Fall

2022

ASAP Connections

Providing Research, Education and Support since 1988

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

ASAP Chiari & Syringomyelia Conference 2022

by Jamie Mayhan

ASAP's 34th Annual Chiari & Syringomyelia Conference was held in Chicago at the end of July after three years of planning. The previous two years, ASAP offered a virtual conference to ensure the safety of our members while continuing to provide a vital program. The pandemic has hampered our traditional plans, but we have remained vigilant to provide top-notch medical information to our CM/SM community. This year Dr. Slavin, ASAP staff and the board worked through many obstacles including everything from shifting speakers around to pulling in several speakers via zoom that couldn't make it to Chicago.

This was my first conference to attend in person since being employed with ASAP. I have always done behind-the-scenes work for the conference but being able to see it all come together was a whole new experience. Putting a face to the many I've talked with over the years was nice. I enjoyed meeting the compassionate physicians who gave their time and energy to help Barbara and Don White's dream continue to be a reality. The patience and empathy of the doctors involved was amazing. Their number one goal was to help the patient. They know there still is much about these disorders that the medical field does not know, and they are still willing to listen and learn. One thing that resonated with me was when Dr. Konstantin Slavin said, "You have to treat the patient, not the scans."

Wednesday's schedule started early afternoon and concluded on Lake Michigan with a dinner cruise and fireworks show. The cruise was a good time for everyone to socialize. Thursday and Friday were full days of lectures with several question-and-answer sessions. The lectures are available online on ASAP's YouTube channel: https://www.youtube.com/c/ChiariSyringomyeliaASAPorg

The attendees were able to have many one-on-one conversations with the speakers to get answers. The confidence the physicians provided people to proceed with their medical care was immense. The physicians also network with each other to obtain peer perspectives and experiences. To quote one of the doctors, "There is no other conference like the ASAP conference."

My hope is that everyone who would like to attend an ASAP conference in person can. The organization has several ways to help members cut their costs, like scholarships and the LEARN program (see page 5). More details are available at **ASAP.org**.

Stay tuned for information regarding the July 2023 conference. ASAP will be celebrating its 35th anniversary.

A lot of walking away will do your life good.

Walk away from arguments that lead

you to anger and nowhere.

Walk away from people who deliberately put you

down. Walk away from the practice of

pleasing people who choose to never see your worth.

Walk away from any thought that undermines

your peace of mind. Walk away from judgemental

people, they do not know the struggle

you are facing and what you have been through.

Walk away from your mistakes

and fears, they do not determine your fate.

The more you walk away from things that

poison your soul, the healthier your life will be.

~Dodinsky

ASAP Board Adds New Director

Ilene Ruhoy, MD, PhD was elected to the ASAP Board of Directors in May 2022.

Originally from New York City, she received her MD at the University of Pittsburgh and trained in both pediatric and adult neurology at the University of Washington and Seattle Children's Hospital. She is a graduate of the University of Arizona Integrative Medicine Fellowship and is also a graduate of the Helms Medical Institute Acupuncture for Physicians certification program. Her PhD is in Environmental Toxicology from the University of Nevada.

She is the new medical director for the EDS/ Chiari Center at Mt. Sinai South Nassau Hospital. Dr Ruhoy is the co-editor of Integrative Neurology, published by Oxford Press in July 2020. She is a sought-after speaker on integrative neurology and has given lectures at professional conferences for the AAN and AANEM.

Watch her 2021 presentation *The Pentad Patient* on the ASAP YouTube channel.
www.youtube.com/watch?v=xzXa1TXSigE&t=2s

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

Happy Fall, Y'all!

I say it every year and I'll say it again: Fall is my favorite time of the year! Cooler weather has arrived (and after this scorching last summer, we need it), football is back, the changing colors of the trees, and the ramp up to the Christmas season—you just can't beat fall! Fall is also a great time to reflect on things; it reminds us of the changes within our own lives and how connected we are to the world around us. All of nature (including people) have a life cycle and go through changes as they age and grow. Some of these changes happen rapidly and some are gradual and less noticeable, but the one constant is that CHANGE happens to everything.

