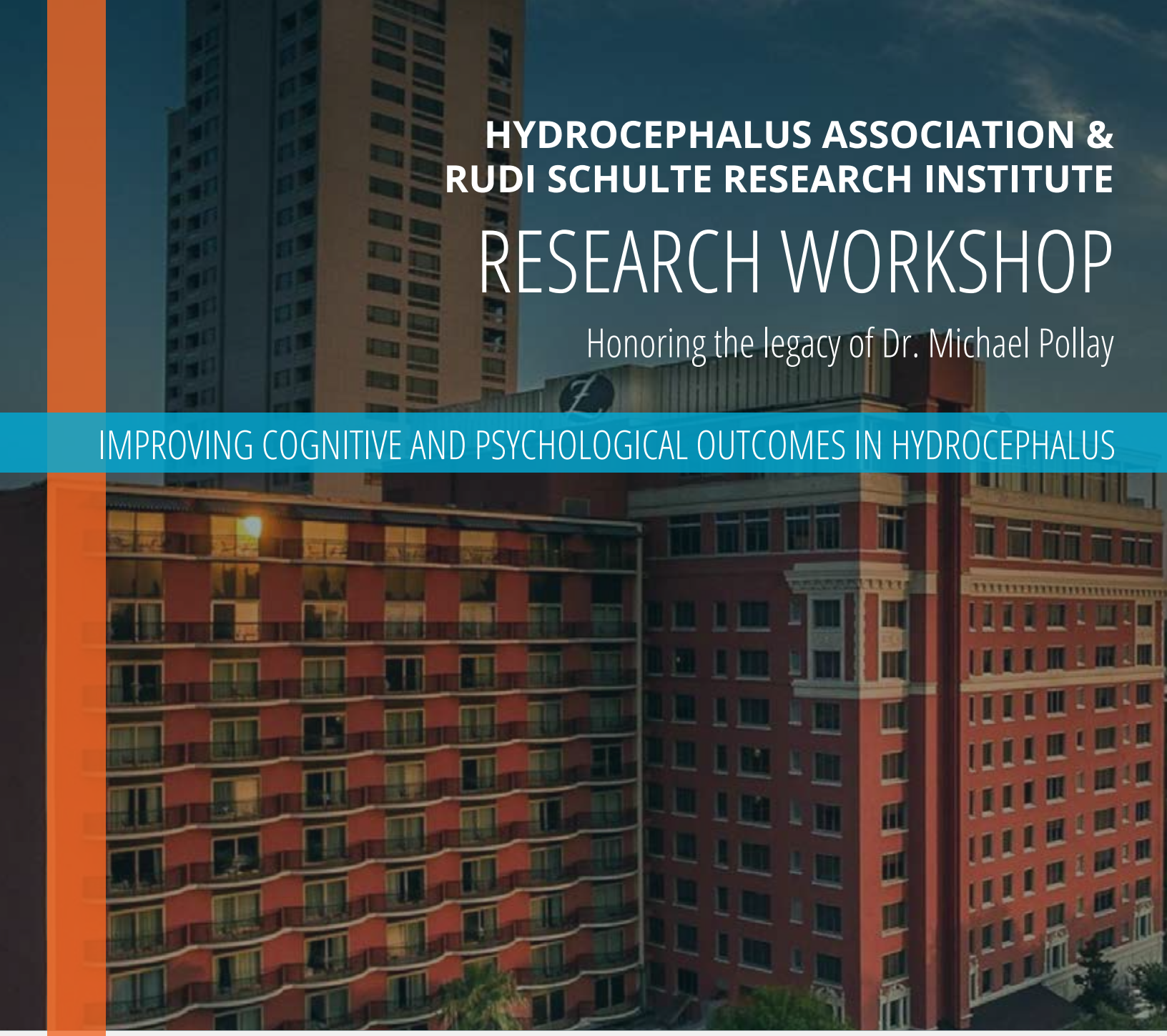

HYDROCEPHALUS ASSOCIATION & RUDI SCHULTE RESEARCH INSTITUTE

RESEARCH WORKSHOP

Honoring the legacy of Dr. Michael Pollay

IMPROVING COGNITIVE AND PSYCHOLOGICAL OUTCOMES IN HYDROCEPHALUS

Thursday, October 20, 2022
7:30 AM - 6:30 PM

Friday, October 21, 2022
7:30 AM - 3:30 PM

Hydrocephalus Association

Hotel ZaZa
5701 Main Street
Houston, Texas, 77005

Welcome Letter:
From HA President and CEO, Diana Gray

Planning Committee

Vera Joanna Burton, MD, PhD
Kennedy Krieger Institute

Nickolas Dasher, PhD
University of Washington

Maria Garcia Bonilla, PhD
Washington University in St. Louis

Mark Hamilton, MDCM, FRCSC
University of Calgary

Lauren Jantzie, PhD
Johns Hopkins University

David Limbrick, MD, PhD
Washington University in St. Louis

Francesco Magano, DO
Cincinnati Children's Hospital Medical Center

Jill Morris, PhD
National Institutes of Health

Shenandoah Robinson, MD
Johns Hopkins University

Jennifer Strahle, MD
Washington University in St. Louis

Michael Williams, MD
University of Washington

Andrew Zabel, PhD
Kennedy Krieger Institute

Welcome to the Hydrocephalus Association (HA) & Rudi Schulte Research Institute (RSRI) 2022 Research Workshop, Improving Cognitive and Psychological Outcomes in Hydrocephalus. HA is thrilled to be able to host this important meeting through the generous support of the RSRI. This workshop has been dedicated to the legacy of Dr. Michael Pollay, friend of Rudi Schulte and long-time RSRI board member until he passed away in February 2021. As we begin this workshop, you will hear 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.

