Hydrocephalus Association
40th Anniversary | 1983-2023

PATHWAYS
HIGHLIGHTS EDITION

Hydrocephalus Association Newsletter, Volume 41, Edition 1, Summer 2023

NEWSLETTER VOLUME
41

HA's 40th Anniversary

As 2023 unfolds, we mark the 40th anniversary of the Hydrocephalus Association. A highlight will be our 40th Anniversary Gala.

4

Department of Defense Research Funding

In 2022, five applications were funded which led to an additional $15.3M in grant awards.

7

WALK to End Hydrocephalus

This year, 43 WALKs will be held across the country, including two new locations. Participants can also enjoy a new and improved mobile APP!

8

HACONNECT Virtual

Join us on Saturday, November 4th for the largest worldwide online conference about hydrocephalus.

JOIN US

AN EVENING BENEFITING
HYDROCEPHALUS ASSOCIATION

Hydrocephalus
Association

40TH ANNIVERSARY Gala

HONORING OUR LEGACY
SHAPING THE FUTURE

FRIDAY
NOVEMBER 10

WESTIN ANAHEIM RESORT
1030 W Katella Ave
Anaheim, California

6:00 PM Cocktail Hour and Silent Auction

7:30 PM Dinner, Live Auction, and Program

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

At the Gala you will enjoy:

- Live entertainment
- Delicious cuisine and drinks
- Silent and live auctions with unique items and experiences
- Connections with fellow community members

Sponsorships, Tables, and Individual Tickets Available
Visit **benefit.hydroassoc.org**

HIGHLIGHTS EDITION

40th Anniversary

Honoring our Legacy and Shaping the Future

As 2023 unfolds, we mark the 40th anniversary of the Hydrocephalus Association (HA). We will celebrate this momentous occasion honoring the association's legacy while also charting a course for an even more promising future.

The initial concept for HA revolved around the establishment of a parent support group. Over the past four decades, we have achieved remarkable accomplishments in support and education, advocacy, and research for the hydrocephalus community.

Throughout the year, we will look back and remember how much you have all helped us get to where we are today and celebrate milestones in our efforts to find a cure for hydrocephalus and improve the lives of those who live with this condition.

Dedicated 40th Anniversary Website

To keep the community engaged and well-informed throughout this celebratory year, we have launched a dedicated website for the 40th Anniversary. Located at **hydroassoc.org/40thanniversary**, this virtual hub acts as a central repository for all the latest updates and exciting developments.

On the site, you will find:

- **Details about the upcoming Gala celebration.**
- **Featured stories and a comprehensive timeline of the association's history.**
- **Special section to share your cherished memories and reflections about HA and our community.**

Gala Celebration

A highlight of our 40th Anniversary will be our Gala celebration. This special event promises to be a memorable occasion where we reflect on past accomplishments while igniting a vision for a brighter future.

Attendees will have the opportunity to immerse themselves in inspiring stories from trailblazing researchers who are at the forefront of shaping the field of hydrocephalus. The Gala will feature live entertainment, delectable cuisine and drinks, and silent and live auctions, providing opportunities to support the cause. Most importantly, the Gala will facilitate connections among fellow community members, fostering a sense of unity and solidarity that will further strengthen our mission.

The 40th Anniversary Gala website provides updated information and additional details regarding ticket purchase options, access to a hotel room block, event schedules and information about the venue and host city.

For questions, please contact Rachel in our Development Department at (240) 483-4181 or rachel@hydroassoc.org.

Throughout the year, we will look back and remember how much you have all helped us get to where we are today.

Please Share Your Cherished Memories and Reflections About HA and Our Community

Department of Defense Research Funding

Final Grants Confirmed

The Office of the Congressionally Directed Medical Research Programs (CDMRP), under the Department of Defense (DoD), manages Congressional Special Interest Medical Research Programs. Within the CDMRP, the Peer Reviewed Medical Research Program (PRMRP), supports research that has the potential to profoundly impact the development and implementation of medical devices, drugs, and clinical guidance that will enhance the precision and efficacy of prevention, diagnosis, and treatment across a wide range of disciplines.

