

HYDROCEPHALUS ASSOCIATION & RUDI SCHULTE RESEARCH INSTITUTE **RESEARCH WORKSHOP**

Honoring the legacy of Dr. Michael Pollay

WHY HYDROCEPHALUS MATTERS: Population Burden, Economic Impact, and Barriers to Care

Tuesday, July 21, 2026

8:00 AM – 5:00 PM

Wednesday, July 22, 2026

8:00 AM – 5:00 PM

JW Marriott Indianapolis

10 S West St
Indianapolis, IN 46204



RSRI



Rudi Schulte
Research Institute



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



WELCOME LETTER

From HA President and CEO, Diana Gray

Welcome to the Hydrocephalus Association (HA) and Rudi Schulte Research Institute (RSRI) 2026 Research Workshop.

This workshop brings together leaders in medicine, science, health economics, industry, and patient advocacy to examine the true burden of hydrocephalus and identify opportunities to improve access to care and strengthen investment in the field. Together, we will explore how better data, stronger care models, and cross-sector collaboration can drive meaningful progress for the hydrocephalus community.

This year's workshop features the following key themes:

- **Defining the Hydrocephalus Landscape:** Examining the population burden of hydrocephalus across the lifespan, while identifying critical gaps in epidemiology and healthcare data.
- **Economic Impact and Investment Opportunities:** Discussing the healthcare and societal costs of hydrocephalus, barriers to innovation, and why hydrocephalus represents an important opportunity for investment in diagnostics, devices, and therapeutics.
- **Chronic Burden on Patients and Families:** Highlighting the quality-of-life, long-term outcomes, and caregiver challenges associated with living with hydrocephalus.
- **Improving Access to Diagnosis and Care:** Exploring disparities in care, transition challenges, and scalable models that can improve access to specialized hydrocephalus care.

Throughout the workshop, patients and caregivers will share their experiences navigating diagnosis, access to care challenges, and the hidden costs of hydrocephalus. Their perspectives are essential for understanding the real-world impact of hydrocephalus and ensuring that future research, policy, and innovation efforts remain patient-centered.

We are excited to foster an environment that brings together diverse perspectives. These conversations and partnerships will help define the next steps for the field and lay the groundwork for more effective, accessible, and equitable care for individuals living with hydrocephalus.

We sincerely thank RSRI for their generous support of this workshop and all participants for contributing their expertise and perspectives to this important effort.

Sincerely,

Diana Gray, MA
President and Chief Executive Officer

Planning Committee

Jay Riva-Cambrin, MD (Chair)
University of Calgary

Naomi Abel, MD
University of South Florida

Mark Hamilton, MDCM
University of Calgary

Olivia Hogue, PhD
Cleveland Clinic

Albert Isaacs, MD, PhD
Nationwide Children's Hospital

Abhay Moghekar, MD
Johns Hopkins University

Daniela Perez Chadid, MD
Rutgers University

Joseph Piatt, MD, MAS
Nemours Children's Health

Brandon Rocque, MD, MS
University of Alabama at Birmingham

Tamara Simon, MD, MSPH
Children's Hospital Los Angeles,
University of Southern California

Rosie Valadez-McStay, MPH
Wild Blue Health Solutions

Research Workshop Agenda

Arrival: Monday, July 20, 2026



Welcome Social: Network & Collaborate

Meet the other workshop attendees and Hydrocephalus Association leadership
Location: **JW Marriott, High Velocity**

**5:00 PM –
6:30 PM**

Day 1: Tuesday, July 21, 2026

Location: **JW Marriott, Floor 2, Rooms 201-205**



Breakfast and Registration | 8:00 AM

Welcome and Workshop Goals

Speaker: Monica Chau, PhD, Hydrocephalus Association

9:00 AM

Hydrocephalus Association (HA) Mission and Vision

Speaker: Diana Gray, MA, Hydrocephalus Association

9:10 AM

Rudi Schulte Research Institute (RSRI) Overview, Honoring Dr. Michael Pollay

Speaker: Gordon McComb, MD, RSRI, Childrens Hospital Los Angeles

9:20 AM

Keynote: Living with Hydrocephalus: A Caregiver's Perspective

Speaker: Heather Bruen, HA Houston WALK Chair and Community Network Leader

9:30 AM

SESSION 1: DEFINING THE HYDROCEPHALUS LANDSCAPE

SESSION GOAL: Establish the size, heterogeneity, and data gaps of the hydrocephalus population across the lifespan