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. Last year, HA wrapped up a comprehensive, patient-centered study to determine the top 20 research priorities for our community. While it was expected that better treatments, fewer surgeries and prevention would top the list, it was profoundly evident that patients care deeply about the complications of living with hydrocephalus that are caused by cognitive challenges with memory, 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.

Our assignment over this two-day workshop is to collaboratively explore the breadth of research in cognitive and neuropsychological assessment, function, modeling, biomarkers, and treatments for children and adults living with hydrocephalus, focusing on areas that hold the most promise for new therapies and improved outcomes. We anticipate active discussion and debate throughout the two days, and expect the proceedings from this workshop to be presented in a white paper, and published in a peer-reviewed journal. Insights from this workshop will inform HA's strategic priority of improving the lives of those living with hydrocephalus at every stage of life.

Thank you for joining us in this pursuit and for sharing your expertise through this collaborative workshop!

Sincerely,

Diana Gray, MA
President and Chief Executive Officer
Hydrocephalus Association

HA & RSRI Research Workshop Agenda

Wednesday, October 19, 2022 | Room: Ultimate Ransom

7:00 PM *Evening Welcome Reception at Hotel Zaza*
Room: Ultimate Ransom

Thursday, October 20, 2022 | Room: Room with a View & Grapevine

7:30 AM *Breakfast and Registration Open*

8:00 AM *Welcome, Introduction, and Breakfast*
Speakers: Diana Gray, MA | Peggy Pollay, RN | Gordon McComb, MD | Monica Chau, PhD | Michael Williams, MD

SESSION 1: BASIC & TRANSLATIONAL SCIENCE

A. BIOMARKERS AND IMAGING THAT TRACK WITH COGNITIVE FUNCTION

MODERATOR: MICHAEL WILLIAMS, MD

8:30 AM Quantitative Structural MRI Findings in Spina Bifida Myelomeningocele: Associations with Hydrocephalus, Attention, and Intellectual Outcomes
Speaker: Victoria Williams, PhD

9:00 AM Substrates of Cognition: The Nexus Between Neural Networks and Immune Function in Hydrocephalus
Speaker: Lauren Jantzie, PhD

9:30 AM Predicting Neurocognitive Outcomes in Posthemorrhagic Hydrocephalus: Insights from CSF and Imaging Biomarkers
Speaker: Jennifer Strahle, MD

10:00 AM Break

B. ANIMAL MODELS FOR COGNITIVE AND PSYCHOLOGICAL ASSESSMENT

MODERATOR: FRANCESCO MANGANO, DO

10:30 AM Large Animal Cognitive Testing in Hydrocephalus
Speaker: María García Bonilla, PhD

11:00 AM Neonatal Motor Skill Tests in Rodent Model of Perinatal Brain Disorders
Speaker: June Goto, PhD

11:30 AM Toward better animal models: Integrating measures of brain activity with translational behavior
Speaker: Jonathan Brigman, PhD

12:00 PM Lunch
Spoken Word: Dani Lucchese, PhD

SESSION 2: COGNITIVE AND PSYCHOLOGICAL PHENOTYPES

A. PEDIATRIC HYDROCEPHALUS ASSESSMENT

MODERATOR: LAUREN JANTZIE, PHD

1:00 PM Cognitive and Neural Phenotypes in Pediatric Hydrocephalus
Speaker: Jack Fletcher, PhD

1:30 PM Early Detection of Motor Impairments in Post Hemorrhagic Hydrocephalus
Speaker: Vera Joanna Burton, MD, PhD

2:00 PM Early Detection of Cognitive Impairment in Post Hemorrhagic Hydrocephalus
Speaker: Gwendolyn Gerner, PsyD

2:30 PM **Break**

B. ADULT HYDROCEPHALUS, NPH

MODERATOR: MARK HAMILTON, MDCM, FRCSC

Intro: Changing the Outcome Paradigm for Adult Hydrocephalus Care

3:30 PM Neuropsychological Considerations with Unrecognized Congenital Hydrocephalus in Adults
Speaker: Nickolas Dasher, PhD

4:00 PM Remembering to Remember in Daily Life
Speaker: Steven Woods, PsyD.

4:30 PM Neuropsychological Performance and Neuropsychiatric Changes in Adults with Idiopathic NPH
Speaker: Irene Piryatinsky, PhD, ABPP-CN

6:30 PM Group Dinner at Sixty Vines (2 mi)
2540 University Blvd, Houston, TX 77005

HA & RSRI Research Workshop Agenda (cont.)

Friday, October 21, 2022 | Room: Room with a View & Grapevine

7:30 AM *Breakfast and Registration Open*

8:15 AM *Welcome and Breakfast*

SESSION 3- TRANSITIONS, TREATMENT AND QUALITY OF LIFE

A. DEVELOPMENTAL TRANSITIONS

MODERATOR: VERA JOANNA BURTON, MD, PHD

8:30 AM Functional and Developmental Transitions in Youth with Hydrocephalus: Considerations for Psychometric Assessment and Phenotype Definition
Speaker: Andrew Zabel, PhD

9:00 AM Post-Traumatic Stress in Pediatric Hydrocephalus
Speaker: Brandon Rocque, MD

9:30 AM The Development of Self-Management in Youth with Spina Bifida: Family and Neuropsychological Factors
Speaker: Grayson Holmbeck, PhD

10:00 AM **Break**

B. TREATMENT AND QUALITY OF LIFE

MODERATOR: NICKOLAS DASHER, PHD

10:30 AM Neurorestoration in Preclinical Model of Post Hemorrhagic Hydrocephalus of Prematurity
Speaker: Shenandoah Robinson, MD

