

ASAP Moving Forward

ASAP Funds New Research

In February, the Board of Directors voted to fund a grant with the University of Wisconsin to study **DNA Methylation in Familial Chiari I Malformation**. Bermans Iskandar, MD will oversee the project in collaboration with Reid Alisch, PhD.



While twin and family studies suggest that Chiari I malformations are genetically inherited, genetic mutations have not been identified as a consistent cause of these malformations. Epigenetic modifications contribute to heritable conditions that can be influenced by environmental factors without a change in the DNA sequence. Thus, it is believed that alterations in epigenetic modifications cause inherited forms of Chiari I that lack

an obvious genetic predisposition but have perceptible lines to environmental conditions.

With saliva obtained from patients with familial Chiari I and unaffected controls, they will investigate the role of epigenetics, specifically DNA methylation, in Chiari I families. Findings from this research will provide critical molecular insights in the heritable basis of these malformations and guide future research directions.

Medical Marijuana for the Treatment of Pain in Patients with Chiari Malformation

Although anecdotal evidence of the pain-relieving effects of medicinal marijuana (MM) is abundant, clinical data does not exist for pain management with MM in adult patients with Chiari malformation (CM). The study co-investigated by Dr Erol Veznedaroglu, Global Neurosciences Institute and Dr Ruth Perry, Cannabis Education and Research Institute, will survey ASAP members with CM to determine their use, frequency, dosage and strain of MM. Participants will be evaluated to determine if they are getting optimal pain relief from their MM strain. The study should provide evidence for an optimal strain of MM to treat pain associated with CM.



Teen Advisory Council Being Formed

The ASAP Board of Directors is looking forward to working with our teens by developing a program that will provide leadership development, community involvement and create future leaders for CM/SM community. ASAP teens can make their voices heard and become involved. The council is available to a select group between the ages of thirteen and nineteen who will spend one year or more assisting ASAP.

ASAP leaders will share their knowledge by helping teens be advocates and ambassadors, learn public speaking, participate in running a fundraiser and engage in our non-profit. We believe they will bring new energy into our mission-based work while developing future leaders for our community. Those interested please contact Patrice Schaublin to receive an information package and application (contact information on page 6).

Private FaceBook Page for CM/SM Teens

ASAP has created a teen FaceBook group for those 13-18 years old diagnosed with Chiari, Syringomyelia and related disorders. The page is monitored by an adult but conversations are teen-led. Participants will have to answer several questions for admission to the group.

The teen years are tough enough, then throw in a disorder that can change so many aspects of daily life. It is nice to know someone really gets what you are going through.

<https://www.facebook.com/groups/asapteens>

ASAP 33rd Annual Conference

ASAP Conference Scholarship

We are looking forward to meeting in person at our Chiari & Syringomyelia Conference.

New Date for ASAP meeting! October 6-9, 2021

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. This ideal location is close to Lake Michigan, 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.

Due to current restrictions, plans are still in development for hotel reservations, meeting registration and our agenda. You can stay up-to-date with conference information at:

<https://asap.org/conferences/2021-conference/>

General Information

Applications for the conference scholarship will be accepted between March 1 and July 30 on a first come first serve basis. This is an extended due date for this year.

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/>

ASAP L.E.A.R.N. Program

To learn more about the ASAP L.E.A.R.N. Program, contact Patrice Schaublin (contact information on page 6) or visit

asap.org/conferences/asaps-l-e-a-r-n-points-program/

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

Spring is here...and so is the pollen. I love the greening of our neighborhood, but I do not do well with the allergies that come with it. Despite the “sneezing and itchy, watery eyes,” I do love springtime. Here in Texas swaths of blue bonnets and other wildflowers

appear to paint even the roadside with brilliant colors.

