

# CONNECTIONS



American Syringomyelia & Chiari Alliance Project

Winter 2025

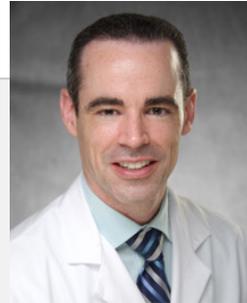
## ASAP'S 37TH ANNUAL CONFERENCE

July 21-24, 2025

Iowa City, Iowa

The 37th ASAP Conference brought together attendees from across the country for a weekend of education, encouragement, and community. Each day included support groups, question-and-answer sessions, and opportunities for personal one-on-one conversations with doctors, giving patients and families space to learn, share, and feel heard.

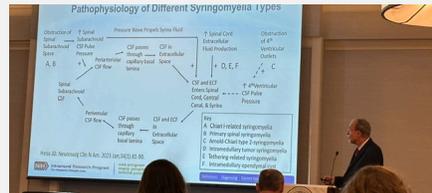
Evenings were filled with celebration and connection through two receptions featuring a comedian, raffles, and spirited ASAP Bingo. We are grateful to everyone who attended and helped make our 37<sup>th</sup> conference meaningful.



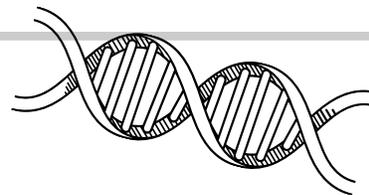
**Esteemed Host  
Brian Dlouhy, MD**

Thank you, Dr. Dlouhy, for your leadership and support. We also deeply appreciate your commitment to CM/SM care and the many Iowa City physicians who shared their expertise with our community.

Dr. Dlouhy is a pediatric and adult neurosurgeon at the University of Iowa Hospitals & Clinics and Stead Family Children's Hospital, specializing in CM/SM and craniocervical junction disorders. He also leads research aimed at advancing the understanding and treatment of these conditions.



## CHIARI & GENETICS



Research suggests Chiari malformation (CM) may have a hereditary component, though it is not a strictly genetic disorder. There appears to be an inherited susceptibility, but no single gene mutation fully explains the condition.

### Genetic Clues from Research

Studies indicate both genetic and structural traits contribute to CM. Familial cases occur in about 3% of pediatric patients, and the condition has been seen in identical twins and triplets, suggesting heredity. Continued on page 4.



## MISSED THE CONFERENCE?

All presentations and Q&A panels are now live on the ASAP YouTube channel. Subscribe to receive notification of new videos.



## BRIDGING NEUROSCIENCE & PATIENT CARE

### 2025 Conference Topics:

- Arachnoiditis
- Chiari Malformation
- Connective Tissue Disorders
- CSF Leaks
- Genetics
- Intracranial Hypo(hyper)tension
- MCAS
- Neurotechnology
- Pediatrics
- Pain/Headaches
- Scoliosis
- Syringomyelia
- Treatment/Surgery

