

ASAP Connections

Providing Research, Education and Support since 1988

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

September is Chiari Awareness Month

Help make a difference for the tens of thousands of children and adults affected by this disorder.

Ways to help:

Social Media - We are constantly on the go, and social media is the go-to for staying connected. What's your favorite social channel to reach a wide audience in a timely manner? FaceBook, Instagram and Twitter reach billions of users monthly.

- Share our daily social media prompts
- Use our September profile picture frame
- Share your personal story and tag us,
- @ASAPorg #ChiariMalformationAwareness #ChiariAwarenessMonth #ASAPforChiari
- Request a local building to be lit up in purple
- Request a State proclamation to make September Chiari Awareness Month

Create A Challenge - Another simple, yet effective way to raise awareness is to host a fundraiser. A local walk, bake sale, chili cook off, golf tournament or live auction are just a few popular ideas. You can create a fun afternoon while spreading awareness and raising funds to promote education. Earn valuable points to attend next year's conference at the same time. For more information visit asap.org/conferences/2024-conference/asaps-l-e-a-r-n-points-program/



Share the Love - Classic silicone bracelets are a great way to show and grow awareness all year long. ASAP has a variety of bracelets you can purchase

and share with family, friends, coworkers, classmates and neighbors. Visit the 'store' on the ASAP.org website to see what is available. <https://ASAP.org/shop/>

Advocate - Those who want to volunteer or give their time and voice have a variety of platforms available with the organization. Advocacy comes in many forms, from donations to a loud voice. There is no right or wrong way to care. ASAP needs those willing to lead. Volunteer with the



Board of Directors, support groups, write articles of interest to our community or share your ideas.

Want your Chiari journey featured in the next edition of ASAP Connections? Send a photo and short story (500 words or less) to Patricia_Maxwell@ASAP.org for consideration.



Synonyms of Chiari

- Arnold-Chiari Malformation (ACM)
- CM
- Hindbrain Herniation
- Tonsillar Ectopia

Subdivisions

- Chiari type 0 (Chiari malformation zero)
- Chiari type I (Chiari malformation I)
- Chiari type II (Chiari malformation II)
- Chiari type III (Chiari malformation III)
- Chiari type IV (Chiari malformation IV)

Upcoming Events 2024

September is Chiari Awareness Month, spread the word.

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

Molly's 7th Annual Mulligan
September 23, 2024
Worthington Manor
Urbana, Maryland
<https://mollysmulligan.com/>

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

"The flower that blooms in adversity is the most rare and beautiful of all."

Fa Zhou, Mulan

Bobby Jones Open Assistance Grant

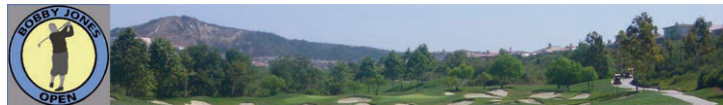
The Bobby Jones Open makes it possible for ASAP members to improve their quality of life and enjoy a more independent lifestyle. Grants up to \$1,000 are available for qualifying ASAP members to assist with the purchase of adaptive equipment and other devices.

You must be a member of ASAP for 6 months prior to applying for the grant, have a diagnosis of Syringomyelia or Chiari, and provide a written quote for total cost of the item. Checks are made payable to both the vendor and ASAP member. Other validating information is outlined in the confidential application available online <https://asap.org/resources/bjo-equipment/> or by contacting the ASAP office.

Past awards have included purchasing ramps, a therapeutic bicycle, accessible shower, lift chair, wheelchair accessories, elevator stair-lift, and more.

The Bobby Jones Open was founded in 1979. Its annual golf tournament raises funds for scholarships, grants and research. Over 350 'Bobs' from thirty-eight states and four countries have participated over the years raising thousands of dollars.

The BJO recently awarded twelve scholarship for the 2024-2025 school year to ASAP members.



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



September is my favorite month of the year. The weather changes, we start getting cooler temperatures, and football reigns supreme once again. Of course, I am biased about my love of September, as both my wedding anniversary (we are celebrating our 23rd this year) and my birthday (oh, darn, it seems my keyboard doesn't have numbers that go that high!) also fall in this lovely month. On top of that, it is when we observe Chiari Awareness Month!

The conference in North Carolina was amazing. Thank you to Dr. Gerry Grant for hosting and putting together a fantastic program. The presentations are being worked on now and should be uploaded to our YouTube channel very soon. Please plan to join us next July in Iowa City, Iowa, when Dr. Brian Dlouhy will be hosting the conference, and we will honor the many years of commitment to the organization of Dr Arnold Menezes.

I know I don't have to tell you this, but Chiari and Syringomyelia STINK! They are conditions that no one can see without complex imaging, and ones that affect everyone who has them uniquely. They are those "invisible conditions" that you certainly know you have, but when others see you, they often tend to think, "Well, you look fine." Depending on the severity of the malformation, where, how wide, and how long your syrinx is, your little "symbiotic friend" could affect you significantly, and quite differently than others.