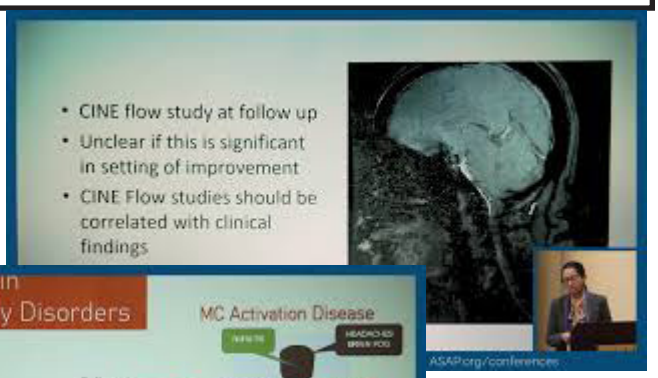
Modern technology has "forced" a lot of change at an increasing rate of speed, especially for those of us born before the internet (or even home computers)! But those changes are not all bad. We shifted into a world where information is at our fingertips, where an "expert"—for better or worse—is just a couple clicks away. In the old days we had to go to the library or struggle to find someone who possessed the knowledge and expertise to help us with our problem or question. Now that information is just a few clicks away, or delivered in mere seconds right to the palm of our hand. The unbelievable future advances once depicted by The Jetsons are now humorously outdated by our current technological standards (flying cars notwithstanding).

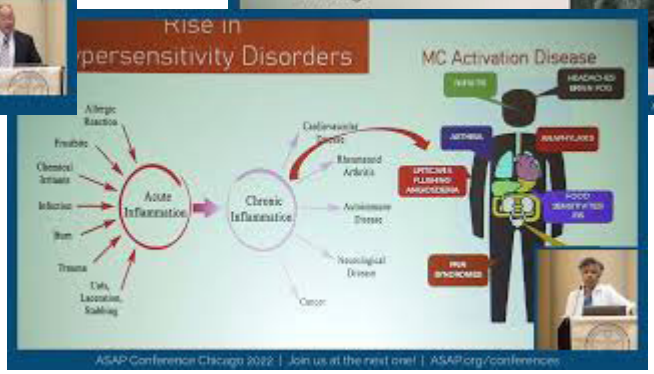
Speaking of a couple clicks or taps away…did you know that the outstanding presentations given at our Annual Conference this past July have been posted to ASAP's YouTube channel and our website? All that first-rate knowledge, experience, and information can be accessed right from your fingertips! Not only that, but now YOU can help all that great information spread like wildfire, as we have added a brand new function on the ASAP website for you to directly share our videos and content with a simple click or tap to your favorite platform. It's really easy, and by doing so we can instantly raise awareness about CM/SM and related conditions to those we know and care about.

Heads up! Coming soon and just in time for holiday gift-giving: a special online auction to benefit our organization! Be sure to keep an eye on the ASAP.org website for more details and how you can bid on the neat and unique items offered. We encourage you to participate and encourage others to do the same, as the money raised will help further our mission!

As always, if you would like to get involved, serve on the board, start a support group, plan a walk, host a fundraiser, spread awareness, join the next conference, or get involved in any way, please don't hesitate to reach out! We'll be happy to get you connected and involved.

And now I have to run…the Browns are playing and my wife is baking my favorite cookie, snickerdoodles! Someone must act as quality control—I guess that will just have to be my job! Like I said, I do love the fall! Please remember, "You may have to live a life within limits, but you can still lead a limitless life!"





2022 ASAP Conference Videos

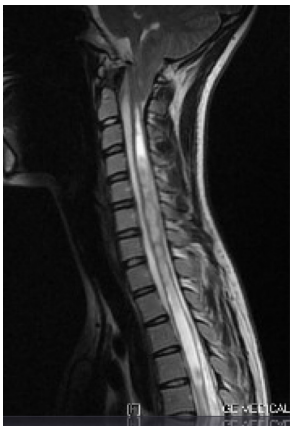
https://asap.org/conferences/2022-conference/2022-conference-videos/

ASAP Funded Research

Long-term outcomes for children with incidentally discovered Chiari malformation type 1: what is the clinical significance?