On a personal note, spring is also a time of renewal and reflection for me. Eighteen years ago, on April 21, 2003, I underwent my decompression surgery. Since my diagnosis of Chiari malformation and Syringomyelia nearly two decades ago, I have had the opportunity to become more aware, informed, and active in and about the CM/SM community. When I was diagnosed, I had never heard about either condition. I just knew what I, personally, had experienced and suffered throughout my life—and finally I had an actual name for what was causing it. That was both exciting and scary—it wasn’t “all in my head,” it was real, but I still didn’t understand too much about it or know anyone else with it. Was I all alone with this “rare” condition? It sure felt like it at the time. But something life-changing happened a few years later. Thanks to the internet, I discovered ASAP and joined a local support group, where I found that I was not alone! There are others with CM/SM, of all ages and experiences. They have family and caregivers who, like mine, are beside us on our journey, doing their best to learn, understand, and support us. Finding ASAP was like waking up to a garden filled with new blooms after a long season of dry earth—it was refreshing, invigorating, and inspirational. I felt moved to join ASAP’s Board of Directors in 2012 so I could actively help “sow the seeds and grow the garden,” so to speak. And since then, I have continued to learn so much more about these conditions and the people who are affected by them—you and me.

In the 33 years since ASAP was first founded by Barbara and Don White, our organization has funded over 1.5 million dollars in research grants and fellowships directly related to Chiari and Syringomyelia and their related issues. That is incredible! We hold a conference every year, including last year’s new but very successful virtual conference, where the community’s leading experts on these conditions share their knowledge and insight directly to an audience of patients, families, and caregivers, as well as fellow medical experts, offering an opportunity to answer questions and provide feedback. Last year over 500 people participated virtually from all over the world—amazing! (Missed it? Have a topic you want to revisit or share? ASAP has made all these presentations available on our website for anyone to view and learn: head to ASAP.org today!)

This year our annual conference will be back LIVE AND IN PERSON in the wonderful city of Chicago, Illinois. Please

note, we have moved the conference to October 6-9 (instead of the usual July) to allow the COVID-19 pandemic extra time to settle down and make travel a bit safer for all of us. Join us in Chicago to meet with and hear from the amazing doctors and presenters on the schedule this year. (We are looking into the possibility of offering a virtual option again as well, so stay tuned to our website for more details.)

We want you! We are always looking for people to join the ASAP Board and help guide this outstanding organization into the future. Feel free to nominate yourself or someone else who is interested in serving. Members do not have to have CM/SM to serve on the Board. We recently started the application process for our new Teen Advisory Council. These young people will become our future leaders and voices. Do you know a teen who may want to serve, learn, and lead?

We want you! We will be holding a virtual auction soon (details available on our website). You can donate goods to the auction, or when it goes live, you can bid on something you like! All proceeds will help ASAP further education, support, and research. Consider other forms of donation as well: monetary, corporate matching, goods or services, beneficiary of property or real estate, AmazonSmile, host a fundraiser, etc. There are numerous ways to give, both actively and passively. We are extremely grateful for the generosity that makes it possible for ASAP to help the CM/SM community.

We want you! Some of our current groups are now using our Zoom platform to get together virtually from the comfort of their own homes. How easy is that. **More information on how to join or start a support group is available on our website.**

Speaking of the website, did you know that we overhauled it last year to give it a fresh new look and better usability? We are trying new ways to foster our mission to improve the lives of people affected by Syringomyelia, Chiari malformation and their related disorders while we find the cure. We want to hear from you. How do you want to be involved? How do you want to be heard? What do you want from our community? What could we be doing better to provide you with the awareness, support, and education that you, your friends, and family need from our organization? The past year has created a shift in how things get done, and we want to be as flexible as we can be to serve the CM/SM community. Let us know. Make your voice heard and reach out to us at info@ASAP.org.

As I always say, you may have to live a life with limits, but you can still lead a limitless life! Don’t let the pollen get you down. Spring becomes summer very quickly (and then football season is right around the corner). Together we can water this garden and make it flourish. Will you help?

ASAP's Origin

by H D (Don) White [March 2004]

People often wonder how ASAP got started. When my late wife, Barbara, and I first married, we literally waltzed across Texas. If, on the spur of the moment we decided to do something, we did it. We went fishing and hunting together. We enjoyed life to the fullest...until 1983, which is when our journey with syringomyelia (SM) began.