11:00 AM Potential Role for Biomarkers and Neurocognitive Assessments in Parsing NPH from Other Neurodegenerative Disorders
Speaker: Abhay Moghekar, MB

11:30 AM Quality of Life: NPH & Meaningful Occupations
Speaker: Nancy Carlson, PhD, OTR/L

12:00 PM **Lunch**

SESSION 4 - MOVING THE FIELD FORWARD

1:00 PM Patient Perspective - Panel
Spoken Word: Robin Ennis, MSW
Speakers: Robin Ennis, MSW | Dani Lucchese, PhD | Amanda Garzon, MA | Gary Chaffee, MS
Facilitator: Monica Chau, PhD

2:30 PM Whole Group Discussion: How to Move the Field Forward
Facilitator: Michael Williams, MD

Topics include:

- Identifying Knowledge Gaps in Research and Clinical Care
- Creating Assessment Toolkits for Cognitive and Psychological Outcomes in Clinical and Preclinical Research
- Key Areas to Move Forward
- Collaborations

3:15 PM Closing Remarks

3:30 PM End of Workshop

Guest of Honor:

Peggy Pollay, RN peg0329@aol.com

Peggy was married to Dr. Michael Pollay for 27 years and they enjoyed traveling throughout the world together. Peggy was an RN and during the last 9 years of her career was Clinic Supervisor for a multi-specialty clinic where 35 sub-specialties met every week. One of those was the neurosurgery clinic where we saw many children with hydrocephalus and the MM (meningomyelocele) clinic.

Workshop Attendees

Denotes Speaker

Bonnie Blazer-Yost, PhD

Professor, Biology

Indiana University - Purdue University Indianapolis
Indianapolis, IN

bblazer@iupui.edu

I am using preclinical animal and tissue culture models to study electrolyte and fluid transport in the choroid plexus epithelium. Our studies are directed toward understanding the basic mechanisms of CSF production and what may be altered in the case of hydrocephalus. We have identified two potential effectors of CSF production in both cultured cells and rodent models and are conducting experiments designed to test these compounds as therapeutic agents for the treatment of hydrocephalus.

Jonathan Brigman, PhD

Associate Professor, Neurosciences

University of New Mexico
Albuquerque, NM

jbrigman@salud.unm.edu

The focus of my work is to further our understanding of the maladaptive behavioral changes that accompany alcohol exposure, drug addiction and numerous neuropsychiatric disorders. Our research focuses on developing models that allow us to investigate the role of both genetic factors and molecular mechanisms in mediating executive control behaviors. One major focus is to improve the translational potential of preclinical models by integrating in vivo measures of neural function with cross-species behavioral measures. Another major focus of the lab is understanding the optimal organization of neuronal firing in neural circuits in vivo, and how alterations in NMDAR may disrupt these patterns, leading to loss of executive control and poorer functional outcome.

Vera Joanna Burton, MD, PhD

Neurodevelopmental Pediatrician

Kennedy Krieger Institute
Baltimore, MD

BurtonJ@kennedykrieger.org

Dr. Burton is a developmental neurologist focused on improving functional outcomes after perinatal brain injury through assessment of risk and early identification of motor and cognitive ability. She provides clinical and research follow-up of high-risk infants in the NICU at Johns Hopkins and in the Infant Neurodevelopment Center at Kennedy Krieger as Co-Director of a multi-disciplinary team that uses a number of standard neurobehavioral assessments to provide comprehensive developmental care. She is also an Assistant Professor in the Johns Hopkins School of Medicine. She will be speaking on early detection models of motor impairment focusing both on tools used in the NICU and outpatient.

Nancy Carlson, PhD, OTR/L

Associate Professor, Occupational Therapy

Elizabethtown College
Elizabethtown, PA

carlsona@etown.edu

Dr. Carlson is an Assistant Professor of Occupational Therapy at Elizabethtown College. She is also a licensed occupational therapy practitioner with over 40 years of clinical experience. A personal journey with her father's NPH diagnosis and shunt surgery shifted her scholarly agenda to explore the impact of NPH on quality of life. Her occupation-based approach provides a unique lens to understand the impact of NPH on daily life and meaningful activity. She engages in faculty-led, faculty-student collaborative research in a historically liberal arts college. Unlike previous quantitative studies that use broad QoL measures, her research focuses on the narrative story of participants using a case base method.

Gary Chaffee, MS

NPH Community Network Leader & Peer Support Volunteer

HA Volunteer
Flower Mound, TX

dallasnphcommunity@hydroassoc.org

I am an active retired senior living with normal pressure hydrocephalus. Most of my working career was in healthcare positions including Operations Manager for SmithKline Laboratories and Executive National Account Manager for Glaxo SmithKline. Since I received a shunt in 2005, I have been an outreach volunteer, peer volunteer, community leader, and advocate for the Hydrocephalus Association. My interests are to increase NPH awareness in the community and to educate families affected by NPH.

Monica Chau, PhD

National Director of Research

Hydrocephalus Association
Houston, TX

Research@hydroassoc.org

Dr. Monica Chau is responsible for planning, managing, implementing, and evaluating all aspects of the research program for the Hydrocephalus Association (HA). Dr.

Workshop Attendees (cont.)

Chau is a neuroscientist with 17+ years of experience in basic science, translational, and clinical research with a focus on regenerative treatments in neurodegeneration. She received her PhD from Emory University in Neuroscience in 2014. Prior to joining HA, she was conducting clinical research on Parkinson's Disease as a Research Assistant Professor in the Department of Neurosurgery at University of Kentucky. She has received awards from the American Heart Association, the American Cancer Society, and the University of Kentucky for her work in cell therapies, ischemic stroke, glioblastoma, peripheral nerve injury, and Parkinson's Disease.