Just yesterday I had an appointment with an orthopedist because I have been experiencing unfamiliar shoulder pain over and above what I would consider my "normal" pain level. I figured that I'd pulled a muscle, or perhaps—given my "impending age"—I'd developed an "older" man's issue like bursitis, something I recently developed in one of my knees.



But NOOO...the doctor reviewed my x-rays, put me through a series of physical tests, and told me it didn't appear to be structural. Although the shoulder looks great, he explained, an underlying issue in the C5-C6 area of the spine is a common "unseen" contributory factor.

Ah, yes: my syringomyelia! The narrowed, sensitive nerve root/endings coming out near a syrinx that cause chronic pain and discomfort. It truly is never an easy answer or remedy. So many around us are completely unaware that we have to manage our lives around these conditions. They don't necessarily see any physical issue, so it doesn't exist in their minds. Even those of us with Chiari and syringomyelia don't always realize that it can be the sneaky culprit behind random, painful changes in our daily lives. That's why awareness is so important and why September is such a great opportunity to raise awareness.

Commit to doing something this month for Chiari Awareness. It could be something grand like Molly's events in Maryland (check out her 10th annual Walk & Roll for a CURE/silent auction and the 7th annual Molly's Mulligan at mollysasapmissions.org), or something simple like talking to your hairdresser about your condition. I have a little fun with this one myself. Every time a new person cuts my hair, I say I want a #2 on the sides and back, faded up and straight across the ears and back. Then I wait until s/he takes the clippers right up the middle of the back of my head, across my Chiari decompression scar, and dramatically warn, "Oh, hey, just be sure when you cut the back that no one can see that scar!" Of course, it's too late, as they just ran the #2 clipper over the area, and I have to laugh and reassure them that I'm only kidding—but it opens up a conversation about CM/SM and why I have that scar in the first place (and no, it's not because I was hit on the back of the head with a bottle at a rock concert!). Simple awareness (and a little humor on my part).

Have a wonderful September and commit to bringing awareness to someone new when you have the opportunity to do so. Always remember, you may have to live a life within limits, but you can still lead a limitless life!

ASAP Funded Research

Timothy M George Fellowship Award presented to Kelsi Chesney, MD

Dr Chesney is a neurosurgery resident at MedStar Georgetown University and associated with Childrens National Hospital. The project, "Tonsillar Manipulation During Chiari I Malformation Surgery: A Multi-Institutional Analysis," was awarded a seed grant of \$17,722.00.



Dr Chesney wrote, "I am particularly drawn to the multi-institutional collaboration that this project plans for. I firmly believe that the future of medicine lies in collective efforts of diverse experts working together to solve complex problems."

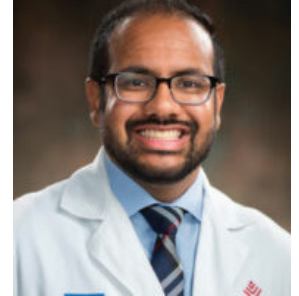
Current literature on the surgical technique for Chiari (CM) consists of case series with variable cohort sizes and follow-up times, yielding disparate results and emphasizing the intricacies of clinical decision-making when dealing with CM patients. Multiple series have demonstrated that tonsillar manipulation is associated with increased postoperative complication risk, such as pseudomeningocele, hygroma formation, and meningitis, as well as higher rates of treatment failure. However, a recent survey of international experts in the field of CM shows that the most experienced surgeons agree that more invasive techniques are the most effective.

While posterior cranial fossa decompression remains the standard of care for symptomatic CM, the extent of intradural work, particularly tonsillar manipulation, remains a contentious issue. The goal of this fellowship project will be to investigate the extent of tonsillar manipulation during surgical treatment of CM as it relates to multiple outcome parameters through extensive data collection across multiple institution.

[To view current and completed ASAP funded research visit <https://ASAP.org/research>]

University of Utah Grant Award, Principle Investigator Vijay Ravindra, MD, MSPH

Validating an Analytical Model for Cerebral Spinal Fluid Flow across the Foramen Magnum in Children with Chiari Malformation with Syringomyelia: A Study of Patients Before and After Surgery



Summary of Research: In a prospective study of children with Chiari malformation with Syringomyelia, we aim to numerically model the velocity of CSF flow at the craniocervical junction and validate the findings against phase-contrast MRI techniques for estimating the velocity.