Barbara first noticed a tingling sensation in her fingers, then her arms, and later experienced weakness in both. The progression was rather fast. Our family doctor referred us to a vascular surgeon, who, in turn, referred us to a neurologist. He ordered a myelogram and made a preliminary diagnosis of syringomyelia. She described her first reaction as one with which many of us are familiar, "Write the prescription, and I will be sure and take it all!" Of course, she would learn it would not be so easy.

A great vacuum of information overshadowed SM. Because MRIs were only just becoming available, very few people were ever diagnosed with the disorder. Few physicians were even aware of the limited amount of information available. Finding a doctor who had treated more than a handful of patients was almost impossible.

After six surgeries, none that would slow the relentless progression of SM, Barbara was told that nothing more could be done. But that didn't stop her from doing something for her fellow SM sufferers. In May of 1988, five years after her diagnosis, Barbara and I officially launched the American Syringomyelia Alliance Project.

When Barbara first contacted the National Organization for Rare Disorders, she discovered that SM was not even on its list. The most NORD could offer were the names of fifteen people known to have the disorder. Barbara found eight more people after a lengthy and extensive search. By appearing on her local television station, she met two others within a hundred miles of her. At that point, she set out to find even more individuals with this disorder.

Determined, Barbara felt strongly that together, all of us could make a difference. We could promote awareness and press for research to one day find a cure.

Besides her networking efforts, Barbara was eager to promote awareness of the disorder among physicians and encourage research endeavors. She searched for doctors

interested in researching syringomyelia, but lack of funds prevented the few she did find from pursuing this goal. Barbara made it clear to me that when she died, she wanted her body to be donated for research purposes. After her death in December of 1991, I honored Barbara's wishes and contacted Dr Batzdorf at the UCLA Medical Center. After completing his research study, Dr Batzdorf sent me a letter. He wrote, in part,

On a very personal note, I want to tell you that the long term aftermath of my involvement in Barbara's care did seem to pay off. Sharing her problems with me did help me focus on the problem of cerebellar ptosis, and I think we have finally come up with a workable solution. [Cerebellar ptosis, also referred to as "slump," occurs when the cerebellum descends through the sub-occipital craniectomy in situations where the craniectomy is too large for the particular patient. It may re-establish conditions that favor filling and distention of a syringomyelic cavity.] It has been many years, but the benefits of your generosity in sharing so much information about Barbara cannot be overestimated.

Committed to finding a cure for syringomyelia, Barbara devoted her life to the establishment of ASAP, a place for those suffering with this disorder to find answers and compassion. Please join us as we remember Barbara and what she has meant to so many; her legacy continues.

[This article appeared in *ASAP Connections* in March 2004. I hear from new members they had no idea ASAP existed. I share this information to ensure their legacy lives.]

ASAP Auctions

Auctions have always played a major role in fundraising at ASAP. From our annual conference to our area walks, and now we are adding online events to reach even more people. So we need more items. A form for donations is available on our website at ASAP.org. On the homepage, scroll down to **2021 ASAP Virtual Action** and click on "Download donation form."

Need a form mailed to you? Just email, call or write the office and let us know. You will find contact information for the office on page 6 of this edition. Be sure to include the completed form with your contribution.

If you have items you would like to donate (any time of the year) please mail them to:
ASAP, 300 N Green St Ste 412, Longview Texas 75601.

Fundraising News

Disc Golf Tournament Benefits Chiari

We sincerely appreciate Jami Harding and DND Disc Golf for hosting a tournament to support Chiari malformation. Sixty-four players came together for a competitive snowy 1st round of singles resulting in two aces. Travis Tyler scored his ace on Hole 5 with Ashley Ann Abbott adding one on Hole 16.

A prize throw-off in the field was followed by a 2nd round of fifty-four players for a random draw doubles. Two more aces were scored by Jessica Beckett on Hole 14 and Greg Estabrook on Hole 16. Coming out on top was Gary Ellsworth shooting a total score of 98 on the day.



