

ASAP Welcomes New Board Members

In October the Board of Directors elected Jeni Adair and Michele Raye to the ASAP Board. John Caemmerer was elected to fill the outgoing position of Cathy Tufts as Vice-President. Michele will fill the position of Secretary as Rich Simon moved to Director-at-Large. Dr Ian Heger moved to the ASAP Medical Advisory Board.



Jeni Adair studied marine biology at the University of Miami and graduated with a double major in Marine Science and Biology, and a minor in Chemistry. She worked briefly in the Bahamas supporting a team of shark researchers at the Bimini Biological Field Station before attending college. After working for

the State of Florida for several years, she returned to school to study veterinary medicine.

Jeni grew up in a small town in Iowa. Although she suffered from headaches all of her life, they did not become severe until her second year of veterinary school in 1998. At that time, she took a medical leave of absence and was diagnosed with Chiari malformation. She spent the next seven years in and out of surgeries. Due to multiple complications she was forced to eventually withdraw from school. Near the end of her surgeries, she met her husband, Erin. They now have two boys, Jayden (age 11) and Sean (age 7).

Over the years, Jeni has attended several conferences and gained valuable knowledge and support from connections made through ASAP. A few years ago, her son Jayden was diagnosed with Chiari, as well. This prompted Jeni to become even more involved with ASAP. She formed the Central Florida Chiari & Syringomyelia Support Group and organized the first annual ASAP Central Florida Walk & Roll for A Cure in 2018. She feels that it is important to provide support to newly-diagnosed patients and parents of patients in the same way that others have done for her. Passionate about raising awareness of Chiari and related disorders, she gives presentations to her sons' classes. Jeni also spoke to representatives from several media outlets as she prepared for the walk and roll.

Jeni contacted the governor of Florida, Ron DeSantis, and spearheaded a drive to make the month of September "Chiari Awareness Month" in Florida. She likewise contacted the mayor of her town, Apopka, Florida to create a similar proclamation for the city. She is an advocate for raising Chiari awareness in her community.



Michele Raye lives in northern California with her teenage daughters. She has been volunteering with ASAP for over three years, leading the ASAP Bay Area Support Group and more recently the online ASAP Southern California Support Group. In addition to her work with ASAP, Michele also volunteers at the hospital where her daughter receives treatment. She is involved with the Department of

Family Centered Care. She is working on forming a Family Advisory Council for neurosurgery. She also runs a non-affiliate online Chiari & Co Prayer Group.

Michele has extensive experience with children and has worked in the childcare field with a wide age range. In 2005 after her children finished preschool, she began working for the local school district in special education. In 2010 she began home-schooling both her children while working but since 2012 she has been home full time. Her oldest daughter attends community college and is pursuing a degree in journalism. Her other daughter is currently finishing high school with the hopes of working with animals.

In 2014 her youngest daughter suffered a second degree traumatic brain injury after being thrown off a horse, head first, into a rail. Within a few years she was diagnosed with Chiari, pseudotumor cerebri, a spinal arachnoid cyst and a cerebrospinal fluid leak. Her daughter has had multiple surgeries including a VP shunt and has found that animals are a great distraction, so she regularly volunteers to help foster kittens.

Michele loves being able to help others, offer support and connect with families through ASAP. In her free time, she loves the beach, bible journaling, reading, gardening and coffee. Michele and her girls also try to get out at least once a month and go on some kind of adventure, exploring new places and spending time together.

ASAP Conference 2021

We are looking forward to meeting again in person at our annual conference.

Save the date!
July 21-24

The meeting will take place at the historic Knickerbocker Hotel in downtown Chicago. This beautiful gothic building dates back to the 1920s, and legend has it that Al Capone's brother, Ralph, ran a speakeasy and casino from the penthouse during Prohibition. In 1970, Hugh Hefner and Playboy Enterprises purchased the property and it operated as Playboy Towers until 1979. The ideal location is close to the lake, shopping, nightlife, restaurants, and more.

Konstantine Slavin, MD will be our host. Professor of Neurosurgery, Dr. Slavin heads the Stereotactic and Functional Neurosurgery section at the University of Illinois Chicago (UIC). A Board certified neurosurgeon, he completed residency in neurosurgery at the Department of Neurosurgery, UIC and the Department of Neurosurgery of the Central Institute of Post-Graduate Training of Physicians, Moscow, USSR. His clinical interests are diverse applications of surgical neuromodulation and functional neurosurgery.

