

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

ASAP Conference

Unfortunately our in-person meeting to be held in October was cancelled due to health concerns for our members and speakers. We are hoping that 'third times a charm' plays true and have rescheduled the meeting for July 2022. We plan to have a completed agenda ready by the end of January with registration and detailed conference information available on our website.

We hosted several webcasts during September and October. The recorded presentations which include lecture and Q&A are available on our YouTube channel.

<https://www.youtube.com/c/ChiariSyringomyeliaASAPorg>

Or go to www.ASAP.org and click on the YouTube icon located in the upper right corner of the screen.

The online auction that was to take place during the conference was also cancelled. Items already donated will be used for the rescheduled auction in 2022.

Member Support

Laurie Swihart's creative pumpkin carving skills resulted in a \$5,000 donation to ASAP from Technology Marketing Toolkit. She won first prize and chose ASAP as a recipient of the award.

The Swihart family have been avid supporters of ASAP for many years. Paying it forward with not only fundraising but supporting other families who find themselves in a similar situation.



Laurie said the support ASAP provided her in the beginning of their journey made a huge difference. She is thankful and tries to provide that same support to other families.

Syringomyelia Associated with Chiari

An article in *Neurosurgery* (volume 88, issue 1) January 2021 described the work of Jacques Lara-Reyna, MD, John Chae, BA, Umberto Tosi, MD, Mark M Souweidane, MD, Rafael Uribe-Cardenas, MD, MHS, Jeffrey P Greenfield, MD, PhD to introduce a grading system focusing on syrinx reduction following Chiari surgery.

Although the connection between Chiari and Syringomyelia is accepted, the debate remains on how best to define changes in the syrinx following surgery.

The objective of the study was to introduce a grading system focusing on syrinx reduction. They expect to be able to predict a patient's prognosis based on reproducible radiological information. Data from 48 patients was compiled. They calculated syrinx cross-sectional area by approximating an ellipse in the largest axial plane. The team compared the percentage of reduction or enlargement following surgery. The percentage change was grouped into four grades: Grade 0 = Increasing size, Grade I \leq 50 percent reduction, Grade II = 50 to 90 percent reduction, Grade III greater than 90 percent reduction.

The results reported a total of 89.6 percent of patients had syrinx improvement after surgery. A total of 5 patients were Grade 0, 14 were Grade I, 20 patients were Grade II, and 9 patients met criteria for Grade III. The mean postoperative syrinx area was 24.1 mm² (0-169 mm²) with a mean syrinx reduction of 62.7 percent.

In conclusion they stated radiological improvement of Syringomyelia can be mathematically defined and standardized to assist in communication in outcome-based trials.



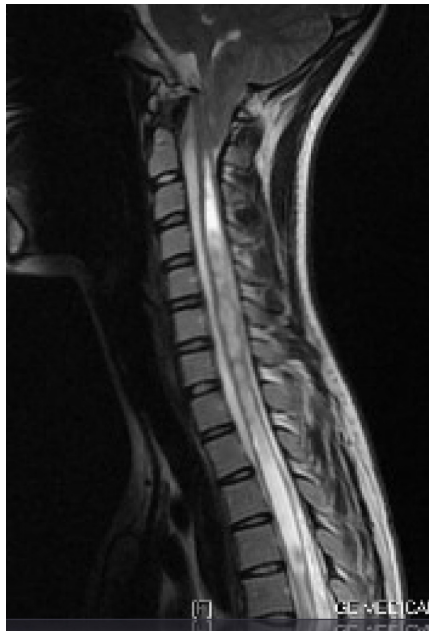
Arachnoiditis is a debilitating disorder that develops after inflammation in the cerebrospinal fluid (CSF) leads to scarring within the CSF pathway and surrounding membranes.

Source of CSF inflammation:

- Infection (meningitis)
- Bleeding (subarachnoid hemorrhage)
- Injected chemicals (spinal anesthetics +/- contaminants)
- Surgical intervention
- Trauma

Scarring effects:

- CSF pathways: Syringomyelia
- Pial membrane: Reduced spinal cord blood flow
- Arachnoid membrane: Tethering of the spinal cord to the surrounding dura



Cannabis Research Project

Dear ASAP members

As part of an ASAP sponsored research project, Global Neurosciences Institute (GNI) and Cannabis Education and Research Institute (CERI) invite you to complete a survey about your experiences with medicinal cannabis.