Sarah Daniel, PhD

Science Writer

Savannah, GA

Sarahdaniel@inscriptoscience.com

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 as a Ruth L. Kirschstein Predoctoral NRSA Fellow. 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.

Nickolas Dasher, PhD

Assistant Professor/ Neuropsychologist

University of Washington
Seattle, WA

ndasher@uw.edu

I am a neuropsychologist in the department of rehabilitation medicine at the University of Washington, and work with patients predominantly with TBI, stroke, brain cancer, and hydrocephalus. I have been with the AHCRN for 4 years and am a co-investigator of a multi-site clinical study assessing the efficacy of shunting on cognitive outcomes in patients with normal pressure hydrocephalus. Regarding the topic of my presentation, I am also investigating the cognitive profile of adults with previously unrecognized and congenital hydrocephalus. A looming question is whether or not the hydrocephalus should be treated if patients are otherwise functioning well, so determining subtle cognitive difficulties unique to hydrocephalus could help determine which patients may benefit from treatment.

Soner Duru, MA

Research Associate

Cincinnati Children's Hospital & Medical Center
Cincinnati, OH

Soner.Duru@cchmc.org

Dr. Duru works in pediatric neurosurgery. He worked on and designed a variety of clinical and experimental studies with small and large animals for congenital central nervous system abnormalities. Dr. Duru agreed to co-design a study with Dr. Jose Luis Peiro for a translational research project investigating fetal intrauterine minimally invasive neurosurgical approaches in congenital isolated hydrocephalus. Drs. Duru and Peiro developed a new experimental congenital hydrocephalus induction model with intracisternal BioGlue injection in the fetal lamb. They also contributed to the scientific community by creating a new model of fetal hydrocephalus in fetal lambs and conducted an innovative endoscopic third ventriculostomy in the fetal period.

Robin Ennis, MSW

Therapist / Licensed Clinical Social Worker

Denver, CO

rlennis02@gmail.com

I am a passionate person who loves advocating for others. One way I do this is through empathy and telling my story. Letting others know that they are being heard and not alone. Even if I am unable to offer an in the moment tangible solution, I have found that active listening can go a long way with people. I spread awareness and education about disability by mentoring future social workers, current/future medical professionals, and those with disabilities. It is my aim to create a more leveling playing field for all.

Ramin Eskandari, MS, MD

Associate Professor of Neurosurgery; Chief of Pediatric Neurosurgery

Medical University of South Carolina
Charleston, SC

eskandar@musc.edu

Dr. Eskandari has been involved in research for 24 years and runs the Pediatric Brain Injury and Hydrocephalus Laboratory at the Darby Children's Research Institute (DCRI) on campus at the Medical University of South Carolina. He has always had a very fervent desire to

maintain basic science research alongside medical innovation and clinical therapeutics. He has maintained active research through internal, state level and philanthropic grant funding. He is actively involved in medical device innovation, optimization and currently, his laboratory has invented a novel cell culture model of elevated intracranial pressure and has collaborated on a novel medical therapeutic to prevent progressive brain injury and hydrocephalus in neonates with brain hemorrhage.

Amanda Fletcher, MD

Neurologist, Cognitive Neurology

Orlando Health
Orlando, FL

amandawvomo@gmail.com

I work as a cognitive neurologist in the memory disorders clinic where we take care of patients with NPH. Our goal is to provide the best quality of care to our patients providing them with the most up to date recommendations and resources.

Jack Fletcher, PhD

Research Professor Emeritus, Psychology

University of Houston
Houston, TX

JackFletcher@uh.edu

Jack M. Fletcher, Ph.D., is Research Professor Emeritus, Department of Psychology, at the University of Houston. He received a BA degree from Davidson College and a Ph.D. in clinical psychology from the University of Florida. For the past 40 years, Dr. Fletcher, a board-certified child neuropsychologist, has worked on issues related to child neuropsychology, including studies of children with spina bifida, traumatic brain injury, and other acquired disorders. The author of over 400 papers, Dr. Fletcher directs an NICHD-funded national learning disability research center. He was PI on an NICHD-funded program project on spina bifida and early hydrocephalus (1998-2010), and an investigator-initiated NINDS award on pediatric hydrocephalus (1988-1998). Dr. Fletcher was the lead psychologist on the MOMS2 fetal surgery trial school-age follow-up.

Judy Froehlich, MBA

National Director of Marketing and Communications

Hydrocephalus Association
Orlando, FL

judy@hydroassoc.org

Judy is the National Director of Marketing and Communications for the Hydrocephalus Association. She earned her Marketing B.S. and her MBA from the University of Central Florida and has more than 25 years of marketing and communications experience, both in the public and the private sector. Prior to HA, her latest role was the Director of Marketing and Communications for the College of Sciences at UCF.

Maria Garcia Bonilla, PhD

Postdoc Research Associate, Neurosurgery

Washington University in St. Louis
St. Louis, MO

mariag@wustl.eduu

My PhD was focused on developing a stem cell therapy in a mouse model of congenital hydrocephalus. It was awarded the grade of Outstanding/ Summa Cum Laude upon graduation in 2019 and the President's Prize in ICCS and SRHSB Joint Conference in St. Louis (2017).

