

Doctors Host Syringomyelia Chiari Conference in China

In July 2017 Doctors Yong Liu and Yongli Lou traveled from Beijing, China to participate in the ASAP conference in Long Island, New York. Upon their return home, they began planning a local meeting. Approximately 50 patients participated in the event held in December. China's largest group manager, Mr Wu Xiuyin, has an established patient group of over 2000. He spoke at the meeting of his experience and encouraged other patients.



Professor Yong Liu is the founding father of the first Syringomyelia Department in China. Since 2001, Professor Liu has been devoted to the study, research and treatment of Syringomyelia, Chiari malformation and CVJ spine and spinal cord diseases. He has operated on over 5,800 patients throughout his career and invented the MIST technique. For the past four years, he has worked on customized 3D printing fusion hardware devices, performed the first 3D-printing tailored titanium plate lock fixation via transoral approach. In 2016 Dr Liu and his team launched the Chiari and Syringomyelia Medical Research Institute which manages a clinical database comprising over 15,000 cases in hopes of providing a platform for a better international communication and cooperation in this field. He is now the Chief of the Syringomyelia Department in Tsinghua University Yuquan Hospital in Beijing.



Dr Yongli Lou, Chief of the Syringomyelia Department in Zhengzhou, China, specializes in Syringomyelia, tethered cord syndrome and CVJ malformation. He also treats Chiari malformation, basilar invagination and atlantoaxial dislocation, spinal tumors, spina bifida, spinal arachnoid adhesion and neuropathic pain. As a protege of Professor Liu, he provides specialized care to patients in Zhengzhong Central Hospital in connection with the institute in Beijing.



During the 2017 ASAP Chiari & Syringomyelia Conference, the international coalition was formed to support research, education and knowledge sharing. China, India, Spain, Italy, England and France will join ASAP in this world initiative to further understand, promote research and find a cure.



Amazon Smiles

Do you shop on Amazon?

AmazonSmile is a website operated by Amazon with the same products, prices, and shopping features as Amazon.com. The difference is that when you shop on AmazonSmile, the AmazonSmile Foundation will donate 0.5% of the purchase price of eligible products to ASAP.

Every item available for purchase on www.amazon.com is also available on AmazonSmile (smile.amazon.com) at the same price.

Since we joined AmazonSmile four years ago, ASAP has received almost \$1,300, simply because our members shop at AmazonSmile and choose American Syringomyelia Alliance Project, Inc as their designated charity.

If you are shopping online anyway, shop at smile.amazon.com/ch/75-2245195 and Amazon donates to American Syringomyelia & Chiari Alliance Project, Inc.

We appreciate your support!

Syringomyelia Awareness

Set of 5 awareness items for just \$5 plus \$5 shipping/handling. Includes bumper sticker, collapsible flyer with pouch, adhesive phone caddy, glow in the dark bracelet and post-it note-pad.

Order online through the ASAP Store, or send a check made payable to ASAP for \$10 and let us know you want the Syringomyelia Awareness set.



One small positive thought in the morning can change the entire outcome of your day!

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:

Patricia Maxwell

Patricia_Maxwell@ASAP.org

Jamie Mayhan

Jamie_Mayhan@ASAP.org

If you find yourself in a downward spiral, grab hold of that thread of hope and pull until you are back on track.

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

It is that time of year again, when we start to thaw out from the winter and set our sights on the renewal of spring. It is also conference planning time for our organization, and this year we are celebrating our 30th annual conference.

If you have not had the chance to attend an ASAP conference previously, we highly encourage you to look into attending this year's milestone event. ASAP offers two ways to help defray the cost of attending: 1) a scholarship to cover part of your admission expense, and 2) our Learn program, through which simply fundraising for ASAP can get you to the conference. Contact us to learn more.

