

ASAP, envisioning a world without the devastating effects of Syringomyelia, Chiari and related disorders

Molly's 9th Annual Walk & Roll Raises \$62,394.50

My name is Molly Lichtenstein. When I was 16, I was diagnosed with Chiari and Syringomyelia after a soccer injury would not heal. After my first surgery, I realized there was a huge lack of awareness in the medical community and the public. That needed to be changed!



From that day on, my life took on new meaning, I have participated in and organized walks for the benefit of Chiari and Syringomyelia since 2009. Last year was incredible. With help from so many people, and despite the challenges that covid threw at us, we had an awesome walk, golf tournament, tennis round robin, and an AMAZING auction. We raised over \$50,000! This is absolutely incredible.

Since my first surgery in 2009, I have had 63 brain and spine surgeries, and I have been diagnosed with many other underlying issues: Ehlers-Danlos syndrome, hydrocephalus, 4th nerve palsy, and tethered cord syndrome. Every year for the last 14 years, that number has continued to climb. I want it to stop at 63 and never get any higher. I know that is short sighted with my degenerative issues, but I want to make a difference.

When I repeat about it being a tough year, it is not for sympathy, but for education. You see, I was under the impression that I would have surgery and be good as new... That was over 60 surgeries ago. I have learned a lot since then and fight with myself constantly about "my path." "We plan, God laughs!" is a slogan I truly live by. Through "failure" after "failure," I have learned that it is all part of the journey, part of my journey.

I don't understand the reasons, but I am confident that part of my grand plan is to raise money for research and awareness of the illnesses that have taken so much from my family and me. But the same illnesses have also given me so much. I have learned to stop and smell the "mums," so to speak. I have learned to appreciate everyday situations. Another saying that has meant a lot over the years, "You don't know what you've got till it's gone," which is so true.

I want to make a change! If I can accomplish anything in life, my wish would be to help find a cure, or a much better treatment, for Chiari and its related conditions. I have come to realize that throughout my life, I will always have setbacks, but as long as I continue to move forward, with the help of my family and friends, anything is possible! The past year has been challenging, but it has shown me that I can genuinely do anything with Molly's Army of Angels surrounding me! Thank you for your continued support and love through this crazy thing we call life!

This year included some new events-- Camp Chiari Kids featuring colored chalk to add a bit more purple and blue to our lives and a few other fun activities, a ladybug release in honor of or in memory of a loved one (to replace the dove balloon release), an auction, an amazing lunch from the grills mad by none other but Darnestown's Men's Night group, and much more.

I am passionate about furthering research in Chiari and Syringomyelia, and I look forward to walking and rolling for a cure each year. This year we raised a total of \$62,394.50 and set our goal for next year at \$100,000. If you would like to join us or help me meet my goal, please contact me Molly_Lichtenstein@ASAP.org for more info.

<https://www.wizathon.com/mollys-asap-walknroll/>

Upcoming Events 2024

May is Syringomyelia Awareness Month!
Share your story with others.

ASAP Annual Conference
July 16-18, 2024
Washington Duke Inn
Durham, North Carolina

September is Chiari Awareness Month,
spread the word.

Central Florida Walk & Roll for a Cure
September 14, 2024
Apokoa, Florida

Molly's 10th Annual
Walk & Roll for a Cure
September 21, 2024
Bretton Woods Recreation Center
Germantown, Maryland

Molly's 7th Annual Mulligan
September 23, 2024
Worthington Manor
Urbana, Maryland

Want to hold an event? Sign up @
<https://asap.org/fundraise/volunteer->

Exciting News!

ASAP 2024 Conference is headed to Durham, North Carolina, famously known as the "City of Medicine." Healthcare is a primary industry including more than 300 medical and health-related companies as well as the Research Triangle Park.

Gerald Grant, MD, Chair of the Department of Neurosurgery at Duke University, will host the meeting which will feature over twenty speakers.

The meeting will start on Tuesday, July 16 and complete in the early evening of Thursday, July 18. In addition to lectures, question-and-answer sessions, and support group meetings, you will be able to participate in several social events.

