

Spring
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

We are moving forward with plans for an in-person meeting in Chicago, Illinois, July 20-23. This is a unique opportunity to not only hear insights from Chiari and Syringomyelia experts but to interact with them directly. Attendees will have the opportunity to ask questions during designated session. Doctors will also speak one-on-one with individuals as time allows.

The conference is designed for speakers to share with their colleagues and those affected by these conditions. So if anyone on your medical team is interested in learning more, please share our conference information with them. Although we cannot address individual cases, we strive to provide a variety of information that will benefit everyone.



On-site registration/check-in will begin at 1:00 PM, July 20 at the Millennium Knickerbocker Hotel. Please try to register in advance so we will have a better understanding of food and space requirements. However if you are unable to do so, you may register at the meeting. Lectures will begin Wednesday afternoon in general session starting at 1:30 (see pages 4-5 for the agenda). We will end the day with an evening dinner cruise on Lake Michigan.

Thursday will be packed full starting with breakfast before the general session which starts at 9 am. Children five to fifteen will have the opportunity to participate in a special program designed to entertain, educate and support. In the evening attendees will have free time to explore the Magnificent Mile, visit with new friends or just relax.

Friday is structured similar to Thursday with the exception of a cocktail hour, plated dinner and entertainment, all included in the registration fee. Attendees may enjoy this time to network, relax and share what they have learned.

The meeting will conclude Saturday morning immediately after breakfast. Attendees may choose to stay an extra night to enjoy the city or just relax in the luxury of the Knickerbocker.

We are in the process of securing parking in the area for those driving. Please contact the ASAP office for more details.



Make Hotel Reservations for ASAP Conference

Millennium Knickerbocker Chicago

Upscale downtown hotel next to the Magnificent Mile

Millennium Knickerbocker Hotel Chicago is the epitome of classic Chicago style, located near Magnificent Mile in downtown Chicago – a famous stretch that's home to over 400 retailers and high-end shops.

Established in 1927, this historic hotel in Chicago has had many identities, including a Penthouse casino and speakeasy once run by the Capone family. You'll find markers of this iconic history all around the hotel as the old world meets the new.

One of the most timeless aspects of the hotel is its commitment to its guests – you can expect 4-star service at every moment of your stay.

- You'll be nestled into the retail haven of Magnificent Mile, Chicago
- Proximity to some of the city's most iconic landmarks like Cloud Gate and 360 Chicago
- Georgian-style Crystal Ballroom with gilded dome ceiling and stunning balcony
- Friendly and welcoming staff that will go above and beyond for you
- A unique history that spans the prohibition era, and even a brief stint as the Playboy Towers

- A choice between over 50 martini types at the 1920's style Martini Bar

Location:

163 East Walton Place
Chicago, Illinois 60601

To make reservation online, go to:

<https://asap.org/conferences/2022-conference/>
scroll down to 'Hotel Reservations' and follow prompts.

To make reservations by phone call Millennium reservations at 1-800-621-8140 Monday – Friday 8:30 am – 5:30 pm EST. Use the promo code 07192022AS. Request your room type (Superior King or 2 Double) for a rate of \$149 (+40.92 tax) per night.

Be sure to give them any special request such as accessibility, shower chair, etc.

We are in the process of securing parking in the area for those driving. Please contact the ASAP office for more details.

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

We are very excited to be back in person for the 34th annual American Syringomyelia and Chiari Alliance Project conference.

After much consideration and discussion, we made the decision to move forward with our in-person conference this summer. We find being in person offers the attendees access to valuable sources of important information, research, and other resources that you've come to expect from ASAP and the annual conference.

We certainly hope that we will see you at our 34th Annual Conference at the historic Knickerbocker Hotel in Chicago on July 20-23, 2022, with our host Dr. Konstantin Slavin. Registration is now open. Scholarships and opportunities to participate in our L.E.A.R.N. program are available now so you can plan ahead: you can find the details at ASAP.org or contact our office with any questions you may have. Not everyone can travel to a conference but attending one in person does offer opportunities a virtual format cannot, such as direct interaction with the presenters, support groups, banquet dinner and networking with fellow attendees.

I would like to thank all our distinguished speakers for their dedication to ASAP. Without their knowledge and expertise and their willingness to share with the rest of us, none of this would be possible. I would also like to thank the Board of Directors and staff of ASAP for your tireless efforts to continue the mission of Don and Barbara White by providing the resources necessary to fund research, continue our outreach efforts and support, and provide education about Chiari Malformation, Syringomyelia, and their related disorders.

And finally, I would like to thank all of you who are planning to be in attendance. Thank you for joining us for this conference, for your support of us as an organization, and for helping to bring awareness, education, and support to everyone in our community.

ASAP is stronger when you're involved!

For more information on how you can help further ASAP's mission, please feel free to reach out to myself, the ASAP Board or the staff at any time. And always remember, you may have to live a life within limits, but, you can still lead a limitless life!



ASAP KIDS For A Cure Club

Agenda

Thursday - July 21

- 9:00 AM Icebreaker Warm-up
- 9:30 AM Introductions
- 10:00 AM Teddy Bear Clinic
- 11:00 AM Guided Imagery
- 12:00 PM Lunch Break
- 2:00 PM Wood Working
- 4:00 PM Release

Friday - July 22

- 9:00 AM Music Therapy
- 9:30 AM Puppetry Work shop
- 10:00 AM Canine Therapy Corp
- 12:00 PM Lunch Break
- 2:30 PM Ask the Doctor
- 3:30 PM Meditation
- 4:00 PM Release

Please note: The schedule is subject to change. It is a work in progress and anticipate adding additional activities.