In the 2022 DoD CDMRP PRMRP cycle, 11 hydrocephalus applications were received. Of these 11, **four of the applications were funded, which led to an additional $15.3M in grant awards!**

Bonnie Blazer-Yost, PhD; Teri Belecky-Adams, PhD;
Dr. Shenandoah Robinson, PhD; and Lauren Jantzie, PhD

IUPUI/Johns Hopkins Collaboration
Focused Program Award: $7.8M

Bonnie Blazer-Yost, PhD; Tim Bentley, BVSc;
Robyn McCain, RLATg; and Greg Knipp, PhD

IUPUI/Purdue University West Lafayette
Expansion Award: $3.9M

Young-Kwon Hong, PhD

University of Southern California,
Technology/Therapeutic
Development Award: $3.3M

Maria Garcia Bonilla, PhD

Washington University, St. Louis
Discovery Award: $300K

Ten Innovator Awards go to Scientists for Their Groundbreaking Research

An unprecedented 10 Innovator Awards go out to scientists for their exciting research.

Despite our limited understanding of the causes of hydrocephalus and the most effective ways to treat it in different communities, the 2022 Innovator Award recipients aim to bring about change. They are investigating novel aspects about the development of hydrocephalus and evaluating innovative treatments to enhance long-term results. Additionally, we have expanded our scope to fund research aligned with our published **Community Research Priorities** to include improving access to care and reducing the burden of current treatments.

Ramin Eskandari, PhD

Associate Professor of Neurosurgery and the Chief of the Division of Pediatric Neurosurgery at the Medical University of South Carolina, Charleston, SC. His research will focus on developing a new drug to reduce post hemorrhagic hydrocephalus after a brain injury.

Ryann Fame, PhD

Assistant Professor of Neurosurgery at Stanford University. Her research aims to understand the causes of hydrocephalus.

Gabriel Haller, PhD

Associate Professor at Washington University in St. Louis. His study aims to understand the causes of hydrocephalus.

Olufemi Idowu, PhD

Consultant Neurosurgeon in the Division of Neurosurgery, Department of Surgery, and Professor at Lagos State University. His project aims to guide policies in low/medium income countries to decrease morbidity in patients with childhood hydrocephalus.

Maria Lehtinen, PhD

Professor at Boston Children's Hospital. Her research aims to identify a new therapeutic path for bleeding in the brain in newborn babies, particularly those born prematurely.

James "Pat" McAllister, PhD

Professor at the Washington University in St. Louis. His proposal aims to develop non-surgical treatments for pediatric hydrocephalus.

Carolyn Harris, PhD

Associate Professor of Chemical Engineering and Materials Science at Wayne State University. One of her projects aims to reduce shunt obstruction. Another project, supported by Team Hydro, aims to develop a new drug to ease the symptoms of those living with hydrocephalus. Also, funded by the Rudi Schulte Research Institute (RSRI), her third project aims to fast-track pharmaceutical drug development for hydrocephalus patients.

Together We Can Transform Lives

Under Pressure, our new national research campaign, will drive the development of non-invasive and/or one-time therapies, improve the screening and diagnosis of hydrocephalus, and improve access to care and quality of life for patients.

We have come a long way since the beginning of our journey to dramatically increase the scope of hydrocephalus research in 2009. We find ourselves at a critical juncture – with so many innovative, new ideas and potential for therapies, devices, and ultimately a cure. We must execute a bold plan now to find the support needed to keep this life-changing or impactful research moving forward and bringing these new ideas to market.