For those needing financial assistance to attend, ASAP has programs available. The conference scholarship information is listed on this page. To learn more about the ASAP L.E.A.R.N. Program, contact Patrice Schaublin. (See contact information listed on page 7.)

ASAP Conference Scholarship

GENERAL INFORMATION

Applications for the conference scholarship will be accepted between March 1 and May 31 on a first come first serve basis.

The ASAP scholarship includes waiver of the registration fee for the applicant. If the applicant is a parent of a minor child with SM, CM or related conditions the child's registration fee will also be waived. If the adult applicant can provide verification from a treating physician that they must travel with a caregiver, that caregiver's registration will also be waived. The scholarship or portions of the scholarship are not transferable. The scholarship also covers half of one hotel room for the scholarship recipient(s) for no more than the four days of the conference.

SCHOLARSHIP REQUIREMENTS

Applicants or child (if applicant is the parent) must have a diagnosis of SM / CM and be a member of ASAP. Membership is free so sign up today if you haven't already.

For a complete list of requirements and an application contact the ASAP office or visit us online at:
<https://asap.org/conferences/conference-scholarship/>

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

Once again it is holiday time, and I am so grateful for all the support you have shown ASAP over the past year, whether by a short note of encouragement, participation in our first virtual conference, or making a donation to help continue our mission. I know I speak for all of us at ASAP when I say we are truly thankful indeed!

This past year has been unlike anything we've ever experienced, and it's been tough. But it has also really brought to light the reality that we are in this together. The COVID shutdowns across the nation have had such an impact on how we live and socialize. We need each other now more than ever.

ASAP is working to help connect us to each other, as we all need to see and hear from others, especially with some of us unable to leave our homes. A few things we are working on that will increase our connectivity to each other:

- We are looking into systems/technology to connect our support groups to those who need them remotely. Some of our support groups meet virtually and we want to expand that so more people can participate. Others have been doing this for a while, so please seek out how to stay connected while being isolated—the resources are out there and we want you to be involved. Look for more information about ASAP's technology platform and virtual support groups to be coming soon.
- Another area we're excited to be developing is our new "Youth Advisory Council," which will be not only a peer-to-peer support group, but also an important youth-led council which will work with the ASAP Board to help us set the direction for programs aimed at our younger members. Many of our youth want to be heard and play an active role in our organization, and we encourage this wholeheartedly.

I believe it is critical that we remain united in our quest to overcome Chiari and Syringomyelia and their related disorders. Conflict and separation do not help anyone. If you are a supporter of ASAP and find the outreach of another group helpful—by all means, get involved with them. What is most important is that you are getting the

resources you need. While we sincerely want ASAP to be your "go-to" source that meets your needs, we also realize that there is much to be found throughout the greater CM/SM community that may be particularly beneficial for your unique situation. Are we afraid of "losing" you? No! Think of it like Santa from the Macy's/Gimbels rivalry in *Miracle on 34th Street*. We want you to benefit from the best that's out there, because we are all on the same team.

Teamwork and doing what is best for your team: that is key, isn't it? Yesterday I witnessed one of the most team-centered acts by a football player in all my years of watching sports. My beloved Cleveland Browns were playing the Houston Texans. Late in the 4th quarter, with 67 seconds left, the Browns were trying to secure their 10-7 lead. Since the Texans were out of time outs, the Browns only needed a 1st down to be able to run out the clock and win the game. On the 3rd down and a short 2 yards, the Browns' quarterback, Baker Mayfield, handed off the ball to running back Nick Chubb. Chubb broke free from all the Texans defenders and sprinted up the sideline 59 yards to what appeared to be a runaway touchdown, which would increase the Browns' lead by another 6 points...when all of a sudden Chubb deliberately stepped out of bounds at the 1 yard line, stopping the clock.

You see, had he scored the touchdown, the Texans would have had another opportunity to get the ball and possibly score, but by stepping out before scoring, Chubb allowed the Browns to retain possession and run out the clock and win the game. Chubb's actions were selfless in the sense that, given a similar circumstance, many professional athletes would opt to pad their own personal statistics and elevate their standing in the game, rather than "take one for the team." Chubb was more focused on ensuring the game was won by his team than what might prop him up personally.

I am committed to doing what is best for the team—and by "team," I mean YOU and me and everyone else affected by Chiari, Syringomyelia, and their related disorders. As 2021 approaches, let us all focus on what we can do for our team to ensure a victory over these conditions. Let's take the win together! And don't forget: you may have to live a life with limits, but you can still lead a limitless life. May you and yours have a blessed holiday season.