This survey is intended for people that are taking medicinal cannabis. GNI/CERI will be using a platform called CareCheck which sends out text messages and email alerts to complete the survey on your mobile device or computer.

If you are interested in participating in this research study, please contact Dr Christina Maxwell (cmaxwell@gneuro.org) at GNI. GNI/CERI will request your name, email address and/or cell phone number in order to electronically distribute the survey. If you have any questions, please feel free to reach out to Dr Maxwell.

strength is made perfect in weakness

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

Thank you!

I do say it, but probably not as often as I should. I do think it a lot; however, sometimes I am just not very good at remembering to say it to those for whom it would be meaningful to hear and bring a smile to their face. I am thankful for my wife, my son, and all my brothers and sisters. I am thankful for my awesome parents who raised all nine of us kids to be good humans. I am thankful for my in-laws who welcomed me into the family with open arms 20 years ago. I am truly thankful for the many people who have impacted and influenced me throughout the years. And I am certainly thankful for YOU and all the supporters of ASAP. You make me smile!

ASAP has been very fortunate throughout the years to have extraordinary supporters and members. While we don't have a magic wand that can fix everything about Chiari, Syringomyelia, and their related disorders, we can, with the help of you, continue to spread awareness, educate people, fund research, and provide support for those who are living with and supporting those affected by these conditions. We are incredibly grateful for that.

Speaking of spreading awareness: Does your neurologist know about ASAP? Does your neurosurgeon? How about your GP, does he or she know? How much do they know about your Chiari or Syringomyelia? It is important that we help bring better understanding to our personal physicians and the medical community as a whole. We have a plethora of resources available for your healthcare providers to better understand what you are dealing with—I strongly encourage you to direct them to our website at ASAP.org.

At ASAP's Annual Conference, a vast array of specialists gather as our guest speakers to discuss their latest research, their experiences, and host an open discussion on treatment options and methods of care. Do you believe your neurologist or neurosurgeon would benefit by better understanding what you are going through? Do you think you would? Then I invite you to mark your calendar for July 20-23, 2022, when we will hold an in-person conference in Chicago, Illinois. Next year's conference will open on Wednesday with a few speakers, followed by a lovely dinner cruise on Lake Michigan to enjoy the evening together and watch fireworks over the magnificent skyline. On Thursday and Friday we will continue with a full schedule of speakers during the day, with a special banquet on Friday evening to share another meal together in a more formal environment.



The conference will wrap up on Saturday morning with our final speakers, then adjourn around noontime, giving everyone a free afternoon to either travel home or enjoy the sights and wonders of the Windy City. Because we have had to go virtual the past couple years, we wanted to make this next in-person conference a little more special for all of us. Breakfast is included each day, so other than your room rate and conference registration fee, you really only need to plan for your lunches each day and dinner Thursday night—the rest, including the dinner boat cruise, is included.

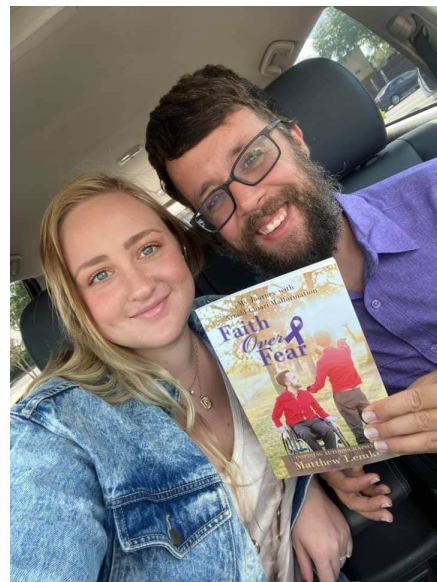
If you are not aware, past conference videos are available on our website and our YouTube channel. We welcome you to watch and share with others. We also held a handful of “mini conferences” on Zoom last month—we have uploaded these talks for those of you who may have missed them or want to revisit the topics discussed.

While ASAP is unable to send direct support or refer you to any specific doctor, we can share the vast knowledge and experience of an organization that has been dedicated to CM/SM for over three decades. Since its founding in 1988, ASAP has been the leader in providing support, awareness, and research. Since then, a few organizations have spun off from our leadership, and others have sprung up within the community, but for 33 years ASAP has remained the steadfast leader serving the CM/SM community and beyond. I still have a dream that other organizations in our community will come together and partner with us to create a big family of mutual resources! Until that day, I pledge to continue to extend the hand of partnership and love in hopes that we can further the important work we are doing for us all—and that one day we can look at each other, smile, and say THANK YOU.