Speakers 2024:

Robert Keating, MD; John Heiss, MD; Brian Dlouhy, MD; Paolo Bolognese, MD; Cormac Maher, MD; Erol Veznedaroglu, MD; Petra Klinge, MD; Anne Maitland, MD; Bermans Iskandar, MD; Carina Yang, MD; Vijay Ravindra, MD; David Knowlton; Herbert Fuchs, MD; Allison Ashley Koch, PhD; Linda Gray, MD; Deb Bhowmick, MD; Vincent Martin, MD; Alexa Bramall, MD; avid Hasan, MD; Jorge Lazareff, MD; Maria Jose Bugalo, MD and Juan Bosco Gonzalez, MD; Michael Levy, MD; John Crawford, MD; more speakers to come

We look forward to seeing you!

Stamp Project

ASAP members and friends have been collecting postage stamps as a fundraiser since the early 90s. It is an easy and fun way to make a difference. Stamps are sold to collectors and stamp clubs with the proceeds going to support programs for the Chiari and Syringomyelia community.

Please send cancelled postage stamps that are in good condition (attached to envelope and trimmed with a 1/4 to 1/2 inch border around undamaged stamp). Forever, special occasion and foreign stamps are accepted as well as postcards. Nonprofit, postage meter and presort stamps are not collectable.

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



Please Note: Articles in this newsletter are not intended as a substitute for medical advice and do not necessarily represent the viewpoints of the editor, Medical Advisory Board or Board of Directors. Please contact your doctor before engaging in any new therapy or medication.

www.ASAP.org

Visit us on the web and be sure to check out our YouTube and FaceBook groups.



A Word From Our President

Eric J Berning

I'm leaving ASAP.

Now that I have your attention, I need to clarify that I am not leaving today, next week, or anytime in the immediate future. However, I am going to leave when my term

expires. But even then, I won't really be leaving, per se; I just won't be serving as the President of the Board any longer. I will remain actively involved with the ASAP organization and its functions, so I guess saying "I'm leaving" is perhaps a bit extreme. But honestly, I hope it got your attention. My term will be expiring in the next few years, and ASAP will need someone to replace me as the President of the Board of Directors. Will that person be you?

ASAP has both a solid governing board and an astute Medical Advisory Board in place, but we NEED YOU. We need new board members to join us, get involved, and support our organization. We need someone to step up and replace me (although, if I say so myself, there really is no replacing me.). The commitment is not overbearing, but it's rewarding: join a bimonthly conference call, participate in the planning and execution of our annual conference, and help make decisions on the future growth and direction of the organization. It requires belief in our cause and a desire to see ASAP's purpose come to fruition and continue its growth throughout the CM/SM community. It will demand just a limited amount of your spare time but command a limitless amount of your heart. (See what I did there?)

If you are interested in securing the future of this organization and its programs, please reach out to me at Eric_Berning@ASAP.org for an application to the board. I look forward to a full inbox.

The process to join is simple: once you've submitted your application, you will be interviewed by me, the VP, and the Executive Director, and then we will present your qualifications to the full board to discuss and vote on your application. So again, I look forward to an inbox filled with inquiries.

ASAP is the oldest Chiari/Syringomyelia support, research, and outreach organization in the United States. Our Board of Directors is based completely on volunteers. We do have a paid Executive Director and office staff. While this distinction makes us stand out from similar organizations within our CM/SM border community, many of those organizations have been started by people who actually originated with and were inspired by ASAP. Often these groups "split off" from ASAP due to a desire to build a different focus, pursuit of the issues, or

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within limits,
but you can still lead a limitless life.*

organizational model than ASAP's.

That being said, times have changed dramatically since ASAP was founded in 1988. The internet and, later, social media have changed the dynamic for access to information and support models. Even more recently, COVID caused an acclimation to alternative ways of approaching the world and reaching out to others. We are adapting to the "new world" but still hold to many of the classic, traditional methods and processes to conduct education, support and research.

As we progress, we are modernizing our scope and reach. ASAP has funded well over two million dollars in research and will continue financially supporting different projects as opportunities arise. In fact, ASAP recently partnered with the organization Conquer Chiari to fund a portion of their research. We have reached out to other organizations within our broader community to offer the same assistance. An open invitation stands should they want or need it. We are a truly special community, and we want to support and encourage our fellow like-minded organizations to achieve our common goals together.

Here at "home base," ASAP is working to modernize and optimize our website, social media, and other outreach options. We currently have a couple of active virtual support groups and would be happy to help you start and facilitate one yourself if that is a way you'd like to get involved. Of course, we are also very excited to be hosting our 36th annual conference in Durham, North Carolina, this summer. Save the dates: Tuesday, July 16 through Thursday, July 18, 2024. This annual conference is the most active and longest enduring conference in the Chiari/Syringomyelia community. We were thrilled by the participation and attendance of last year's conference in San Diego, and hope to surpass that attendance in Durham.