## THANK YOU SPEAKERS

**Paolo Bolognese, MD**  
Oceanside, New York

**Brian Dlouhy, MD**  
Iowa City, Iowa

**Linda Gray Leithe, MD**  
Durham, North Carolina

**John Heiss, MD**  
Bethesda, Maryland

**Bermans Iskandar, MD**  
Madison, Wisconsin

**Jamila Hamdan**  
Madison, Wisconsin

**Safwan Jaradeh, MD**  
Stanford, California

**Petra Klinge, MD**  
Providence, Rhode Island

**Jorge Lazareff, MD**  
Los Angeles, California

**Michael Levy, MD**  
San Diego, California

**Anne Maitland, MD**  
Charleston, South Carolina

**Vincent Martin, MD**  
Cincinnati, Ohio

**Rahul Rastogi, MD**  
Iowa City, Iowa

**Vijay Ravindra, MD**  
San Diego, California

**Rebecca Reynolds, MD**  
Iowa City, Iowa

**Samantha Schutt, ARNP**  
Iowa City, Iowa

**Erol Veznedaroglu, MD**  
Philadelphia, Pennsylvania

**Stuart Weinstein, MD**  
Iowa City, Iowa

**Saul Wilson, MD**  
Iowa City, Iowa

**Mario Zanaty, MD**  
Iowa City, Iowa

**Moss Zhao, DPhil**  
Stanford, California

**Leah Zhorne, MD**  
Iowa City, Iowa



## FROM OUR PRESIDENT

Eric J. Berning



Thank you for being a member and supporter of ASAP. You are why we are here. Many years ago when the organization was first formed, there was no internet and there weren't many resources available to learn about these conditions and their related disorders. Now we have a plethora of resources ([www.asap.org](http://www.asap.org)) and multiple organizations dedicated to the research and education of these conditions. Each organization out there sprouted from the ASAP tree but branched out to achieve the end goal in different ways. That is okay. We embrace the diversity of thought and perspective pursued by each organization, as the ultimate goal is to find the answers we all seek.

ASAP is a solid organization with a 100% volunteer board of directors. Encouragingly, we are in great financial condition for long-term continued support of this community. Our ability to continue the goals of providing funding for critical research and ongoing education/support for patients and providers is stronger now than ever before. What we need more of, however, is your involvement! If you have a passion for these conditions and those affected by them, please consider joining our amazing volunteers to help lead the future of this organization. I encourage you to reach out to me directly so we can have a discussion about how you can become more involved: [Eric\\_Berning@asap.org](mailto:Eric_Berning@asap.org).

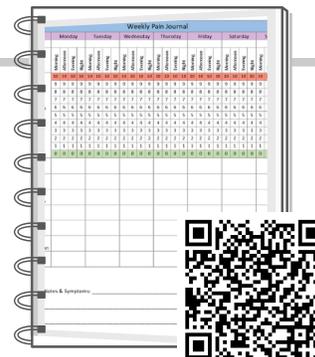
I will close with a very heartfelt THANK YOU to the board, the staff, the doctors, the researchers, and professionals that contribute so greatly to our community—your dedication is immeasurable and so valued by all of us. Many thanks to every one of YOU within our ASAP community for the edifying support, encouragement, and feedback you share with us to make ASAP the premiere organization it is today. We couldn't do it without you!

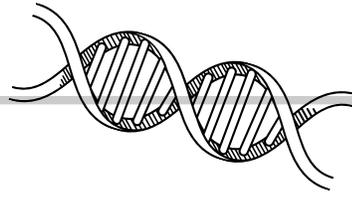
Eric J Berning  
*President*  
American Syringomyelia & Chiari Alliance Project

## COMMUNICATING YOUR PAIN

Learn how to communicate chronic pain more clearly so you can be heard and understood by medical professionals and loved ones. This page offers practical tips for describing pain location, sensation, severity, triggers, and daily impact. A pain journal can help track patterns, improve treatment decisions, and restore a sense of control. With guidance, you can better prepare for appointments and conversations about your pain.

Download our free pain journal template to start advocating confidently for your care.





## CHIARI & GENETICS CONTINUED

Chiari often overlaps with connective-tissue and craniofacial syndromes such as Ehlers-Danlos, Noonan, and Robin Sequence. These links suggest that genes affecting collagen and cranial development may influence susceptibility.

### **Yale University: Investigating Genetic Patterns**

An NIH-supported Yale study used whole-exome sequencing on families with multiple affected members. Researchers identified rare variants in genes tied to connective tissue and craniofacial development, reinforcing that inherited structural traits may raise Chiari risk. Though no single causative gene emerged, findings support a multifactorial model involving genetic predisposition and molecular regulation.