One of the real joys of the holiday season is to say thank you and to have this opportunity to wish you good health, peace and happiness.

from your friends at ASAP

September Chiari Awareness Walk and Roll

Even with virtual walks this year, ASAP received over \$38,500 to support programs and research, thanks to the efforts of Molly Lichtenstein and Jeni Adair and their support teams. On September 19 Molly held her 6th Annual ASAP Walk and Roll for a Cure. In addition to her walk she also held a golf tournament, online auction, and several other small events held throughout the year. On the same day, Jeni hosted her 2nd walk and is currently making plans for number three on September 25, 2021.



Thank you to everyone who participated. Kudos for staying safe by walking in your individual locations.



Nine Steps to Better Health

By Gerard L Guillory, MD

I have helped a number of employer groups educate employees on 10 simple but often-overlooked steps toward better health. Here's a brief overview:

1. Add probiotics to your diet. If you find your digestive tract grumbling more than you think it should, you might want to replenish your gut's probiotics. Probiotics are living, beneficial bacteria that occur naturally in the human intestinal tract and are essential to healthy digestion. A growing body of evidence suggests that probiotics help treat and prevent various forms of diarrhea, ulcerative colitis, Crohn's disease, irritable bowel syndrome, small-bowel bacterial overgrowth, and lactose intolerance. Probiotics also may help prevent colon cancer.
2. Beware MSG and aspartame. If you regularly experience severe headaches, dizziness, muscle aches and digestive discomfort, the cause may lie in your diet. Monosodium glutamate and aspartame are common food additives that are culprits in many common medical complaints. MSG contains glutamic acid, and aspartame contains aspartic acid. These substances, both of which are neuroexcitatory amino acids, have been associated with headache, nausea, impaired ability to concentrate, attention deficit disorder, dizziness, flushing, muscle aches, digestive complaints and more.
3. Avoid trans fats. Trans fats were engineered by food scientists who wanted to boost the shelf life of processed foods by reducing rancidity. This is achieved by adding hydrogen atoms to vegetable oils, rendering the fat more rigid and stable. When you ingest trans fats, your body tries to incorporate the rigid fats into its cell walls, causing damage in the process. The damage occurs because trans fats aren't pliable like normal fats. Metabolizing them is like forcing the square peg into the round hole.
4. Take appropriate supplements. Americans spend more than \$17 billion a year on nutritional supplements, but few of us know what we are getting for our money. Quality standards tend to be hit-or-miss among supplements manufacturers, and individual consumers don't always know what kinds and amounts of supplements they need. The kinds and amounts of supplements you take should be based on your individual health status, which your physician or nutritionist can help you gauge, and on your budgetary requirements.
5. Take Omega-3 fatty acids. Some fats are essential to good health; for example, the Omega-3 fatty acids found in fish oil, cod-liver oil and flaxseed oil. According to some experts, the most serious problem with the

American diet today is the scarcity of Omega-3 fatty acids in our foods. Omega-3 deficiency has been associated with anxiety, depression, attention deficit disorder, cardiovascular problems and arthritis.

6. Take supplemental vitamin D. Another common deficiency involves vitamin D; in fact, some medical experts are referring to this as an epidemic. Recent studies have linked vitamin D deficiency to a range of medical problems such as diabetes, chronic fatigue, osteoporosis, hypertension, multiple sclerosis, at least 16 types of cancer, and other diseases, including influenza. Vitamin D is unlike other vitamins in that our bodies manufacture it when touched by sunlight. Yet many of us spend little time in the sunlight, especially in the winter and early spring. When warmer weather arrives, we apply sunscreen in order to prevent skin cancer. Without supplemental vitamin D, few of us are likely to get as much as we need.
7. Get your blood tested. If you suspect that you have vitamin D deficiency, ask your physician to perform a simple blood test and, based on the results, to help you determine how much vitamin D your body needs for optimal health. You also might want to undergo a blood test to determine whether your hormones are balanced. This is crucial for patients who are taking statins (medications that reduce cholesterol) as both vitamin D and the sex hormones are synthesized from cholesterol. One other test you might consider: Researchers are finding that gluten sensitivity is more common than previously thought. A blood test can determine whether you are glutensensitive. Symptoms may include autoimmune disorders and diabetes.
8. Reduce inflammation. Inflammation is a natural and vital part of the body's response to injury, helping fight infections and ward off cancer, but it can go awry. Poor diet, lack of exercise and ineffective responses to stress contribute to the problem. Reducing chronic inflammation can help delay or, in some cases, reverse the aging process. Changing your diet, engaging in regular exercise and managing stress more effectively are critical parts of any plan to achieve these goals.
9. Listen to your physician. Don't overlook the value of all the usual advice that physicians and other health-care professionals offer: stop smoking; work out regularly and appropriately; learn to manage stress more effectively; keep your weight within recommended limits; and get a good night's sleep.