We would love for everyone to have the opportunity to take advantage of the one-on-one experience of interacting with the world's leading experts in the treatment, care, and research into Chiari and Syringomyelia. While we realize travel is not always feasible for everyone, that doesn't mean you have to completely miss out on hearing the information our renowned speakers have to share. Did you know the previous year's conference presentations are posted on our YouTube page? If you were unable to attend in person—or perhaps you were there but wish to revisit a topic of interest—you can view each individual speaker just by pulling up the ASAP YouTube page on your favorite device!

I initially became involved with ASAP through a local support group meeting. How are you getting connected? Do you have a support group? Are you able to organize and raise funds to support the outreach programs? We all can do a little bit to help someone else. How can we help you?

Every organization needs people to get involved in order to remain viable and operational. Likewise, ASAP needs people like you, people who have a heart for those with our shared and similar conditions, to serve. Please contact us if you would like to volunteer some of your time, talent, or resources—or if there is a need we can assist with serving you. We are here for you!

I hope to see many of you at this year's conference in Orlando, and am excited to meet new faces and reunite with familiar ones. It's an event not to be missed! In the meantime, be well—and remember to live your life within your limitations, but without limits!

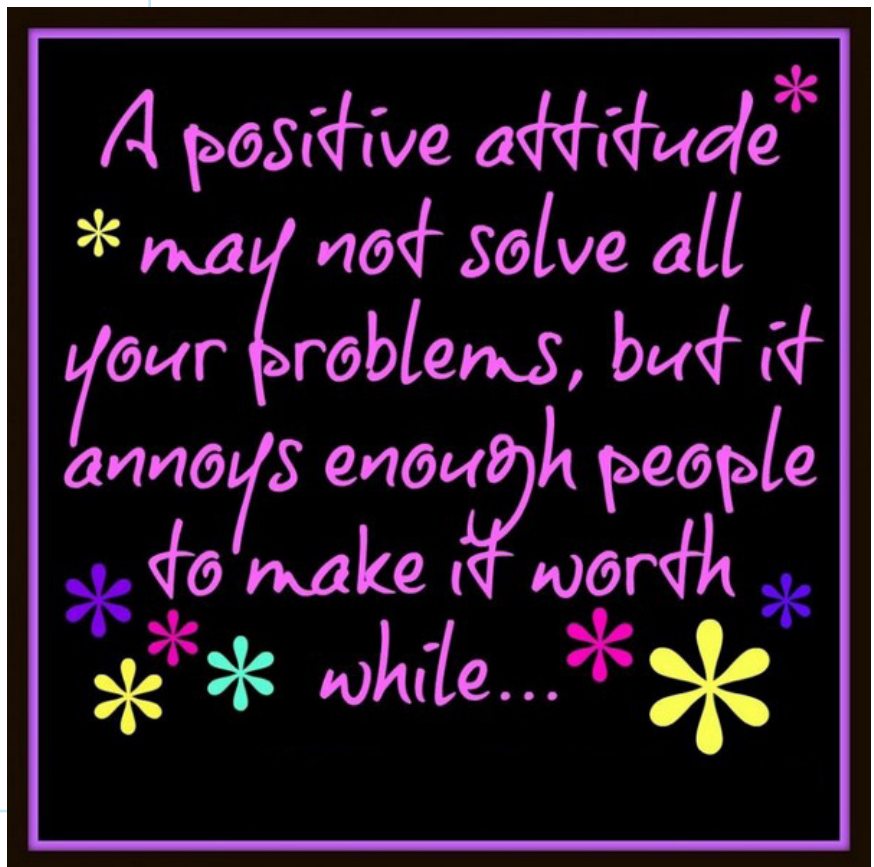
People Who Inspire Us

We've all heard stories of inspirational people. Individuals who have overcome great hardships yet managed to excel in life. People who endured tragedy but through their own personal strength help others to overcome. Someone who has the courage to push through their fears, and make us want to be better, stronger, bigger, and more of who we are.

Do you have that person in your life? Someone whose encouragement helped get you through a hard patch. A person whose positive attitude gave you strength. A friend who makes you want to fight for the best quality of life you can have.