### **Duke University: Familial Traits and Structure**

At Duke, Dr. Gerald Grant's team studied familial Chiari cases using imaging and genetic data. Some families shared reduced posterior fossa volume or altered cranial base angles, increasing the chance of tonsillar herniation.

Genes involved in bone and connective-tissue formation, such as GDF (growth and differentiation factor) genes, CHD3/CHD6, and collagen-related genes, appear to play roles. Genetic factors may differ between pediatric and adult cases or in those with Ehlers-Danlos Syndrome. These results support the idea that genetically influenced structural traits underlie Chiari, even without a single gene identified.

### **Epigenetics and Inherited Susceptibility**

Beyond genetics, researchers are examining epigenetic mechanisms—changes in gene expression rather than DNA sequence. Epigenetic modifications like DNA methylation can be influenced by environment, inflammation, or stress.

An ASAP-funded University of Wisconsin study found unique methylation patterns in families with multiple affected members, especially in genes related to craniofacial and brain development. These results suggest Chiari may arise from altered gene expression shaping brain and skull formation, potentially explaining why severity varies within families.

### **Current Research Directions**

Modern studies combine genetic sequencing and epigenetic profiling to clarify Chiari's origins. Promising gene candidates include:

- FBN1 – connective-tissue integrity (Marfan syndrome)
- GDF3/GDF6 – bone and craniofacial development
- CHD genes – linked to macrocephaly
- Collagen/extracellular-matrix genes – COL7A1, COL6A5, COL1A2, COL5A2
- PI3K pathway – molecular signaling

While these findings highlight key pathways, no gene has been proven to cause Chiari.

## **PARENT RESOURCES**

Explore ASAP's Parent Resources page for websites, tools, and guides to support families of children with CM/SM. From chronic pain and educational advocacy to scholarships, medical grants, and travel help, these resources assist parents in navigating care, schooling, and daily life.

## MATCHING GIFTS

**\$2.86 billion** is donated through matching gifts every year.

If you or your spouse's employer participates in employee workplace giving, you may be able to double or even triple the impact of your gift. Find more ways to donate at [ASAP.org](http://ASAP.org).

### SAVE YOUR CANCELED POSTAGE STAMPS

Collecting postage stamps is a simple, fun way to support the CM/SM community. Stamps are sold to collectors and clubs, with proceeds funding community programs.

Please send cancelled stamps in good condition (on the envelope, trimmed with a 1/4"-1/2" border). Forever, special occasion, foreign stamps, and postcards are welcome. Nonprofit, postage meter, and presort stamps are not collectable.

Mail stamps to:  
Charles Petkevich ASAP Stamp Project  
6202 SW 2nd Court, Plantation, FL 33317

## DONATION RECOGNITIONS

We are honored to recognize the donors who gave in tribute to someone special and helped advance ASAP's mission this year.

### In honor of Donor

#### Lindsay Basile

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David Kalish

#### Richard French

Mary Philo

#### Cliff Shipe

Debi Kagle

#### Larry Underwood

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# MOLLY'S 11TH WALK & ROLL

For eleven years, ASAP Board member Molly Lichtenstein, has hosted an Annual Walk & Roll for a Cure. Molly has shown unwavering commitment to the Walk & Roll tradition and CM/SM cause. Even after undergoing her 66<sup>th</sup> surgery, Molly hosted her 11<sup>th</sup> fundraiser just weeks later, contributing over \$60,000 to CM/SM research through ASAP. In addition to her annual golf tournament, the Walk & Roll featured a silent auction, beautiful mum sale, t-shirt sale, live music, dedicated sponsors, and a note from ASAP Board member, Dr. John Heiss. Past events also included tennis and pickleball tournaments.

This is a fantastic event for families near Gaithersburg, MD, and we look forward to Molly's 12<sup>th</sup> Walk & Roll in September 2026.