As always, remember that while you may have to live a life within limits, you can still lead a limitless life! And while you're at it, thank someone today. It will make them—and you—smile.

Chiari Awareness Lights Up September

Jeni Adair, Molly Lichtenstein, their families and friends continue to spread awareness even during these unusual times. Their efforts on behalf of the Chiari / Syringomyelia community surpass expectations every year. Thank you ladies for your organizational skills and determination. The Central Florida virtual walk and book signing, hosted by Jeni, raised over \$6,000. Molly's 7th walk, combined with tennis and golf tournaments, raised over \$45,000.



The Pentad Patient and Chiari

When I first heard the word pentad I was not sure what that meant. What I found was a definition of a person diagnosed with five different conditions. While watching Dr Ilene Ruhoy's presentation, I learned how this may involve those diagnosed with Chiari malformation.

The most common diagnosis includes:

Hypermobility Ehlers-Danlos Syndrome (hEDS)

- Joint hypermobility (can be diagnosed with a two minute test in your doctor's office using the Brighton Score)
- Skin hyper-extensibility
- Tissue fragility
- Increased bruising
- Weakened vessel and visceral organ walls

MCAS (innate activation)

- Mast cell activation syndrome is a condition that causes mast cells to release an inappropriate amount of chemicals into your body. This causes allergy indicators and a wide range of often confusing symptoms.

Auto-immunity (adaptive activation)

- When the adaptive immune system is constantly being activated over time it can become auto-reactive, turning on itself.

Small Fiber Neuropathy, Dysautonomia and Dysmotility

- Small fiber neuropathy is a condition characterized by severe pain attacks that typically begin in the feet or hands. As a person ages, the pain attacks can affect other regions. Some people initially experience a more generalized, whole-body pain. The attacks usually consist of pain described as stabbing or burning, or abnormal skin sensations such as tingling or itchiness. In some individuals, the pain is more severe during times of rest or at night. The signs and symptoms of small fiber neuropathy usually begin in adolescence to mid-adulthood.
- Dysautonomia is a disorder of the autonomic nervous system such as POTS.
- Dysmotility is a condition in which muscles of the digestive system become impaired. Changes in the speed, strength or coordination occurs in the digestive organs.

Cranial Cervical Instability, Tethered Cord and Chiari

- Cranio cervical instability is a medical condition where there is excessive movement of the vertebrae at the atlanto-occipital joint and the atlanto-axial joint, that is, between the skull and the top two vertebrae (C1 and C2).
- Tethered Cord is a neurologic disorder caused by tissue attachments that limit the movement of the spinal cord within the spinal column.

The Pentad Patient is available at

<https://www.youtube.com/watch?v=xzXa1TXSigE>

Let Your Light Shine

Being the light to others can mean a variety of things. For starters you are not only making someone else's day better but helping yourself as well. When you bring others happiness, it makes you happy.

Don't forget to smile

Your smile is one of the most genuine and selfless things you can share with others. You never know how much you can brighten someone's day with this simple act.

Listen with intent

This is such a selfless act that people rarely do nowadays. We're so focused on listening to respond that we never listen for the sake of actually listening and processing what the other has to say.

Give genuine compliments

Giving compliments is such a selfless act. Words have more power than you realize and you can either make or break someone's day.

Be friendly

Similar to your smile, friendliness goes a long way. This means going out of your way to talk to strangers, helping them, or meeting new people. You'd be surprised by the kind of impact you have on even those you barely know.

Share your optimism and gratitude

We live in a world where negativity is often the main focus. Share your positive attitude with others.

Give what you can

Giving not out of compulsion but out of sincerity and generosity is the best thing you can do for others. It doesn't have to be a grand gesture as you'll be surprised how others appreciate even the simplest things such as friendships, compliments, and even laughter.

Empathize with others

There's a difference between empathy and sympathy wherein empathy means putting yourself in someone else's shoes. Empathy and selflessness are deeply intertwined. When you empathize with others, you make them feel understood. Through empathizing, you're reminding them that they're not alone in their pain or in whatever it is they're feeling.

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 \$5 (or more) donation to the organization. Please indicate whether the gift is 'in honor of' or 'in memory of' and provide name and mailing address of the person you would like to honor.