We would like to run a column featuring people diagnosed with Chiari, Syringomyelia and related disorders. Maybe you know someone with these disorders who is an inspiration or maybe who have the disorder(s) and someone inspired you.

You can nominate an individual, submit a story, or share your own story. Stories should be uplifting, positive and inspirational. Please submit your suggestions to patricia_maxwell@ASAP.org.



Meet Kimberly McFarland

by Karen McFarland

After years of frustrating symptoms (falling, constant headaches, pain) and misdiagnoses, my daughter Kimberly was finally properly diagnosed with Syringomyelia, Chiari malformation and tethered cord at age 3. That diagnosis was just the beginning of a long path of tests, surgeries, medications and therapies.

Her first surgery, immediately after diagnosis was performed locally and involved placing a syringosubarachnoid shunt to 'treat' her Syringomyelia. Within weeks, we realized that this surgery had not helped her at all and had actually worsened her condition and we sought out a specialist in the field but it required traveling almost 800 miles for the consultation and subsequently three surgeries.

Kimberly tried multiple pain medication for chronic leg pain and was seen by two separate pain clinics. At one point they were running her through trials of methadone and morphine and the elementary school nurse was a little intimidated by the list of medications that she was coming in on. Her greatest relief from the pain came from acupuncture and massage treatments and she went weekly for those treatments in addition to time consuming physical therapy appointments.

Due to the leg pain worsening by walking on hard surfaces, she used a motorized scooter to get around in school. While this helped her mobility, it did not help her self-esteem as it caused other kids to view her as 'different'. During Kimberly's eighth and ninth grade, she had many absences for headaches which forced her to stay in bed with the curtains drawn. We added up her absences once and all told she missed about a year of school. Fatigue and memory loss were also side effects of the medications that she was taking that greatly affected her on a daily basis.

Through all of this, Kimberly loved to learn and was motivated to keep on top of her work and pursue her dreams. She worked hard and studied harder. I have told Kimberly since she was little that I know she is going to make a difference in the world someday. Well, that day may be sooner than we think. She is graduating from Mary Washington University in a few weeks with a Bachelor's degree in Biology and I am proud to say that she has just been accepted to medical school! Certainly the strength she needed to overcome the pain and all that is associated with these conditions helped her get to where she is now and will help her get through medical school. It will also help her as a doctor as she will certainly empathize with what her patients are going through. As the saying goes, when life hands you lemons make lemonade. Kimberly certainly does exemplify that.



Kimberly traveled to Ecuador last summer to learn medical Spanish and work in a health care clinic.



Kimberly has scaled many types of mountains in her life.

Getting Off Opioids: 6 Tips From a Pain Expert by Peter Abaci, MD

As pressure to cut back on prescription opioids continues to mount, doctors and patients are feeling the heat. If you have been on long-term opioid therapy and are now being asked to switch to a different pain management method, you may feel concerned and fearful about weaning off opioids.

To better understand why coming off opioids can be such a challenge, consider how our bodies handle opioids. We each have a naturally occurring internal opioid system that not only regulates pain, but also impacts our social interaction, cardiovascular health, metabolism, stress, learning, mood, respiration, digestion, immune function, sexual activity, and reward and addiction. In other words, just about everything that goes on in the body can be impacted by our internal opioid system to some degree. So, when we consider replacing our natural coping mechanisms for things like stress, social bonding, and reward-gratification with prescription painkillers, we start to get a sense of why pulling them away can be such a challenge. On top of dealing with concerns about how to manage the pain, there is also the struggle to regain equilibrium in managing basic life functions.