Become a sponsor



## LEARN POINTS FUNDRAISING

All fundraisers are eligible to participate in ASAP's LEARN Points Program. Participants receive one point for each dollar donated by sponsors to their personal fundraising page. Then trade-in your points for discounts to our annual conference.



## REMEMBERING DR. ARNOLD MENEZES

With great respect and sadness, we announce the passing of Dr. Arnold Menezes, a visionary leader in neurosurgery.

Dr. Menezes completed his neurosurgical training at the University of Iowa, where he spent more than five decades transforming pediatric and spinal neurosurgery. His groundbreaking contributions to neurosurgical techniques have established a global standard for treating complex craniovertebral conditions. This work

revolutionized advancements in the treatment of Chiari malformation and other skull-based abnormalities.

Dr. Menezes aided ASAP's mission for three decades. Over time, he has held distinguished positions on the Board of Directors, Medical Advisory Board and Research Committee. His leadership has played a crucial role in advancing care for both children and adults affected by Chiari malformation and syringomyelia. We extend our utmost gratitude to Dr. Menezes for his contributions to the ASAP organization and Chiari patients worldwide.

His legacy lives on in the lives he saved and the surgeons he trained. "He will be remembered not only for his extraordinary contributions to medicine, but for the way he lived—with integrity, curiosity, and a heart full of devotion to those he loved."

## DISABILITY RESOURCES

Living with Chiari or syringomyelia can bring unique challenges—but help is available. Visit our Disability Resources page for guidance on applying for benefits, understanding legal rights, and finding support.

### WORKPLACE ACCOMMODATIONS FOR DISABILITY PATIENTS

If you're looking for help with special accommodations at work due to Chiari malformation, syringomyelia, or a related condition, there are several great resources that can guide you.



**1. Job Accommodation Network (JAN) Website -**

Askjan.org offers free, confidential guidance on workplace accommodations and employment issues.

**2. Your HR Department -** If you're employed, your Human Resources department is the place to start internally. Ask about ADA accommodations (Americans with Disabilities Act), modified work hours, remote work or ergonomic adjustments, time off for medical care.

**3. Disability Rights Legal Centers -** If you're facing pushback, you can consult with a disability rights attorney or local legal aid services. Many nonprofits offer free consultations if you need help understanding your rights.

**4. Support Communities -** Join our Facebook groups and ask for shared templates and real-life examples from others who've requested accommodations.

Read more about workplace disability, including a sample letter to your human resources manager on our Disabilities Resources page at ASAP.org.

## MONTHLY SUPPORT GROUPS



### ASAP Virtual Support Meetings

Monthly virtual support group sessions are offered by ASAP at 7:00pm EST every third Tuesday of the month. Meetings will be held over Zoom. These virtual sessions are led by a moderator and a medical professional. Meetings begin March 2026.

### Global Neurosciences Institute Virtual Support

GNI and Dr. Vez, from ASAP's Medical Advisory Board and Research Committee, offer a support group for Chiari Malformation and related disorders every first Wednesday of the month. These virtual sessions are led by a moderator and a medical professional.

American Syringomyelia & Chiari Alliance Project  
P.O. Box 1586 Longview, Texas 75606-1586

# ASAP



The American Syringomyelia & Chiari Alliance Project (ASAP) is a tax-exempt 501(c)(3) organization. Our goals include providing a clearinghouse for information on Syringomyelia (SM), Chiari malformation (CM), and related conditions.



## RESEARCH

ASAP funds research and fellowships to advance studies on Chiari, syringomyelia and related disorders. We partner with the medical community to drive innovation and improve patient care.



## EDUCATION

Our education goals include increasing awareness, early identification of patients and a deeper understanding on the symptoms, causes and management of the disorders.



## SUPPORT

No one should face chronic illness alone. ASAP provides a wide range of resources to help patients navigate their journey with confidence and connection.

## BOARD OF DIRECTORS

We extend our gratitude to the doctors of the ASAP Medical Advisory Board and Research Committee.

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