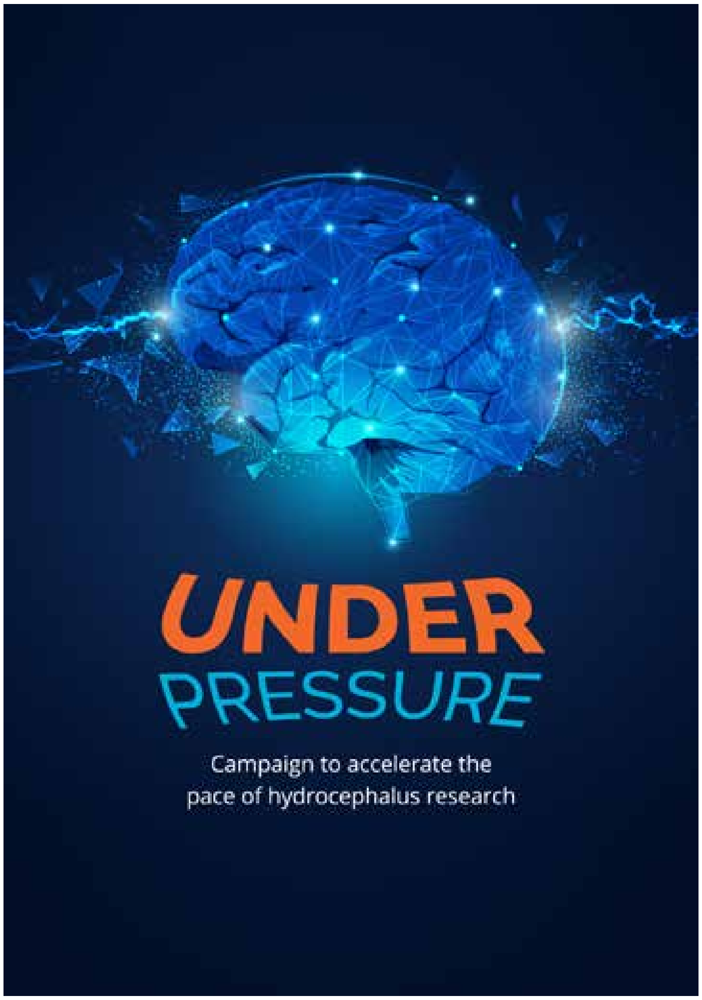
Help Us Relieve This Pressure!

Over the last 13 years, HA has injected $13.8M in grant money to scientists. In turn, these scientists have invested this initial funding into their research to help them secure $73M in additional federal grants through the National Institutes of Health (NIH), the Department of Defense (DOD) and other foundations. HA's initial investment into research has multiplied.

Our awardees would not have secured these grants without the initial investment from HA, made possible by our supporters.

There are many ways that HA supporters can choose to help:

1. **Unrestricted outright gift in any amount**
2. **Unrestricted multi-year pledge**
   (minimum $25,000 over a term of up to 5 years.)
3. **Personalized gift**
   (minimum investment $50,000 outright or pledged.)
   - Designation to one of the four cornerstones of HA's research programs.
   - Innovator Award (minimum investment $50,000.)
   - Designation to one of the five Community Research Priority Areas.



Please help accelerate our research trajectory by supporting the Under Pressure Campaign today.

For more information contact Linda Riley at linda@hydroassoc.org

WALK to End Hydrocephalus

There are 43 WALKs taking place throughout the country including two new WALK locations.

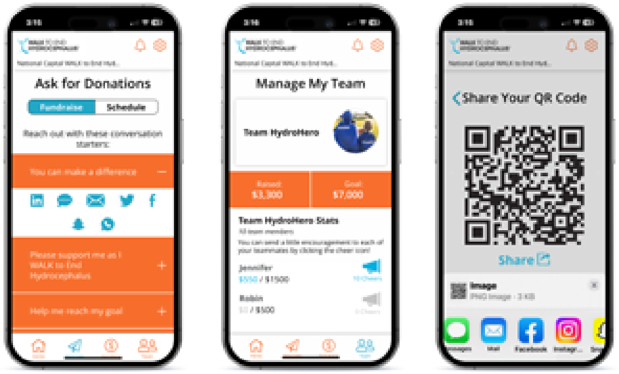
Whether you are WALKing in San Francisco in its 30th year, Denver in its 20th year, Dallas and Cleveland each in their 10th year, or joining us virtually from a city that does not have a WALK – you'll meet others impacted by the condition and help us raise much-needed funds for our research, education, support and advocacy programs.