Authors: Laurence Davidson, Tiffany N Phan, John S Myseros, Suresh N Magge, Chima Oluigbo, Carlos E Sanchez, Robert F Keating

In an article published online, 23 November 2020 in Child's Nervous System (2021) the authors examine Chiari malformation as an increasingly common incidental finding on magnetic resonance imaging (MRI). The proportion of children with an incidentally discovered CM1 who upon further evaluation require operative intervention for previously unrecognized signs and symptoms of neurological compromise or significant radiographic findings (syringomyelia) is unclear. An extensive long-term single-institution patient series was evaluated to better clarify the likelihood of surgery in patients who present with an incidentally discovered CM1.



Only patients under 18 years of age who had an incidentally discovered CM1 and at least 12 months of clinical follow-up were included in the study.

A total of 218 consecutive patients were included. The mean age at the initial neurosurgical evaluation was 6.5 years (range 5 months to 18.4 years), and the mean duration of clinical follow-up was 40.6 months (range 12 to 114 months). Initial MR imaging was most commonly obtained for the evaluation of seizures (15.1%), nonspecific headaches (not occipital or tussive) (14.7%), trauma (9.6%), and developmental delay (7.8%). Of the patients studied that eventually required surgery, we identified two groups: those operated before 6 months since presentation and those operated after 6 months.

A total of 36 patients (16.5%) underwent a decompression with 22 patients (61.1%) receiving surgery within 6 months and the remaining 14 patients (38.9%) beyond 6 months. Patients undergoing early surgery (10.1%) initially presented with a significant syrinx or were noted to have an occult neurological dysfunction, whereas a smaller subset of patients (6.4%) eventually required surgery over time due to the development of new symptoms or a de novo syrinx. Only the presence of syringomyelia was statistically significant for the need of a surgical intervention, while age, sex and degree of tonsillar herniation were not.

In conclusion, evaluation of a large group of patients with an incidentally discovered Chiari malformation demonstrated that most patients may be managed conservatively, especially in the absence of syringomyelia. However, there is a subset of patients who will go on to develop a de novo syrinx or neurological symptoms that are new or progressive during follow-up, which should be evaluated by imaging of the brain and spinal cord. The presence of syringomyelia was associated with need for early surgical intervention. However, for patients without syringomyelia, surgical intervention is uncommon but may be delayed up to several years after presentation; therefore, long-term clinical follow-up is recommended.

Long-term outcomes of Posterior fossa decompression for Chiari malformation type 1: which patients are most prone to failure?

The role of an osseous-only posterior fossa decompression (PFD) for Chiari malformation type 1 (CM1) remains controversial. A team of doctors from George Washington University and Children's National Hospital reviewed long-term outcomes for patients with CM1 undergoing a PFD to evaluate if there was any difference for failure when compared to patients undergoing a PFD with duraplasty (PFDD).

Consecutive patients surgically treated at a single tertiary pediatric neurosurgery clinic over a 25-year period with at least 5 years of follow-up were evaluated. PFD patients were compared to those that initially received a PFDD. Demographics, surgical indications and surgical approach, outcomes and complication were reviewed.

A total of 60 patients were included in the study of which 25 underwent PFD and 35 underwent PFDD. The average age at surgery was 7.41 years which included children from under one year to 18 years. Those who received a PFD had a lower rate of radiographic syrinx improvement, especially in the setting of holocord syrinx. Failure rate was significantly higher in the PFD group. However, complications were slightly higher in PFDD group.

In conclusion the study supports that posterior fossa decompression provides a safe treatment option with similar clinical improvements and lower post-operative complication rate compared to posterior fossa decompression with duraplasty, albeit at the cost of a greater chance of reoperation, especially in the setting of a holocord syrinx. Patients with a holocord syrinx should be considered for a PFDD as their initial procedure.

The authors received financial support from the American Syringomyelia and Chiari Alliance Project, (ASAP) for the clinical research at Children's National Hospital.

[Article published in Child's Nervous System (2021) 37:2891-2898
https://doi.org/10.1007/s00381-021005280-y]

ASAP's L.E.A.R.N. Points Program
Leadership, Education, Awareness, Research, Now!