ASAP Conference Schedule

Wednesday, July 20, 2022

Time	Speaker	Topic
1:30 PM	Eric Berning, ASAP President	Welcome
1:35 PM	TBD	TBD
2:00 PM	Ulrich Batdorf , MD UCLA	Syringomyelia Without Chiari
2:30 PM	Erol Veznedaroglu, MD Global Neuroscience Institute	Controversies in Chiari
3:00 PM	Dave Knowlton	Cannabis for Chronic Pain (The Hights & Lows of Pot for Pain)
3:30 PM	Speaker Panel	Question and Answer Session
5:15 PM	Attendees meet in hotel lobby for transportation to Navy Pier for Dinner Cruise	

Thursday, July 21, 2022

Time	Speaker	Topic
9:05 AM	Child Life Specialist University of Chicago	How a Child Life Specialist Can Improve the Medical Experience
9:35 AM	Bermans Iskandar, MD University of Wisconsin/Madison	Review of the Chiari Zero Malformation: What is it, and what isn't it?
10:05 AM	John Oró, MD, FAANS	Enhancing Your Recovery Following Chiari Surgery
10:30	Brian Dlouhy, MD University of Iowa	Chiari Malformation Associated with Bony and Ligamentous Abnormalities Causing Craniocervical Instability
11:00 AM	Speaker Panel	Question and Answer Session
	Lunch Break	
1:00 PM	Gerald Grant, MD Duke University	Chiari I: Myth Busters
1:30 PM	John Heiss, MD NIH/NINDS	Arachnoiditis & Syringomyelia
2:00 PM	Robert Keating, MD Children National Hospital	Long Term Outcomes
2:30 PM	Paolo Bolognese, MD Chiari EDS Center	Craniocervical Instability
3:00 PM	David Frim, MD University of Chicago	Speech Impairment in Patients with Symptomatic CM1
3:25 PM	Speaker Panel	Question and Answer Session

ASAP Conference Schedule

Friday, July 22, 2022

Time	Speaker	Topic
9:05 AM	Ilene Ruhoy, MD Chiari EDS Center	Pain Management in Connective Tissue Disorders
9:35 AM	Anne Maitland, MD	Balancing the 3-Legged Stool of Ehlers Danlos Syndrome, Mast Cell Activation Disease and Neuropathy
10:05 AM	Cormac Maher, MD University of Michigan/Ann Arbor	Chiari and Pregnancy
10:30	Petra Klinge, MD Warren Alpert Medical School	The Concept of Human Tethered Cord Syndrome-Classification of Co-morbidities and Coexisting Pathologies
11:00 AM	Speaker Panel	Question and Answer Session
	Lunch Break	
1:00 PM	Physical Therapist	TBD
1:30 PM	Konstantin Slavin, MD University of Illinois Chicago	Drainage of Syrinx in Syringomyelia - Should it be done more often?
2:00 PM	Psychologist	TBD
2:30 PM	Carina Yung, MD University of Chicago	A Glimpse Inside: MRI of Chiari and More
3:00 PM	Jorge Lazareff, MD UCLA	MM & ABJ the Narrative of People with Chiari
3:25 PM	Speaker Panel	Question and Answer Session
4:05-5:00 PM	Support Groups	
6:30-7:15 PM	Cocktail Reception	
7:15-10:00 PM	Banquet Dinner and Entertainment	

Saturday, July 23, 2022

Time		
7:30-9:30 AM	Breakfast	
9:00 AM	ASAP Wrap-up and Farewell	

*** Please note: The agenda is subject to change.**

Please visit <https://ASAP.org/conferences/2022-conference> for up-to-date information

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.

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ASAP's Chiari & Syringomyelia Conference

July 20-23, 2022

Attendee Registration Form

Contact Information

Name: _____
Address: _____
Phone: _____ Email: _____

Additional Attendees

Please add contact information if different from above. List each child's name and age..

Name: _____
Name: _____

List additional attendees and contact information if needed on back.

Fees

Number

Sub-total

Adult registration *	_____ x \$175.00	_____
Children's registration: ages 5 - 15 *	_____ x \$ 65.00	_____
Additional banquet tickets: ** (Fri evening)	_____ x \$ 75.00	_____
Additional dinner cruise (Wed evening)	_____ x \$100.00	_____
Family pack: 2 adults, 2 children (ages 5-15) *	_____ x \$425.00	_____
Day rate: Circle day Wed, Thurs, Fri or Sat***	_____ x \$ 50.00	_____

*Includes Wednesday dinner cruise, Friday banquet & breakfast (Thursday, Friday, Saturday)

** For those who will only attend the banquet on Friday evening

***Day rate includes breakfast and lectures only (no breakfast on Wed)

Special diet request (vegetarian, gluten free, etc): _____

Note: By submitting this form and/or attending the conference, you agree to allow ASAP to use photographs and/or videos taken of you in ASAP's promotional materials. You understand that ASAP will not publish or record any personally identifiable information without your express written consent.

Payment Information

Payment Type: Check Credit Card Total Amount Enclosed (see sub-total above): \$ _____
Credit Card Type: Visa MasterCard Discover American Express
Cardholder Name (please print): _____
Credit Card Number: _____ Expiration Date: _____
Cardholder Signature: _____

Return completed form with payment to ASAP, PO Box 1586, Longview TX 75606-1586



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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