The event which raised \$4,050.00 was attended by local ASAP members who provided support and educational materials.

We thank everyone who took part in the DND charity event especially the thirty-six hole sponsors. Servpro of Augusta Waterville donated a Bobby Harris mystery box. Trucking Good Food provided an excellent lunch. Crystal Brooke Putek printed the players' cards. The entire Tillson family hosted a fantastic event. Thank you to all the local businesses and individuals who participated, sponsored or donated.

May Syringomyelia Awareness Month

We would like to thank everyone for spreading awareness during the month of May. Your efforts over the years to educate the general public are paying off.

K & Co. Dance Studio Coin Drive

Nine-year-old Payge lives with Chiari and takes dance from K & Co. Dance Studio, LLC. The last few years the studio has held fundraisers in honor of their students, donating proceeds to various organizations.

Usually monies are raised through different events like a bake sale but due to the pandemic they opted for a coin drive this past year. Payge got to choose where the money would go and chose two organizations, one being the American Syringomyelia & Chiari Alliance Project, Inc to support research.

Special thanks to Amanda Ott Henderson of K & Co. Dance Studio, Payge and family.



Walk and Roll for a Cure

We currently have two walks scheduled for September. Since that is Chiari Awareness Month, it is a favorite time to hold an event. We welcome fundraisers year round so feel free to pick a time that works for you.

Molly's 7th Annual Walk and Roll for a Cure September 18
<https://www.wizathon.com/mollys-asap-walknroll>

Central Florida Walk and Roll for a Cure September 25
<https://www.wizathon.com/centralflorida-asap-walknroll>

Please help support these events or organize your own. We can help you set up your walk with a dedicated website, guidelines and support. Contact Patrice Schaublin for more information (contact information on page 6).

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

Payge Henderson
K & Co. Dance Studio LLC

Jacqueline Babitts
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Sharon Davis

Claire Mockler
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Jaelyn Greenwood
JoEllen Geddes

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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 committees, help with fundraising, awareness and fill positions on our Board of Directors. Complete the volunteer form on our website.

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

Or you can contact Patrice Schaublin.



“ASAP Member!”

**We are in the process of updating our database.
Please let us hear from you to ensure your information is current.**

Name _____

Address _____

City _____ State _____ Zip _____

Email _____ Phone# _____

Yes, I would like to continue receiving the newsletter.

I have Syringomyelia, Chiari malformation, other related disorder _____

I have a child or family member with the disorder

We have multiple family members diagnosed with _____

I am interested in participating in ASAP-sponsored research.

Please remove me from your mailing list.

Return form to: ASAP, Inc., PO Box 1586, Longview TX 75606-1586

ASAP has recently created a FaceBook group specifically for friends and family of persons diagnosed with Syringomyelia and Chiari malformation. <https://www.facebook.com/groups/asapfamilyandfriends>

A Caregiver Bill of Rights

I have the right

- to take care of myself. This is not an act of selfishness. It will give me the capability of taking better care of my loved one.
- to seek help from others even though my loved one may object. I recognize the limits of my own endurance and strength.
- to get angry, be depressed, and express other difficult feelings occasionally.
- to reject any attempt by my loved one (either conscious or unconscious) to manipulate me through guilt, anger, or depression.
- to receive consideration, affection, forgiveness, and acceptance for what I do from my loved one for as long as I offer these qualities in return.
- to take pride in what I am accomplishing and to applaud the courage it has sometimes taken to meet the needs of my loved one.
- to protect my individuality and my right to make a life for myself that will sustain me in the time when my loved one no longer needs my full-time help.
- to expect and demand that as new strides are made in finding resources to aid physically and mentally impaired persons in our country, similar strides will be made toward aiding and supporting caregivers.
- to maintain facets of my own life that do not include the person I care for, just as I would if he or she were healthy. I know that I do everything that I reasonably can for this person, and I have the right to do some things just for myself.



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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