Where are you WALKing this year?

Scan or visit

hydroassoc.org/find-a-walk-near-you

THE **NEW** AND **IMPROVED WALK APP** IS HERE!



Send messages through Facebook, email, text, Twitter, Snapchat, WhatsApp, and LinkedIn.

View individual and team fundraising progress and encourage your team members with texts and cheers.

Easily share your fundraising page with a QR code.

ANDROID APP ON Google play   Download on the App Store

PLEASE NOTE: The app is **only available to registered WALK participants**.

If you haven't registered, please register for an event near you at hydroassoc.org/walk.

TO START A WALK IN YOUR AREA

Please contact Marina Thompson
at marina@hydroassoc.org

HACONNECT

VIRTUAL

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.

Register today and secure your spot at the most anticipated event of the year!

Social Networking

Friday, November 3rd

8:00–9:30 PM ET

Main Conference

Saturday, November 4th

3:00–9:00 PM ET

Kids Camp

Sunday, November 5th

3:30–5:30 PM ET

To learn more and register visit hydrocephalusconference.org

Don't Miss Our Upcoming Events!

50 States Drive for the Cure

September 2023

Bennett Wilson's son, Dean, was born with hydrocephalus. In an effort to raise awareness about this condition, Bennett and his team transformed the minivan they used to drive Dean to his doctor's appointments and brain surgeries into an endurance race car! This unique and creative approach not only draws attention to hydrocephalus, but also serves as an inspiring symbol of resilience and determination. By repurposing the minivan, they have turned a symbol of medical challenges into a powerful vehicle for spreading awareness and promoting support for individuals and families affected by hydrocephalus.

The current world record for touching all 50 of the United States stands at 133 hours, 10 minutes. Set by a group in a rental car in 2022. With their team's extensive experience in endurance driving and logistical planning, we have come up with a strategy to take almost 24 hours off the record, without the need for excessive speed.

They will start in Honolulu, HI and fly chartered to Juneau, Alaska. Exit the plane on the tarmac to complete the requirement that you must touch the ground in each state. Then immediately fly to the small regional airport in Pasco, Washington. The rest of the route can be seen on the map on the left.

Check back to our HA social media channels for more updates on the Drive for the Cure and to follow Bennett's drive.

Coast to Coast for Hydrocephalus

November 2023

Meet the Touchberry family, Todd and his wife, Jennifer, his daughter Elizabeth and Elizabeth's Mom, Brandy Stevens. In August 2000, Todd and his wife Brandy were so excited that they were going to be parents. However, Brandy wasn't prepared for the news she got when she went for her standard ultrasound. Their baby girl was diagnosed in utero with several abnormalities in her brain, including hydrocephalus, and Todd and Brandy were told that her prognosis was not good. Elizabeth is now 21 years old and has been fighting and beating the odds all of her life. She only spent ten days in the NICU, not the months that they had suggested.

Photo Credit: Cal Cary/The Sumter Item

They have done a lot of fundraisers over the years, but nothing has been quite as epic as what they have in store for November 2023! They are planning a coast-to-coast trip in one of their Ford Model T's. No problem, it's only 3000 miles! And in a 103-year-old Ford Model T! #Coast2Coast4Hydrocephalus

They will hit the road on November 17, 2023, leaving from the east coast in South Carolina and planning to cross the finish line on the west coast in California, all within 13 days. Hopefully, beating the current 14-day record. Their goal is to raise at least $10/mile and donate funds to assist with critical research to help those living with the condition and eventually find a cure. All through Elizabeth's Fluid Fighters.