Syringomyelia is characterized radiographically by the presence of a slender fluid-filled cavity within the spinal cord. It is a common occurrence in patients with Chiari malformation type I (CM-I), which is characterized by displacement of the cerebellar tonsils greater than five millimeters below the foramen magnum with a resultant alteration or obstruction of the normal flow of cerebrospinal fluid (CSF). The behavior of the CSF can be mathematically described as Newtonian. In CM-I, the aberrant CSF dynamics at the foramen magnum create a syrinx within the spinal cord, which typically occurs in the cervical region but may extend into the thoracic spine or the medullary structures (intra canalicular).

The proposed study aims to develop an initial analytic understanding of this complex region, which represents a significant knowledge gap. We anticipate these findings will serve as pilot data and a stepping stone to understanding fluid-flow implications of the disease process, with hopes of tailoring treatment for children with Syringomyelia based on the information gathered.

2024 ASAP Conference Videos Available on our YouTube Channel Soon

SUBSCRIBE TO OUR YOUTUBE CHANNEL

for conference video updates & more



SCAN ME

@ChiariSyringomyeliaASAPorg

How to Manage Changes in Barometric Pressure

If you know you can predict the weather better than your local meteorologist, you're not alone. We've heard all our lives that people with arthritis can tell you when a storm is coming so why does it seem so unusual that those affected with these disorders can do the same thing? Chiari and Syringomyelia is all about pressure, right? It only makes sense that changes in the barometric pressure are going to affect you. The next time you think a storm is coming because of an increase in symptoms, you're probably right.

Barometric pressure, which is the weight of the air above us, affects the body in several ways, especially when it changes rapidly. Symptoms of barometric pressure changes can vary in intensity depending on the individual and the degree of pressure change.

Symptoms can include:

Fatigue & Headache Issues

Weather Fronts: Changes in barometric pressure associated with weather fronts can impact the body. For example, a sudden drop in pressure before a storm can trigger migraines or headaches in susceptible individuals. Some people also report joint pain or increased sensitivity to pain with changing weather conditions, although scientific evidence is mixed on this.

Sinus Issues

Pressure Imbalance: The sinuses are air-filled cavities, and rapid changes in barometric pressure can cause discomfort or pain if the pressure inside the sinuses doesn't equalize quickly.

Respiratory Effects

Oxygen Availability: At lower barometric pressures, such as at high altitudes, the air is less dense, and there is less oxygen available, which can make breathing more difficult. People with respiratory conditions or allergies might experience exacerbated symptoms under these conditions.

Cardiovascular Effects

Circulation: Changes in barometric pressure can affect blood circulation. For instance, at high altitudes, the heart has to work harder to pump oxygen-rich blood through the body. Some individuals with cardiovascular issues might experience increased strain.

Gastrointestinal Issues

Gas Expansion: In low-pressure environments, gases in the digestive tract can expand, potentially causing bloating or discomfort. This is more noticeable during air travel or high-altitude activities.

Psychological Effects

Mood and Sleep: Some people might notice changes in mood and irritability or sleep patterns with fluctuating barometric pressure. While not fully understood, this could be related to the body's overall stress response to pressure changes.

Can traveling to varying altitudes affect the body?

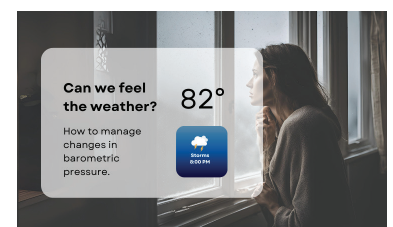
Yes, traveling to varying altitudes can affect the body, primarily due to changes in oxygen levels and atmospheric pressure. Your body has mechanisms to adapt to different altitudes, but the rate of acclimatization and the severity of symptoms can vary widely between individuals. The body usually acclimates to pressure increase over time by producing more red blood cells to carry oxygen more efficiently. If you're planning to travel to high altitudes, it's a good idea to ascend gradually, stay hydrated, and be aware of the symptoms of altitude sickness. At moderate altitudes (2,500 to 8,000 feet / 750 to 2,400 meters), some people might begin to notice mild symptoms of altitude sickness, such as headaches, dizziness, or shortness of breath, especially if they ascend rapidly.

In general, most people adapt to normal barometric pressure changes without issue, but those with certain health conditions or who are sensitive to pressure fluctuations might need to take extra precautions.

To alleviate physical discomfort from changes in barometric pressure, try these steps:

1. **Stay Hydrated:** Drink plenty of water to help maintain fluid balance.
2. **Use Humidifiers:** Keep indoor air moist to ease respiratory issues.
3. **Manage Allergies:** Take antihistamines when needed.
4. **Exercise:** Light physical activity can improve circulation and reduce discomfort.
5. **Warm Compresses:** Apply heat to sore areas to relieve pain.
6. **Deep Breathing:** Practice relaxation techniques to reduce stress and tension.

These strategies can help minimize discomfort associated with barometric pressure changes. We always recommend consulting with your doctor for professional advice if symptoms persist or increase.