As I said above...I look forward to hearing from you and know that I will be "leaving" the organization in your capable hands. Until then, remember: You may have to live your life within limits, but you can still lead a limitless life.

Tips for Traveling with Syringomyelia, Chiari & Chronic Pain

by Jennifer Sadrak

Traveling can often be stressful without the added burden of chronic pain conditions. Following this guide will help you enjoy a safe and comfortable journey. Always check with your health care provider with any questions or concerns prior to traveling.

Arrive to the airport early, especially if you need assistance. Having extra time will allow you to take breaks or move around to keep up good circulation before boarding your flight. You can arrange special services in advance when booking your flight.

Carry on all “pain management must-haves.” Double check your packing list for the essentials, like medication, disposable heating/cooling pads, braces, pain creams, a neck pillow and any other comfort items. Bring gum for “popping ears” and a couple anti-inflammation snacks, especially if you have food sensitivities.

Documentation of your illness, along with your doctor’s name and phone number, can be helpful at TSA checkpoints or if you happen to need medical assistance. Providing a physician-signed medical letter detailing your chronic pain condition may help obtain special accommodations, like an upgraded seat, extra blankets or pillows or permission to move around when needed.

Emergency contact setup is available on smart phones. Add a trusted individual for emergency responders to call and add any medical concerns to your Medical ID on your phone. First responders can access this information without your phone’s password. Consider wearing a medical alert bracelet with this information so it’s always on your person.

Fill any prescriptions or pain medicine well in advance. Have enough for the duration of your trip plus several extra days’ supply in case of unforeseen delays.

Ground transportation may also be a part of your journey. Thankfully, there are increasing options for comfortable rides. App services like UberWAV, and Lyft AccessMode Pilot allow wheelchair access. If renting a specially equipped van is needed, services like Accessible Vans of America or Freedom Motors may be helpful.

Hydration is key to feeling your best and avoiding chronic pain. Bring a lightweight refillable water bottle to fill for free once you pass through security.

You may want to consider a trusted friend by your side. It may be possible to get permission for a companion to accompany you through security and boarding. Contact the airline in advance to learn how.

Keep moving as much as possible. Long periods of time sitting can make back and neck pain worse. Try stick-on heating pads or a brief walk to get circulation moving.

Medication is a top priority. If you have medications that need to be kept cold, bring a lunch box with freezer pack and make sure there’s a refrigerator in your hotel room to store them.

Neck support is critical for resting comfortably with chronic Chiari and syringomyelia neck pain. Don’t forget a supportive travel pillow and also a blanket. Airports and planes are notoriously cold.

Obtain precheck enrollment, beginning with an online application. TSA PreCheck or a Global Entry membership can help you speed through airport security screening. Check the Department of Homeland Security’s Trusted Traveler Tool for more information about pre-boarding and other services.

Research what assistance is available and if you qualify for medical assistance. The U.S. Department of Transportation provides a guide on Wheelchair and Guided Assistance. Contact the airline and airport 48-72 in advance to request accommodations. With advance notice, the airport can provide wheelchair access, luggage help, elevator access, tips getting through security and early boarding.

Ship luggage or heavy and bulky items to your destination. Check prices for local carriers or try services like Luggage Free, Send My Bag and Lugless that handle delivery directly to your hotel or other locations.

Traveling by train might be your most comfortable option. Not only do you have more space to sit, but you also can stand up and stretch during the ride.

U.S. Department of Transportation provides a full list of services that airlines are required to provide individuals with disabilities on their website. Visit transportation.gov for more info.

Wear comfortable clothes and pack a good pair of shoes for walking or standing, especially if you’re sightseeing. You may even want to bring a back-up pair, but pack as light as possible to avoid the stress of carrying unnecessary weight.

Expect the worst and be prepared (with more than that extra pair of shoes). You may even want to book an extra day or two for resting, especially if traveling a long distance.

You are not invisible. Airline personnel are trained to assist anyone who self-identifies as needing assistance services. You can obtain a sunflower lanyard from customer service to signify an invisible illness.

TSA Cares provides details about screening policies and what to expect at security checkpoints. If you find yourself in need of special accommodations, ask a TSA agent for a “passenger support specialist” at the airport.

Spreading Awareness

Awareness doesn't just happen once or twice a year.