Continue to follow the latest updates on the Touchberry's Coast 2 Coast Tour at hydroassoc.org/coast-2-coast and help raise awareness and much-needed funding for research to help find a cure for hydrocephalus and to help those living with the condition.

Community Networks

It's important to know that you're not alone on your journey with hydrocephalus. Our Community Networks provide localized support, education, and empowerment through community.

Our network hosts educational events, support group meetings, and other gatherings that enable individuals and families to connect.

National Virtual Meetups

TEENS

Teens Hang-Out

This group is a place for teens with hydrocephalus. We'll hang-out, maybe play an icebreaker game, talk, and hopefully make some new friends.

When: 1st Sunday of the month
Contact: Elizabeth Holthouse, Olivia Maccoux, and Tomas Rodriguez, Teen CN Co-Leaders
Email: info@hydroassoc.org

ADULTS WITH HYDROCEPHALUS

Breaking Barriers Men's Talk (Adults 19 and older)

This group is a safe place where men, ages 19 and older, can share their experiences, support one another, and enjoy the company of other men that understand the journey of living with hydrocephalus.

When: 4th Wednesday of the month
Contact: Alex Trujillo, Peer Support Volunteer and Group Lead
Email: mensgroup@hydroassoc.org

Young Adults in their 20s Meet-Up

This group is a safe place to meet other young adults in their 20s living with hydrocephalus.

When: Every Saturday
Contact: Lauren, Kaitlyn, Ian, Elizabeth, Genesis, MacKenzie, and Aparna, 20s CN Co-Leaders
Email: info@hydroassoc.org

30ish–Living Life to the Fullest HANG-OUT

This group is a place to learn, share, and support others aged 29–40 navigating the journey of hydrocephalus.

When: 3rd Friday of the month
Contact: Dani Lucchese, Sara Stottler, and Janay Harris, 30s CN Co-Leaders
Email: info@hydroassoc.org

Flourishing in Mid-Life: Group for Women Age 40–65

This group is a place to learn, share, and support other women navigating the journey of hydrocephalus and mid-life.

When: 4th Thursday of the month
Contact: Patricia (Patty) Jillson and Lynn Beirl, Group Co-Leaders
Email: info@hydroassoc.org

PARENT'S GROUPS

Parents of Middle School Age Children Group

This group is a place to join other parents to exchange experiences about entering and navigating this especially awkward time of life.

When: 2nd Monday of the month
Contact: Susan Fiorella and Sonja Niemi
Email: info@hydroassoc.org

Parents Supporting Parents of Adult Children with IDD

This group is for parents of adults living with hydrocephalus and intellectual and developmental disabilities. Our community is diverse in the many ways and degrees that hydrocephalus impacts our loved ones.

When: 3rd Thursday of the month
Contact: Jackie Mullock, PA Community Network Leader **Email:** easternpacommunity@hydroassoc.org

FAMILY AND RELATIVES GROUP

L1CAM Family and Relatives Meet-Up

This group is designed to be a source of encouragement, support, and share helpful resources for families and relatives of those with hydrocephalus. Our space to learn more about the impacts of the L1CAM syndrome on families within our community.

When: 3rd Tuesday of the month
Contact: Alison Kandrovy
Email: info@hydroassoc.org

NPH

National NPH Meet-Up

The NPH Community Network is a group for all those living with NPH. We all need to see old friends, and new faces, and have some fun with a community that knows us in a way that only those living the NPH journey do.

When: 3rd Wednesday of the month
Contact: Gary Chaffee
Emall: dallasnphcommunity@hydroassoc.org

For a complete list of HA events online

hydroassoc.org/events

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4340 East West Hwy, Suite 905
Bethesda, MD 20814

NEWSLETTER
VOLUME
41

Thank you!

Thank you for participating in our online fundraising challenges! Your steps and your voice help us move the needle forward in raising funds for critical hydrocephalus research. **This year's challenges have raised more than $105k so far!**