Now, I am a Postdoctoral Fellow at Washington University in St Louis. Along with Dr. McAllister and Limbrick, I developed a large animal model of hydrocephalus for evaluating emerging CSF shunt technologies and ETV-CPC. In 2010, our group established an HCRN CSF Repository and have acquired more than 3000 CSF samples to investigate the pathogenesis of hydrocephalus and develop markers of long-term neurodevelopment. My projects are focused on the role of neuro-inflammation on molecular pathogenesis of pediatric hydrocephalus.

Amanda Garzon, MA

Chief Operations Officer

Hydrocephalus Association
Bethesda, MD

amanda@hydroassoc.org

Amanda is the Chief Operations Officer for the Hydrocephalus Association (HA), working to find innovative ways to grow revenue that support the diverse research and patient-focused programs of the association. Prior to joining HA, Amanda served as the Director of Operations for iConstituent, a software firm specializing in communications and database solutions for elected officials, particularly Members of Congress. She holds a Bachelors of Arts in Political Science from Bryn Mawr College and a Masters in International Affairs from Columbia University's School of International and Public Affairs.

June Goto, PhD

Assistant Professor, Pediatric Neurosurgery

Cincinnati Children's Hospital Medical Center
Cincinnati, OH

June.Goto@cchmc.org

Dr. Goto's lab investigates how neonatal hydrocephalus affects perinatal neural cell development, particularly of which are not responding

Workshop Attendees (cont.)

to shunt-surgery. Recently, we found that the NF-kB signal-mediated neuroinflammation can be a medical target to improve myelination and neonatal locomotor function using the Ccdc39 mouse mutants with robust neonatal hydrocephalus. Our data and others suggest that proper management of neuroinflammation in early brain development may be significant to prevent/ameliorate developmental deficits in neural network formation in neonatal hydrocephalus.

Gwendolyn Gerner, PsyD

Assistant Professor, Neuropsychology

Kennedy Krieger Institute
Baltimore, MD

gerner@kennedykrieger.org

Dr. Gerner's clinical work and her research focus on neurodevelopmental and neurobehavioral outcomes following perinatal brain injury, as well as neonatal risk stratification for severe neurodevelopmental complications. Dr. Gerner is a Clinical Psychologist, licensed in Maryland, with a specialization in Developmental Neuropsychology. She serves as a neuropsychologist and the Co-director in the Infant Neurodevelopment Center at Kennedy Krieger Institute and is an Assistant Professor in the Department of Psychiatry and Behavioral Sciences at The Johns Hopkins University School of Medicine. Dr. Gerner will be speaking about the detection of major cognitive morbidities associated with perinatal brain injury with post hemorrhagic hydrocephalus.

Diana Gray, MA

President and CEO

Hydrocephalus Association
Bethesda, MD

Diana@hydroassoc.org

Diana 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.

Mark Hamilton, MDCM, FRCSC

Professor of Neurosurgery

University of Calgary
Calgary, Alberta

mghamilton.hydro@gmail.com

Dr. Hamilton is a Professor of Neurosurgery at the University of Calgary, Chair of the Adult Hydrocephalus Clinical Research Network (AHCRN), Immediate Past President of the Hydrocephalus Society, a member of the Board of Directors of the Hydrocephalus Association (HA), the Vice-Chair of the Medical Advisory Board (MAB) of HA and a member of the Board of Directors of Hydrocephalus Canada. His current main clinical and research interests are the diagnosis and management of hydrocephalus in adults.

Carolyn Harris, PhD

Associate Professor, Chemical Engineering and Materials Science

Wayne State University
Detroit, MI

caharris@wayne.edu

Carolyn Harris has a PhD in Bioengineering from the University of Utah and a BSE in Biomedical Engineering from Purdue University. She did her postdoctoral work at Seattle Children's Research Institute. She has been focused on shunt obstruction and understanding the biological response to neuroprosthetics for most of her career.

Jonathan Hendricks, MS

Senior Research Engineer of Pediatric Neurosurgery

McGovern/UTHealth/Children's Memorial Hermann
Houston, TX

jonathan.hendricks@uth.tmc.edu

I develop novel 3D printable designs for parts used in Post-hemorrhagic hydrocephalus research. Additionally, my research interests include automating tasks, such as tissue type categorization, through scripting and combining multiple computational imaging modalities to generate images or models of ROIs.

Alexandra Hochstetler, PhD

Postdoctoral Fellow, Pathology

Boston Children's Hospital
Boston, MA

alex.e.h.95@gmail.com

My research interest is in the pathophysiological mechanisms which contribute to hydrocephalus. My primary focus is choroid plexus biology and CSF secretion.

Grayson Holmbeck, PhD

Professor, Psychology

Loyola University Chicago
Chicago, IL

gholmbe@luc.edu

Dr. Grayson Holmbeck is Professor of Clinical Psychology in the Department of Psychology at Loyola University Chicago. His research interests include the adaptation to physical disabilities and chronic illness during childhood, adolescence, and emerging adulthood. He is currently the PI on an NIH-funded longitudinal study of adolescents and young adults with spina bifida, focusing on self-management and the transition from pediatric to adult health care, as well as related family, psychosocial, and neuropsychological factors. He also studies the effectiveness of a camp-based independence program for children, adolescents, and young adults with spina bifida.

Lauren Jantzie, PhD

Associate Professor of Pediatrics, Neurology and Neurosurgery

Johns Hopkins University
Baltimore, MD

LJantzie@jhmi.edu

Dr. 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.