Every year since 1989 the ASAP national conference has been an invaluable resource. Attendees have the pleasure of hearing about the latest research, developments, treatment methods and much more regarding CM, SM, and related disorders. Presentations during this conference are given by doctors and other professionals who are at the cutting edge of their respective fields.

Hearing from past attendees and recognizing that cost is a prohibitive factor for many attending the conference, ASAP's LEARN Points Program was designed to allow people the opportunity to participate in this event. We urge you to consider this program, and join us in our mission.

1. All participants must set up a personal fundraising page. Patrice Schaublin will work you to plan and execute an event. Please contact her at Patrice_Schaublin@ASAP.org

2. For every dollar donated, the participant will be awarded one point ($1 = one point). Example: An individual or team raises $500 through their fundraising page. That individual receives 500 points.

3. If participant is holding a fundraising event, points will be awarded on the net contribution raised by the individual organizing the event. Donations made by individuals or teams participating in the points program will be treated as an expense and deducted from the gross. Example: A walk raises $5000, expenses paid by ASAP equal $500, and additional individuals or teams participating in the points program raise $1000. There is a $1500 dollar deduction from that event gross leaving a net of $3500.

4. Any individual or team setting up a personal fundraising page to participate in an event agrees to donate 10% of any points awarded to the event organizer. Example: An individual or team raises $1000 dollars for the event, the L.E.A.R.N. participant receives 900 points, and the event organizer receives 100 points.

5. Other than what is outlined above, points will not be transferable to other program participants. ASAP retains all rights as to the final determination of points awarded.

6. Airfare, round trip, will be booked and paid for by participant. Participant will fill out the reimbursement form (to be mailed by request from ASAP) and return, postmarked no later than 2 weeks after the event, for reimbursement up to $350 for every 5000 points earned. There will be no reimbursement for any other travel expenses, i.e., sightseeing, cab, airport shuttle etc.

7. If participant elects to drive, round trip mileage to the conference venue will be reimbursed at .40 cents per mile up to $250 for every 5000 points earned. Final mileages will be verified and determined by ASAP. Participant will fill out the reimbursement form (to be mailed by request from ASAP) and return, postmarked within two weeks of the event. No travel expenses other than those listed above will be eligible for reimbursement, i.e., sightseeing, tolls, cab, limo, shuttle, airport transportation etc.

8. Accrued points have no cash value. There are no reimbursements other than those outlined above.

9. Participants will be responsible for any and all costs not included in the conference registration, i.e., meals, sundries, charges to hotel room, gift shop purchases, etc. All additional purchases and expenses will be the sole responsibility of the participant.

10. The purpose of this program is to allow people who want to attend the ASAP national conference an opportunity to do just that. There will be no reimbursements for unused points and ASAP reserves the right to make the final decision regarding validity of all claims for reimbursement.

11. All risks associated with attendance at the conference will be participants own. Participants agree to hold ASAP harmless against any claims resulting from that participants' attendance at the ASAP national conference.

12. ASAP reserves the right to cancel this program at any time without notification.

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
Jonathan Melendez
Nancy Melendez
Michael Kirlin
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Online Shopping

When you shop at smile.amazon.com you can generate AmazonSmile donations for American Syringomyelia & Chiari Alliance Project, Inc.

Since we joined in 2014, ASAP has received almost $7,000 in donations.

Thank you for selecting ASAP as your charity of choice at AmazonSmile!

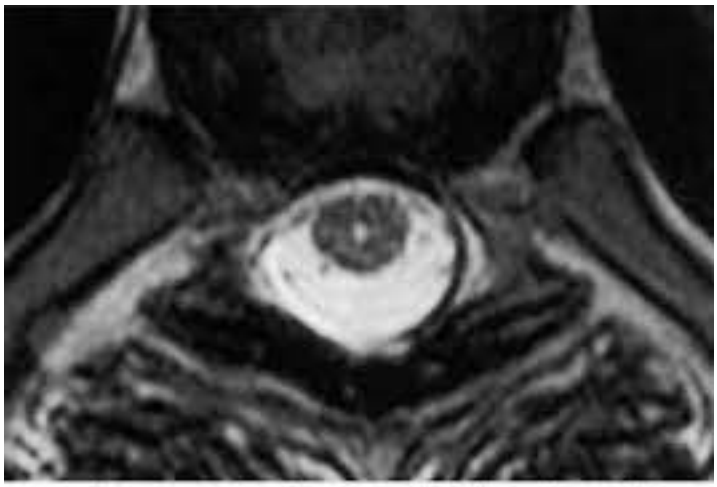
2022 ASAP Virtual Auction

November 22-28

Tell your family and friends!