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

Jen Vasek

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Judy Hunt

Katherine Schweizer

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Holly Astrausky

Lilly Hamm

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Marvin Tepper**Joseph Block**

Stephen & Arlene Sharkey

Jacque Pike

Molly Lichtenstein



Volunteers Needed

We are currently seeking someone with accounting experience who would like to serve on the Board and fill the position as Treasurer. This position would require you to attend meeting via teleconference four to five times a year, review financial statements, develop a budget and approve expenditures. Interested parties should contact Eric Berning via email at Eric_Berning@ASAP.org for an application.

We are always looking for volunteers to serve on committee, help with fundraising, awareness and fill positions on our Board of Directors. You can complete the volunteer form on our website.

<https://asap.org/volunteer/>

Or you can contact Patrice Schaublin via email at Patrice_Schaublin@ASAP.org.

When You See Your Doctor

One of the most important things you can do is to make the most of the time you spend with your doctor.

If you're a new patient, check out your doctor's website, which should include forms you will need to bring on your first visit. Fill them out at home and bring them with you. If your doctor doesn't have a website and hasn't sent you any forms to fill out, contact the office to see if they can send you the new patient forms to fill out in advance. Having this information already prepared should help shorten your wait.

Before you call for the appointment, list and prioritize the issues you hope to address. When you make the call, mention all the reasons for the visit. This will help the staff allocate an appropriate amount of time for your visit.

It is important to make a list of your medical conditions and your medications (and doses). Also make a list of any vitamins and supplements you take.

Keep a diary regarding your health, medications and life events. Often, the onset of medical problems coincides with other changes—a new prescription or supplement, a change in diet, new sources of stress.

At check-in, let the medical assistant know whether you need refills for any prescriptions. Often, he or she can begin to take care of this while you are seeing the doctor.

Bring your insurance card, identification and social security information.

Finally, if you recently changed primary care physicians, consider seeing your old doctor, even if he or she isn't a part of the network with which your health plan contracts. Many plans cover out-of-network care; the patient simply pays a higher co-payment. It may be worth the extra expense to hang onto a relationship built over many years.

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

Why Idiopathic Syringomyelia

The medical definition of idiopathic is - relating to or denoting any disease or condition which arises spontaneously or for which the cause is unknown.

Unfortunately it is not always possible to determine the cause of a syrinx so people are told they have idiopathic Syringomyelia. Even after a spinal injury, it could be many years before neurological symptoms manifest. It is possible to develop a syrinx that does not cause any neurological symptoms or the symptoms may be attributed to another cause. Since the spinal injury can be minor you might not even remember or know that damage occurred resulting in the spinal fluid entering the cord.

Treating Idiopathic Syringomyelia

When a Chiari malformation is present in a person diagnosed with Syringomyelia, decompression of the cerebellum tonsils can prevent the syrinx from progressing and even cause it to collapse. In cases where they cannot determine the cause, your doctor will want to take a more conservative approach of monitoring the syrinx and treating symptoms with medication, physical therapy, etc.

Outgoing Board Members

Special thanks to Bridget Maher and Cathy Tufts for their dedication and service to ASAP.

Bridget served on the board from October 2016 through August 2020. She was involved in fundraising and awareness through multiple events for many years before being elected to the board. As a Director she worked on multiple committees including the annual conference, helping to chair the KIDS program.

Cathy was elected to the Board in 2014. During her two terms she served as Secretary and later as Vice-President. Cathy became involved with ASAP when her son was diagnosed. She hosted several large walks in the Houston area. As a Director, Cathy served on multiple committees and volunteered at the conferences. She was instrumental on the development of the virtual conference this year.

Again thank you Bridget and Cathy for everything you do for the Chiari and Syringomyelia community.

Contact Information

American Syringomyelia & Chiari
Alliance Project

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

Staff:

Jamie Mayhan, Programs Director
Jamie_Mayhan@ASAP.org

Patricia Maxwell, Operations Director
Patricia_Maxwell@ASAP.org

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





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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Colorado Chiari Institute
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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.

Mail: ASAP Connections
PO Box 1586
Longview, TX 75606

Editor: Patricia Maxwell
Email: Patricia_Maxwell@ASAP.org