MODERATOR: Monica Chau, PhD

Current Data Sources, Gaps, & Opportunities: Why Hydrocephalus is Undercounted

Speaker: Tamara Simon, MD, MSPH, Children's Hospital Los Angeles

9:50 AM

Pediatric Hydrocephalus: Population, Etiology, Healthcare Utilization, and Outcomes

Speaker: Vijay Ravindra, MD, University of Utah

10:10 AM

Adult (Non-iNPH) Hydrocephalus: Population, Diversity & Secondary Data Analysis

Speaker: Albert Isaacs, MD, PhD, Nationwide Children's Hospital

10:30 AM

iNPH Prevalence and Incidence *(virtual presentation)*

Mats Tullberg, MD, PhD, University of Gothenburg

10:50 AM



Break | 11:10 – 11:25 AM

Research Workshop Agenda (cont.)

SESSION 2: HYDROCEPHALUS AS AN INVESTMENT AND INNOVATION OPPORTUNITY

SESSION GOAL: Make the business and innovation case for hydrocephalus and clarify why hydrocephalus is an open therapeutic and investment opportunity

A. Market & Innovation Perspectives

MODERATOR: Monica Chau, PhD

Hydrocephalus as an Investable Market

Speaker: Adam Zysk, PhD, Madison Scientific

11:25 AM

Alternatives to Shunts: Pathways From Idea to Market

Speaker: Charles Matouk, MD, Yale University

11:45 AM

Early-Stage Innovation Pathways Through SBIR/STTR *(virtual presentation)*

Speaker: Jessica Forbes, PhD, NIH-NINDS

12:05 PM

 **Lunch | 12:20 PM – 1:10 PM**

Nice to Meet You: University Innovation and Tech Transfer Offices

Speaker: Scott Olson, MBA, Wayne State University

1:15 PM

B. Emerge Industry and Investor Panel

1:30 PM

MODERATOR: Scott Olson, MBA

Session Topic: Why Invest in Hydrocephalus and What Would Accelerate Progress?

- Barriers to investment
- What data does industry need (e.g., EMR, payer, outcomes)?
- What the “next device or therapy” for hydrocephalus could be

Panelists: Eric Heinz, MBA, Heinz Ventures, LLC; Caitlin Morse, BrainSpace; Tim Hopper, MBA, Cerulean Scientific; Patrick Dugan, MBA, Integra LifeSciences

C. Interactive Breakout Session

2:20 PM

MODERATORS: Monica Chau, PhD and Scott Olson, MBA

Session Topic: Barriers and Priorities for Investment

- Major barriers to investing in hydrocephalus research
- Barriers to connecting medical needs to investors
- What different stakeholders need in order to invest
- Strategies to overcome these barriers
- Purpose: Directly inform the priorities/roadmap white paper

Full-Group Report-Back

2:50 PM

 **Break | 3:20 – 3:30 PM**

Research Workshop Agenda (cont.)

SESSION 3: THE CHRONIC BURDEN TO PATIENTS AND FAMILIES

SESSION GOAL: Highlight quality of life, mental health, and long-term outcomes, and elevate lived experience and unmet needs

MODERATOR: Samantha Lanjewar, PhD

Quality of Life After Shunting and ETV: The Present and the Future

Speaker: Jay Riva-Cambrin, MD, University of Calgary

3:30 PM

PTSD and Psychosocial Burden in Patients and Caregivers

Speaker: Elizabeth McRae, PhD, University of Alabama at Birmingham

3:50 PM

Patient and Caregiver Panel

- Barriers to accessing care
- Diagnosis difficulties
- Hidden costs of hydrocephalus

4:10 PM

Panelists: Heather Bruen; Kenneth Iserson, MD; Susan Fiorella, MPP, MS; Kayla Gray, MS

Closing Remarks

Speaker: Monica Chau, PhD, Hydrocephalus Association

4:55 PM

END OF DAY 1 | 5:00 PM



Group Networking Dinner | 6:30 – 9:00 PM

Location: **Skyline Club, One American Square, 36th floor, Indianapolis, IN 46204**

Attire: Business or cocktail



Join HANDS for updates
hands.hydroassoc.org



HANDS

Hydrocephalus Association
Network for Discovery Science

Collaboration • Innovation • Impact

Research Workshop Agenda (Day 2)

Day 2: Wednesday, July 22, 2026

Location: **JW Marriott, Floor 2, Rooms 201-205**

Breakfast and Registration | 8:00 AM

Welcome and Opening Remarks

Speaker: Monica Chau, PhD, Hydrocephalus Association

8:50 AM

SESSION 4: THE ECONOMIC AND SYSTEM BURDEN OF HYDROCEPHALUS

SESSION GOAL: Quantify healthcare system burden, show how complications and inefficiencies drive cost, and set the foundation to improve access to care