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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Chiari 101

Chiari malformations are a group of complex brain abnormalities that affect the area in lower posterior skull where the brain and spinal cord connect. The underlying anatomy of Chiari malformations is thought to be present at birth (congenital), although in many cases they may not become clinically apparent until adulthood. In extremely rare cases, a Chiari malformation may be acquired during life. The exact cause of Chiari malformations are not known, but often the cavity near the base of the skull (posterior fossa) is narrow and abnormally small in relation to the size of the cerebellum, which this portion of the skull encloses.

Researchers believe that in some cases the small posterior fossa may cause the developing brain, specifically the cerebellum and the brainstem, to be pushed downward. Part of the cerebellum (known as the cerebellar tonsils) may protrude (herniate) through the foramen magnum, which is the normal opening found in the occipital bone at the base of the skull. The tonsils may thus interfere with the flow of cerebrospinal fluid (CSF) to and from the skull and spinal canal, potentially leading to accumulation of cerebral spinal fluid in the subarachnoid spaces of the brain and spine. A Chiari malformation can also cause pressure on the brain and produce hydrocephalus (pressure due to excessive cerebrospinal fluid accumulation in the brain) and the spinal cord, potentially causing a wide variety of symptoms.

In fact, no two cases of Chiari malformation are exactly alike and the associated symptoms are highly variable. The severity of Chiari malformations can vary dramatically as well. In some cases, affected individuals may not develop any symptoms (asymptomatic); in others, severe, potentially debilitating or life-threatening symptoms can develop.

Traditionally, Chiari malformations have been defined and classified by how much of the cerebellar tonsils protrude through the foramen magnum. A diagnosis of a Chiari malformation usually signifies that the cerebellar tonsils protrude below the foramen magnum (often cited as at least 5 millimeters, though this is controversial). However, researchers have determined that the length of tonsil descent in a Chiari malformation does not always correspond to the severity of symptoms or to the response to treatment. In fact, some individuals are classified as having Chiari malformation type 0, in which there is minimal or no descent of the cerebellar tonsils. These individuals still have symptoms associated with a Chiari malformation, most likely due to abnormalities in the flow of cerebrospinal fluid within the skull and spinal canal.

Research is ongoing to understand the complex, underlying mechanisms that cause Chiari malformations.

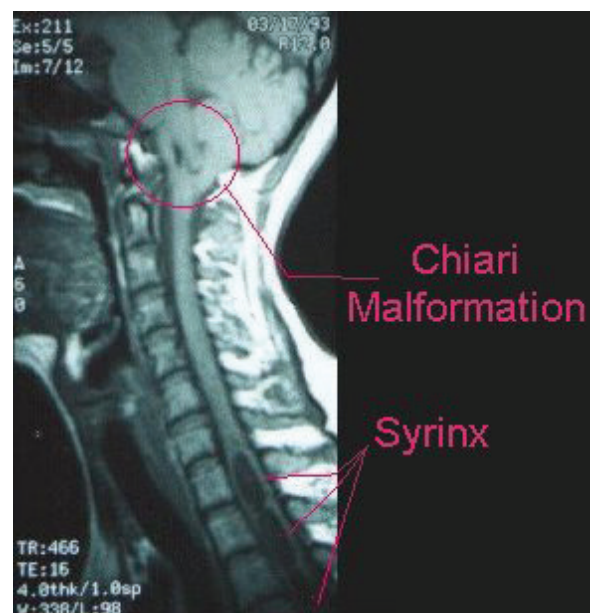
Syringomyelia 101

Syringomyelia, often referred to as SM, is a chronic disorder involving the spinal cord. The condition occurs when cerebrospinal fluid (normally found outside of the spinal cord and brain) enters the interior of the spinal cord, forming a cavity known as a syrinx.

This syrinx often expands and elongates over time, destroying the center of the spinal cord. As the nerve fibers inside the spinal cord are damaged, a wide variety of symptoms can occur, depending upon the size and location of the syrinx.

There are two major types of SM. In most cases it is related to a congenital malformation involving the hindbrain (cerebellum) called a Chiari I malformation. This malformation occurs during fetal development and is characterized by downward displacement of the lower part of the brain (cerebellar tonsils) beneath the foramen magnum, into the cervical spinal canal. This displacement blocks the normal flow of cerebrospinal fluid. When normal flow is obstructed, a syrinx can form in the spinal cord. Not all patients with Chiari malformations will develop a syrinx, however.

SM can also occur as a complication of trauma, meningitis, tumor, arachnoiditis, or a tethered spinal cord. In these cases the syrinx forms in the section of the spinal cord damaged by these conditions. As more people are surviving spinal cord injuries, more cases of post-traumatic SM are being diagnosed as the syrinx can form years after the trauma.





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.

ASAP Connections is published quarterly for ASAP members. Your contributions of articles, letters, and photos are encouraged. The editor reserves the right to edit any article in order to accommodate space.

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