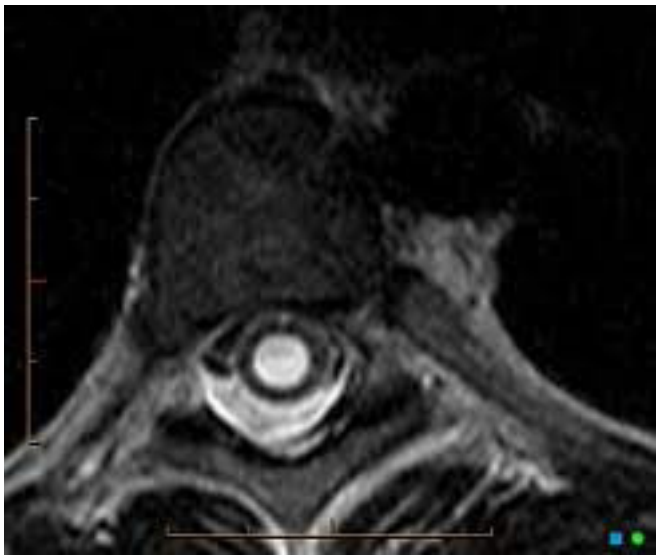
An email blast will be sent with the link to view items and place bids. Items include theme baskets, original artwork, gift cards, jewelry, collector model cars, and so much more. Find your unique holiday gifts at our virtual auction.

Dilated Central Canal



With the advancement of MRI technology, individuals are being diagnosed with very small syrinxes that we were unable to detect in years prior. Some people will be told they have a slit-like syrinx or dilated central canal. These are generally 1-2 mm wide in diameter and are often described as a “nonexpansile” syrinx. To understand why this small cavity is present, a review of normal anatomy is helpful.

The spinal cord forms as a tube. On the inside of the tube is a small fluid cavity called the central canal. This disappears during development or during infancy. When the central canal does not completely close, a small leftover of the canal can be seen on MRI and is referred to as a “persistent central canal.” A radiology report may contain the phrase “a small syrinx versus a persistent central canal.” A repeat MRI may be recommended in order to determine a definite diagnosis. This often causes stress for the person waiting and hoping for a concrete diagnosis.



Our current understanding leads us to recommend that if the dilation of the central canal is not associated with any other known cause of a syrinx (such as the Chiari malformation, a tethered spinal cord, or tumor) it is likely to be a benign finding that will not cause any symptoms and is not likely to grow or enlarge. To make sure, a follow up MRI is usually ordered. In cases where an underlying condition known to be associated with syrinx formation is present (such as a Chiari malformation) or if repeated imaging shows a change in the dilation, then it is more likely to be a true syrinx that should be evaluated and monitored accordingly.

Molly's 8th Annual ASAP Walk and Roll for a Cure

This year's Molly's walk along with Molly's Mulligan (a golf event benefiting ASAP), Molly's Match (tennis event benefiting ASAP), and Molly's Amazing Auction were an unbelievable success! And let me tell you, it was thanks to the AMAZING people who donated their time and energy to pull it together. DRUMROLL PLEASE The total amount we raised this year with the four events was over $51,000. When I started fundraising years ago, I had no idea we would get to this point. I am forever grateful for every sponsor, donor, walker, and prayer warrior who helped make these events a success. Not only did we raise a boatload of money that will go to research, but we raised so much awareness between all the different groups of people. That is amazing.

THANK YOU ALL SO MUCH

I am FOREVER grateful,
Molly Lichtenstein

American Syringomyelia & Chiari Alliance Project Inc.
P.O. Box 1586 Longview, Texas 75606-1586

ASAP®

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

AMERICAN SYRINGOMYELIA CHIARI ALLIANCE PROJECT

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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