MODERATOR: Daniela Perez Chadid, PhD

Framework: The Patient-Centered Value Report

Speaker: Casey Quinn, PhD, Patient-Centered Outcomes Research Institute (PCORI)

9:00 AM

Patient-Centered Burdens & the Healthcare System

Speaker: Casey Quinn, PhD, Patient-Centered Outcomes Research Institute (PCORI)

9:10 AM

Caregiver Burden and the Hidden Economics of Hydrocephalus

Speaker: Susan Fiorella, MPP, MS, Parent who works in the medical field

9:25 AM

Epidemiology of NPH and Inpatient Healthcare Burden

Speaker: Abhay Moghekar, MD, Johns Hopkins University School of Medicine

9:45 AM

Hydrocephalus Healthcare Use: How We Might Do Better with What We Already Know

Speaker: Joseph Piatt, MD, MAS, Nemours Children's Hospital Delaware

10:05 AM

Why This Matters: Real World Application

Speaker: Richard Xie, PhD, RA Capital Management

10:25 AM

Break | 10:45 – 11:00 AM

MODERATORS: Monica Chau, PhD, Casey Quinn, PhD, and Richard Xie, PhD

Breakout Activity

- What patient-centered values are most important and where are there gaps?
- What are next steps?

11:00 AM

Research Workshop Agenda (cont.)

SESSION 5: IMPROVING ACCESS TO DIAGNOSIS AND CARE

SESSION GOAL: Identify barriers to access and next steps; highlight scalable and realistic care models

MODERATOR: Michael A. Williams, MD

Patient Perspective: The Diagnostic Journey

11:40 AM

Speaker: Kenneth Iserson, MD, MBA, The University of Arizona

Adult Access to Care

11:55 AM

Speaker: Mark Hamilton, MDCM, University of Calgary

Racial Disparities in Hydrocephalus: Mortality and Shunt Revision

12:15 PM

Speaker: Brandon Rocque, MD, MS, University of Alabama at Birmingham

 **Lunch | 12:35 – 1:30 PM**

Transition: How Advanced Practice Provider Models Can Increase Access to Care

1:35 PM

Speaker: Bermans Iskandar, MD, University of Wisconsin

Establishing Adult Hydrocephalus Centers

1:55 PM

Speaker: Ryan Lee, MD, Vanderbilt University

Models of Care & Transition Panel

2:15 PM

- APP-led care models
- Pediatric-to-adult transition
- Clinic sustainability and staffing
- Cost and systems implementation

Panelists: Naomi Abel, MD; Mark Hamilton, MDCM; Ryan Lee, MD; Bermans Iskandar, MD

Break | 3:00 – 3:15 PM



Breakout Activity: Improving Access to Care

3:15 PM

- Systemic and insurance-level barriers
- Patient-level access challenges
- Workforce shortages and how to expand adult specialty care
- Goal: Identify pragmatic solutions that address both access and workforce limitations simultaneously

Research Workshop Agenda (cont.)

SESSION 6: FUNDING AND RESOURCES

SESSION GOAL: Equip attendees with funding, infrastructure, and collaboration opportunities

MODERATOR: Samantha Lanjewar, PhD

NIH NINDS Funding Opportunities

Speaker: Jill Morris, PhD, National Institute of Neurological Disorders and Stroke (NINDS)

3:55 PM

CDMRP Peer Reviewed Medical Research Program (PRMRP) Funding Opportunities

Speaker: Kathryn Argue, PhD, Congressionally Directed Medical Research Program (CDMRP)

4:10 PM

PCORI Funding and Resources

Speaker: Casey Quinn, PhD, Patient-Centered Outcomes Research Institute (PCORI)

4:25 PM

Hydrocephalus Association Funding Opportunities and Partnerships

Speaker: Samantha Lanjewar, PhD, Hydrocephalus Association

4:40 PM

Closing Remarks

Speaker: Monica Chau, PhD, Hydrocephalus Association

4:50 PM

END OF WORKSHOP | 5:00 PM



For more information visit:
hands.hydroassoc.org/research-workshop



Hydrocephalus Association & Rudi Schulte Research Institute

RESEARCH WORKSHOP

Honoring the Legacy of Dr. Michael Pollay



R S R I



Rudi Schulte
Research Institute



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



6903 Rockledge Drive, Suite 740

North Bethesda, MD 20817

(888) 598-3789 | www.hydroassoc.org | info@hydroassoc.org

[f](#) [X](#) [@](#) [v](#) [in](#) @hydroassoc