In Honor of
Donor

Jacqueline Babitts
Steven & Rosa Babitts
Molly Lichtenstein
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**If you can
not do great
things do
small things in
a great way.**

**What you
do today
can improve
all your
tomorrows.**

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ASAP Virtual Auction

The auction scheduled for October 2021 has been rescheduled to take place next year. Be sure to check the website for updates. Thank you to everyone who has contributed.

A form for donations is available on our website at ASAP.org. On the homepage scroll down to **2022 ASAP Virtual Auction** and click on **Download donation form**.

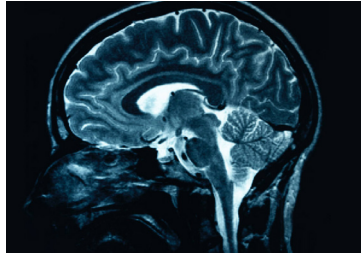
Items should be mailed to the ASAP office:

ASAP, Inc
300 N Green St Ste 412
Longview TX 75601



Complex Regional Pain Syndrome

Complex regional pain syndrome (CRPS), also called reflex sympathetic dystrophy syndrome, is a chronic condition in which high levels of nerve impulses are sent to an affected site. Experts believe that CRPS happens because of dysfunction in the central or peripheral nervous systems.



What Causes Complex Regional Pain Syndrome?

CRPS most likely results from multiple causes that produce similar symptoms. Some theories suggest that pain receptors in the affected part of the body become responsive to catecholamines, a group of nervous system messengers. In cases of injury, the syndrome may be caused by a triggering of the immune response, which may lead to the inflammatory symptoms of redness, warmth, and swelling in the affected area. For this reason, it is believed that CRPS may represent a disruption of the healing process.

It most often appears after an injury. But it also can be triggered by an infection, heart attack, stroke, cancer, neck problems, or pressure on a nerve.

What Are the Symptoms of Complex Regional Pain Syndrome?

The symptoms of CRPS vary in their severity and length. One symptom is continuous, intense pain that gets worse rather than better over time. If CRPS happens after an injury, it may seem out of proportion to the seriousness of the injury. Even in cases involving an injury only to a finger or toe, pain can spread to include the entire arm or leg. In some cases, pain can even travel to the opposite extremity.

Other symptoms of CRPS include:

- Burning pain
- Sensitivity to touch or cold
- Swelling and stiffness in affected joints
- Motor disability, with decreased ability to move the affected body part
- Changes in nail and hair growth pattern; there may be rapid hair growth or no hair growth.
- Skin changes. It can involve changes in skin temperature, blotchy, pale, purple or red skin, etc. People with CRPS may have skin that sometimes is excessively sweaty.

Symptoms may be heightened by emotional stress. The effects of complex regional pain syndrome can grow more serious with time. So the sooner you find out if you have it, the better.

How Is Complex Regional Pain Syndrome Diagnosed?

CRPS is diagnosed primarily through observation of the following symptoms:

- The presence of an initial injury
- A higher-than-expected amount of pain from an injury
- A change in appearance of an affected area
- No other cause of pain or altered appearance

How Is Complex Regional Pain Syndrome Treated?

The goal of treatment is to relieve painful symptoms associated with the disorder. Therapies used include psychotherapy, physical therapy, and drug treatment, such as topical analgesics, narcotics, corticosteroids, osteoporosis medication, antidepressants, and anti-seizure drugs.

Other treatments include:

- Sympathetic nerve blocks: These blocks, which are done in a variety of ways, can provide significant pain relief for some people. One kind of block involves placing an anesthetic next to the spine to directly block the sympathetic nerves.
- Surgical sympathectomy: This controversial technique destroys the nerves involved in CRPS. Some experts believe it has a favorable outcome, while others feel it makes CRPS worse.
- Intrathecal drug pumps: Pumps and implanted catheters are used to send pain-relieving medication into the spinal fluid.
- Spinal cord stimulation: Electrodes placed next to the spinal cord, offers relief for many people with the condition.

What Is Recovery Like?

If your treatment starts within a few months after the symptoms appear, there's a good chance your pain will ease up or go away. Children and teenagers generally have the best luck.

How Can I Take Care of Myself?

Long-term pain can take a toll on your mind and emotions. Being depressed or other psychological troubles can make it harder to recover. So tell your doctor. Therapy, lifestyle changes, and medication may help.

Your doctor should also be able to connect you with other health professionals who can help. They might teach you relaxation or meditation techniques, for instance. And in support groups, you can draw from other people's strength and share yours with them.



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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