The Florida support group had a great showing at Apopka City Hall for Light-it-Purple in honor of Chiari Awareness Month. Several long-time members, as well as quite a few new people, participated. Once introductions were made, the attendees shared their stories. Board member Jeni Conrad Adair said, "I got so many thank-yous, and it was just another re-affirmation for me of why what we do is so important."



In February of this year, Jeni participated in her local Paws in the Park. She shared information about Chiari and Syringomyelia, both in humans and in dogs. The Central FL chapter also plans to hold an ASAP Walk & Roll in September 2024.

We would love to hear more stories like these. Please contact Patricia_Maxwell@ASAP.org if you have an event to share.



Remember ASAP...

When It's Time to Remember Loved Ones

Our appreciation to everyone who made a recent donation to ASAP on behalf of their friends and loved ones.

We will send an acknowledgement card to individuals or families when you make a donation of \$5 or more donation to the organization. Please indicate whether the gift is 'in honor of' or 'in memory of' and provide the name and mailing address of the person you would like to honor.

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Unexpected kindness
is the most powerful,
least costly and most
underrated way to
change a life.



ASAP Contact Information

Mailing Address:
PO Box 1586
Longview, TX 75606-1586

Physical Address:
300 North Green Street, Suite 412
Longview, TX 75601-7337
Phone: 903-236-7079
Fax: 903-757-7456
Toll-free: 800-ASAP-282
Email: info@ASAP.org

Patrice Schaublin,
Executive Director
Patrice_Schaublin@ASAP.org
Phone: 585-747-9651

Jamie Mayhan,
Programs Director
Jamie_Mayhan@ASAP.org

Patricia Maxwell,
Operations Director
Patricia_Maxwell@ASAP.org

Histological Investigation of the Posterior Atlanto-Occipital Membrane in Pediatric Patients with Chiari Malformation

This study funded by ASAP with principal investigator Vijay M Ravindra, MD, MSPH has completed. An article published in PLOS ONE in January 2024 reported the following findings.

Introduction:

The fibrous posterior atlanto-occipital membrane (PAOM) at the craniocervical junction is typically removed during decompression surgery for Chiari malformation type I (CM-I); however, its importance and ultrastructural architecture have not been investigated in children. We hypothesized that there are structural differences in the PAOM of patients with CM-I and those without.

Methods:

In this prospective study, blinded pathological analysis was performed on PAOM specimens from children who had surgery for CM-I and children who had surgery for posterior fossa tumors (controls). Clinical and radiographic data were collected. Statistical analysis included comparisons between the CM-I and control cohorts and correlations with imaging measures.

Results:

A total of 35 children (mean age at surgery 10.7 years; 94.3% white) with viable specimens for evaluation were enrolled: 24 with CM-I and 11 controls. There were no statistical demographic differences between the two cohorts. Four children had a family history of CM-I and five had a syndromic condition. The cohorts had similar measurements of tonsillar descent, syringomyelia, basion to C2, and condylar-to-C2 vertical axis (all $p > 0.05$). The clival-axial angle was lower in patients with CM-I (138.1 vs. 149.3 degrees, $p = 0.016$). Morphologically, the PAOM demonstrated statistically higher proportions of disorganized architecture in patients with CM-I (75.0% vs. 36.4%, $p = 0.012$). There were no differences in PAOM fat, elastin, or collagen percentages overall and no differences in imaging or ultrastructural findings between male and female patients. Posterior fossa volume was lower in children with CM-I (163,234 mm³ vs. 218,305 mm³, $p < 0.001$), a difference that persisted after normalizing for patient height (129.9 vs. 160.9, $p = 0.028$).

Conclusion:

In patients with CM-I, the PAOM demonstrates disorganized architecture compared with that of control patients. This likely represents an anatomic adaptation in the presence of CM-I rather than a pathologic contribution.

Dr Ravindra presented his finding during the annual ASAP conference held last July in San Diego, California. The presentation was videotaped and is available on the ASAP YouTube channel. 2023 Conference Dr. Ravindra "Morphological/Ultrastructural Investigation....in Children with CM" <https://www.youtube.com/watch?v=v6gZsv4i6sc>





ASAP's Mission: to improve the lives of persons affected by Syringomyelia, Chiari malformation and related disorders while we find the cure.

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ASAP Connections

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.

We offer a supportive network of programs and services and fund research to find better therapies and cures. ASAP is supported by tax deductible donations.

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Mail: ASAP Connections
PO Box 1586
Longview, TX 75606

Editor: Patricia Maxwell
Email: Patricia_Maxwell@ASAP.org