David Limbrick MD, PhD

Neurosurgeon in Chief

St. Louis Children's Hospital/
Washington University
St. Louis, MO

limbrickd@wustl.edu

David D. Limbrick Jr., MD, PhD, 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 peer-reviewed articles and has led several federally funded clinical trials. Dr. Limbrick serves on the Editorial Boards of Journal of Neurosurgery: Pediatrics, Neurosurgery: Online, and Fluid and Barriers of the CNS. For the past five years, he has served on the Children's Medical Executive Committee and co-led Strategic Planning for Pediatric Neurosciences at WU/SLCH, observing growth in faculty and in clinical metrics, including surgical case volume. He has received numerous awards, including the Humanism in Medicine Award from Washington University and is among the Top 10% of Faculty Physicians for Patient Satisfaction.

Dani Lucchese, PhD

Adjunct Faculty/Doctoral Student

University of Arizona and CUNY NY/AZ

Dlucchese531@email.Arizona.edu

My research examines access to higher education with a particular focus on disabled and gender expansive people.

Francesco Mangano, DO

Chief, Division of Pediatric Neurosurgery

Cincinnati Children's Hospital Medical Center
Cincinnati, OH

francesco.mangano@cchmc.org

My interest in the basic science of hydrocephalus began with a study of the description of the microglial response in the H-Tx rat model in 1998. During my early career development plan, we formed a team to further investigate the pathophysiology of pediatric hydrocephalus using immunohistochemistry, advanced neuroimaging, and neurocognitive testing. Our group has focused on the study of clinical pediatric hydrocephalus by correlating non-invasive imaging biomarkers (DTI) to neurobehavioral outcomes in pre- and post-shunted hydrocephalic children including most recently patients with fetal myelomeningocele repair.

Workshop Attendees (cont.)

Pat McAllister, PhD

Professor, Neurosurgery

Washington University in St. Louis
St. Louis, MO

pat.mcallister@wustl.edu

As a basic neuroscientist, my interdisciplinary research includes a variety of translational approaches to advance understanding of the pathophysiology of hydrocephalus and develop improved treatments for this disorder. By developing shunting and endoscopic procedures, advanced neuroimaging techniques, and pharmacological interventions in various animal models, I have contributed to what is known about the potential for neuroprotection and neuronal recovery, the effects of anti-inflammatory agents, and the pathophysiology of post-hemorrhagic hydrocephalus in gyrencephalic animals.

Gordon McComb, MD

Chief Emeritus for the Division of Neurosurgery

Children's Hospital Los Angeles
Los Angeles, CA

gmccomb@chla.usc.edu

Dr. McComb is CHLA's Chief Emeritus for the Division of Neurosurgery and currently serves as an attending physician. During his 36 years at CHLA, he has led as Chief of Neurosurgery, but also as a five-term President of the CHLA Medical Group and a former member of the Board of Trustees for the hospital. His prolific research has advanced the diagnosis and treatment of infants and children with disorders such as hydrocephalus, neural tube defects, and more. His primary clinical interests include hydrocephalus, spina bifida, brain, and spinal cord tumors/trauma, Chiari malformations, and Craniosynostosis.

Brandon Miller, MD, PhD

Assistant Professor, Pediatric Neurosurgery

University of Texas Health Science Center at Houston
Houston, TX

brandon.a.miller@uth.tmc.edu

Dr. 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.

Abhay Moghekar, MB

Associate Professor, Neurology

Johns Hopkins University
Baltimore, MD

am@jhmi.edu

My research focuses on identifying fluid (CSF and blood) biomarkers of aging and neurodegenerative disorders with a focus on specific CSF disorders like NPH and IIH.

Jill Morris, PhD

Program Director of Neuroscience Division

NINDS
Bethesda, MD

jill.morris@nih.gov

Jill A. Morris, PhD is a Program Director at the National Institute of Neurological Disorders and Stroke. She is responsible for both disease and basic research portfolios. Her disease research portfolio includes hydrocephalus, neurofibromatosis and multiple rare neurological disorders. Her basic grant portfolio includes technology development for gene-targeted therapies including gene, ASOs and RNAi therapies as well as delivery methods. Prior to coming to the NIH, she was an Assistant Professor in the Department of Pediatrics in the Feinberg School of Medicine at Northwestern University. Her laboratory studied the function of schizophrenia susceptibility genes in neurodevelopment.

Steven Paul Woods, PsyD

Professor, Psychology

University of Houston
Houston, TX

spwoods@uh.edu

Dr. Woods is a Professor of Psychology at the University of Houston and an Adjunct Professor of Psychological Science at the University of Western Australia. He is a clinical neuropsychologist whose research focuses on the application of theoretical models of cognition to everyday functioning and health in HIV and aging.

Karen Peart, BSN

RN Care Coordinator

Orlando Health
Orlando, FL

karen.peart@orlandohealth.com

I work in the Memory Disorder Clinic with Dr. Fletcher and I triage calls with patients that have different degrees of cognitive impairments and coordinate their care with the clinic. I also manage the requirements for the grant we receive from the state. I am interested to learn more about hydrocephalus and its impact on cognition as well as daily life.

Irene Piryatinsky, PhD, ABPP-CN

Licensed Psychologist; Board Certified Neuropsychologist

Assistant Professor of Neurology – Tufts University School of Medicine
Boston, MA

info@npevaluation.com

Among Dr. Piryatinsky's primary clinical interests are geriatric neuropsychology and neurodegenerative disorders, including the assessment of mild cognitive impairment, differential diagnosis of dementia, and providing meaningful, evidence-based recommendations for patients and their families. Movement disorders, pre/postsurgical evaluations for deep brain stimulation candidates and normal pressure hydrocephalus are additional areas of expertise.

