around IVH, and the effects of the injury on short and long term on cellular and connectivity levels as well testing possible compounds to diminish inflammation and its long term effect.

#### **UPCOMING EVENTS HOSTED BY THE HYDROCEPHALUS ASSOCIATION**



### National Conference on Hydrocephalus HA CONNECT

Virtual

#### November 3-5, 2023

Join the largest worldwide online conference about hydrocephalus!

Gain invaluable insights and knowledge that can make a real difference in your life or the life of a loved one. Our program is packed with informative sessions and engaging discussions. You'll have the chance to learn from leading professionals and discover new strategies for managing hydrocephalus.

#### Learn more:

hydrocephalusconference.org



### Hydrocephalus Association 40<sup>th</sup> Anniversary Gala

Anaheim, California

#### November 10, 2023

Join us as we celebrate 40 years of impact, dedication, and support for our community.

Enjoy live entertainment, delicious cuisine and drinks, silent and live auctions with unique items and experiences, and opportunities to connect with fellow community members and raise critical funds to change the future of hydrocephalus!

#### Learn more:

benefit.hydroassoc.org



# Innovator Award Grant Cycle

#### Cycle opens February 2024

The Hydrocephalus Association proudly awards grants to brilliant scientists to fund their high-impact research projects with the potential to transform the field of hydrocephalus through the understanding of disease mechanisms and the development of novel therapies.

#### Learn more:

hydroassoc.org/ha-grants

# Notes



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