Linda Riley

National Director of Development

Hydrocephalus Association
Boise, ID

linda@hydroassoc.org

Linda is the National Director of Development at the Hydrocephalus Association. Prior to HA, Linda worked in leading chapters of the Juvenile Diabetes Research Foundation (JDRF) in Southern California, fundraising for Scripps Health in San Diego, and held her most recent position with JDRF as Leadership Giving Director, West Region. Linda holds a Bachelor of Arts in Business Administration from Cal Poly State University, San Luis Obispo, CA, and studied Fundraising at UC Irvine and Nonprofit Leadership at Columbia University.

Shenandoah Robinson, MD

Professor, Neurosurgery

Johns Hopkins University
Baltimore, MD

srobin81@jhmi.edu

Dr. Robinson received her MD at Northwestern University Feinberg School of Medicine and completed her residency in Neurological Surgery at Case Western Reserve University School of Medicine. She is nationally recognized in the treatment of pediatric epilepsy and spasticity. As a pediatric neurosurgeon, her subspecialty areas of focus include hydrocephalus, epilepsy and cerebral palsy. Her research focuses on optimizing clinically relevant models of different types of perinatal brain injury, including acquired infantile hydrocephalus from hemorrhage, infection and trauma to test pharmacotherapies. Dr. Robinson's goal is to restore neurodevelopment, and prevent or treat existing hydrocephalus using non-surgical strategies. Dr. Robinson sees patients at the Johns Hopkins Outpatient Center's Neurosciences Clinic, the Kennedy Krieger Institute, and the Mt. Washington Pediatric Hospital.

Brandon Rocque, MD, MS

Associate Professor, Neurosurgery

University of Alabama at Birmingham
Birmingham, AL

brandon.rocque@childrensal.org

My research focuses on the psychological impact of hydrocephalus and its treatment on children and their families. The goal is to understand how common these conditions are, how best to screen and identify them, and how to offer support when needed. Ideally, by fully recognizing and treating these conditions, we can improve the experience of hydrocephalus treatment for all.

In addition, my research focuses on the study and optimization of transition from pediatric models of health care to adult care for adolescents and young adults with neurosurgical conditions, particularly hydrocephalus.

Manish Shah, MD

Pediatric Neurosurgeon

UTHouston
Houston, TX

Manish.n.shah@uth.tmc.edu

Dr. Manish Shah is Associate Professor of Pediatric Neurosurgery at the University of Texas Medical School at Houston. He received his undergraduate degree in physics from Princeton University, his medical degree from Vanderbilt University in Nashville, TN, and completed his neurosurgery residency training at Washington University/Barnes-Jewish Hospital in St. Louis, MO. After residency, he completed fellowship training in pediatric neurosurgery at Washington University/St. Louis

Workshop Attendees (cont.)

Children's Hospital in St. Louis, MO under the tutelage of world-renown pediatric neurosurgeon, Professor Tae Sung Park. During his neurosurgical training, he completed an NIH T32 sponsored clinical, translational, and basic science research fellowship in Neurological Surgery, Radiology and Functional Neuroimaging under Professor Marcus Raichle. He also had additional training as a Specialist Registrar in Neurological Surgery at Beaumont Hospital in Dublin, Ireland under Professor Ciaran Bolger, an expert in spine surgery. He now works on infrared imaging in hydrocephalus.

Cynthia Smith Seidel, PhD

Staff Neuropsychologist

Martinsburg VAMC
Martinsburg, WV

Cynthia.smith-seidel@va.gov

I would like to do fMRI to measure frontal lobe changes post shunt in NPH; also interested in apathy, anxiety, depression, and PTSD.

Jennifer Strahle, MD

Associate Professor, Neurosurgery

Washington University in St. Louis
St. Louis, MO

strahlej@wustl.edu

CSF disorders are the most common reason for neurosurgical intervention in pediatric patients. For the majority of patients, it is not known how hydrocephalus develops, including those with Post-hemorrhagic hydrocephalus, the most common form in the US. We study through basic science and clinical-translational investigations how hydrocephalus develops and how neurodevelopment is altered after IVH, particularly through modulation of the subventricular zone, and if any repair mechanisms exist. Ultimately our goal is to develop preventative treatments for hydrocephalus. In addition to the study of pathologic CSF disorders we aim to understand the nature and role of CSF circulation during normal development in order to inform our study of the pathologic conditions of hydrocephalus.

Margaret Tish, BS

Graduate Student, Neurology

University of Iowa
Iowa City, IA

margaret-tish@uiowa.edu

I am characterizing kaolin induced hydrocephalus as a model for NPH. We have analyzed the gait and micturition of these mice and are currently exploring different cognitive tests, as well as testing the ICP of these mice and inserting shunts. The goal is to combine this model with other neuroscience techniques (Cre-conditional tracing, optogenetics, chemogenetics) so we can target specific neurons and pathways to treat the symptoms of these mice.

Tessa van der Willigen, MPhil, MAPP

Visiting Scholar, Psychology

Georgetown University
Washington DC

tessavanderwilligen@gmail.com

Tessa van der Willigen spent approximately 30 years in international macroeconomics, with the majority of those years at the International Monetary Fund (IMF). At the IMF, following a long stint of program and research work on different countries, she managed the divisions responsible for strategy in varying areas, and her last position was as Chief of Staff to the Managing Director. Originally from the Netherlands, she was educated in France and at Oxford and Cambridge Universities, first in zoology and later in economics. More recently she completed a master's degree in positive psychology at the University of Pennsylvania and trained as a mindfulness meditation teacher under renowned teachers Jack Kornfield and Tara Brach. Tessa is currently a Visiting Scholar in the Psychology Department at Georgetown University, conducting research focused on autonomy, authenticity, and well-being. Leveraging her background in positive psychology and mindfulness, she is also a collaborator on an intervention to increase psychological resilience in families with hydrocephalus, and offers very popular mindfulness courses and workshops through HA. Tessa is a Vice-Chair of HA's Board of Directors, chairs its Finance Committee, and co-chairs its Research Committee.

William Whitehead, MD

Professor, Neurosurgery

Baylor College of Medicine
Houston, TX

wewhiteh@texaschildrens.org

I have focused on clinical research to improve outcomes for children with hydrocephalus and collaborated with the HCRN on many studies.

Michael Williams, MD

Professor, Neurology and Neurological Surgery

University of Washington
Seattle, WA

maw99@uw.edu

Dr. Williams has over 30 years of clinical and research expertise including patients with all types of hydrocephalus, ages 18 years and older. He established hydrocephalus centers at Johns Hopkins Hospital and

the University of Washington. He co-directed the first NIH hydrocephalus workshop in 2005, and co-founded the International Society for Hydrocephalus and CSF Disorders and the Adult Hydrocephalus Clinical Research Network. He has published multiple papers on adult hydrocephalus. He is co-author of an NIH multi-center placebo-controlled trial of shunt surgery in NPH.

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.

Victoria Williams, PhD

Assistant Professor

University of Wisconsin, School of Medicine and Public Health
Madison, WI

vwilliams@medicine.wisc.edu

Dr. Williams is a clinical neuropsychologist and Assistant Professor of Medicine at the University of Wisconsin - Madison. Her work uses advanced neuroimaging techniques to investigate brain-behavior relations within the most dynamic periods of the lifespan, development and senescence. Her prior research has focused on neurodevelopmental disorders (dyslexia and spina bifida), whereas her post-graduate work has leveraged aging populations to elucidate associations between subclinical variation in modifiable systemic health factors (such as cerebrovascular health, insulin sensitivity and physical fitness), structural brain integrity, and risk for neurodegenerative disease.

Andrew Zabel, PhD

Pediatric Neuropsychologist

Kennedy Krieger Institute
Baltimore, MD

zabela@kennedykrieger.orgu

Dr. Zabel is board-certified in clinical neuropsychology by the American Board of Professional Psychology and is a pediatric neuropsychologist at the Kennedy Krieger Institute with 20 years of experience assessing children, youth, and young adults with congenital and acquired hydrocephalus. He is also an Associate Professor of Psychiatry and Behavioral Sciences in the Johns Hopkins University School of Medicine. Dr. Zabel received his doctoral degree in clinical psychology from Drexel University of Philadelphia, PA and his clinical research focuses upon the adaptive functioning of individuals with white matter disruption, including a number of medical conditions linked with hydrocephalus.

Kathrin Zimmerman, MD, MSPH

Resident Physician

University of Wisconsin
Madison, WI

KZimmerman2@uwhealth.org
kzimm1@uab.edu

Kathrin Zimmerman is a resident physician at the University of Wisconsin in the division of Otolaryngology-Head and Neck Surgery. Her research interests include the psychosocial impact of pediatric surgical care on patients and their families, and the utilization of community-based participatory research to address health disparities and improve patient quality of life. As an NIH TL1 Clinical Research Fellow, she studied the psychosocial impact that neurosurgical care has on pediatric hydrocephalus patients and their caregivers. She has been awarded the Hydrocephalus Association Young Investigator Travel Award twice consecutively for her research on traumatic stress experienced by pediatric hydrocephalus patients and their caregivers.research to address health disparities and improve patient quality of life. As an NIH TL1 Clinical Research Fellow, she studied the psychosocial impact that neurosurgical care has on pediatric hydrocephalus patients and their caregivers. She has been awarded the Hydrocephalus Association Young Investigator Travel Award twice consecutively for her research on traumatic stress experienced by pediatric hydrocephalus patients and their caregivers.

Workshop Attendees (cont.)

Kathryn Argue, PhD

Deputy Program Manager, Peer Reviewed Medical Research Program

CDMRP

Ft. Detrick, MD

Kathryn.j.argue.civ@health.mil

I am the Deputy Program Manager for the Peer Reviewed Medical Research Program, one of the Congressionally Directed Medical Research Programs. We receive an annual appropriation from Congress along with a list of topic areas. For the past 8 years Hydrocephalus has been included in our topic areas and we have released program announcements to fund research in Hydrocephalus. Our funding opportunities have covered everything from basic mechanistic bench work all the up to and including large scale clinical trials. I am looking forward to telling the other attendees about our funding opportunities and learning more from the researcher attendees about the state of the science and more from the patient and advocacy groups about the areas of greatest need.

Joel Geerling, MD, PhD

Assistant Professor, Neurology

University of Iowa

Iowa City, IA

joel-geerling@uiowa.edu

I am a cognitive neurologist and neuroscientist. In my lab, we study neural circuit connections and gene expression patterns in the brain. We focus on neural circuits that control homeostatic functions like appetite, arousal, thermoregulation, and bladder control. Some of our most exciting new work involves neurons that may control continence, and we use a mouse model of normal pressure hydrocephalus (NPH) to identify more precisely which neural circuits are responsible for maintaining urinary continence. This work will help us understand what causes urinary urgency, frequency, and incontinence symptoms, and this information will help us tailor future therapies to help prevent or reverse those specific symptoms in patients with NPH.

Notes

For more information visit:
www.hydroassoc.org/Researchworkshop

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Houston, Texas, 77005

Hydrocephalus Association & Rudi Schulte Research Institute

RESEARCH WORKSHOP

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Hydrocephalus Association
4340 East West Highway, Suite 905
Bethesda, Maryland 20814
www.hydroassoc.org
(888) 598-3789

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