If you find yourself in a position of needing to reduce or wean off your prescription opioids, I recommend working with your doctors to put together a well-thought-out strategy for long-term success. Based on the latest research, some of my own experience, and the experience of other experts, here are some tips to help you and your physician work toward a successful medication transition:

- **Emotional support is a must:** Weaning opioids is anxiety-provoking and stressful for almost everyone, so it is important to build your support structure before you start the process. A pain psychologist or counselor can help manage some of those fears and can also help you explore behavioral-based approaches for pain management. Stay connected with your support team throughout the weaning process and have regular scheduled appointments and meeting times already in place.
- **Slow and steady wins the race:** I had a chance to catch up with Beth Darnall, PhD, a Stanford psychologist and leading pain researcher, to talk about her recently published study in JAMA Internal Medicine on ways to effectively wean opioids. She notes that patients do the best when they are not forced to wean too quickly, but rather approach it voluntarily and at their own pace. In other words, you can expect this to go more smoothly when you are a key part of the decision process. In fact, Dr. Darnall found that for the patients who hung in there, the pain did not get worse based on measurements of pain intensity and pain interference.
- **Consider MAT:** MAT stands for medication-assisted treatment for opioid dependence, and it combines the use of medications, like buprenorphine, with behavioral

therapy. Most experts agree that medication assistance works better for opioid detox than abstinence in cases of significant dependence. In my experience, buprenorphine can be an effective tool as part of a comprehensive treatment plan for the treatment of opioid-dependence coupled with chronic pain. Unfortunately, there is still a lot of pushback from insurance plans in covering medications like buprenorphine despite demand for greater access. Be prepared to be a squeaky wheel!

- **Find an acupuncturist:** Many of my patients find acupuncture helpful when going through the medication transition process. It can help diminish withdrawal symptoms, quell anxiety, and reduce pain. Auricular acupuncture, which focuses on pressure points around the external ear, is often particularly helpful for detox and can be done easily and safely. Both the World Health Organization and the National Institute of Health have recommended acupuncture as an aid for detox treatment, although well-designed scientific studies to support this still seem to be lacking.
- **Have a vision:** Most patients that I meet tell me that they don't want to stay on their medications forever, but they just don't know what else to do and are afraid to let go. This might be a good time to explore alternative treatments that will align you with the goals that you have for yourself. If you see yourself stuck in a rut but wanting to be more active, more engaged, and happier with life, now is the time to come up with a plan that can actually get you there.
- **Dive deeper:** Going beyond painkillers is in some ways an opportunity to better understand both your body and your inner self to get to the root underlying causes of the pain. If you have been treating things like tight muscles, stiff joints, stress, and even panic attacks mostly with pills, then you probably haven't fully addressed some of the core causes of why you hurt, and therefore have missed out on opportunities for recovery. Seek out behavioral health practitioners and movement experts who can help you make this not just a tapering process, but a true healing process!

Becoming an active part of the weaning process can help diminish your fear, anxiety and stress. As legendary basketball coach John Wooden once said, "Things turn out the best for the people who make the best of the way things turn out."

{Peter Abaci, MD is the Medical Director and Co-Founder of the renowned Bay Area Pain and Wellness Center. His innovative strategies for integrative pain treatment have helped restore the lives of thousands struggling with pain. His book, Conquer Your Chronic Pain, A Life-Changing Drug-Free Approach for Relief, Recovery, and Restoration, is considered a must read for anyone dealing with chronic pain.}

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 recipient.

In Honor of Person
Donor

DeCoursey Gardner

Paula Gardner

Sara Siman

Emilio Solernou

Gilbert & Cristina Beauperthuy

Jose Maria

Coralia Diaz

Jose Siman

Lambertus Yde Veltman

Lawanda Loftus

Jacqueline Babitts

Steven & Rosa Babitts

Philip Benoit

Windell & Carolyn Dixon

My Body Pump Friends,

Cathy, Evie & Tricia

Lynda Tubridy

In Memory of
Donor

Robert Hoover, Jr.

Ronda Hoover

Laura Putney

Foulston Siefkin

Attorneys at Law

Cherie Campos

Adrienne Clark

Albany Widler

Alexandria Bush

Andrew Nolan

Betty Schnoebelen

Cheryl Riggan

Christina Ramsey

David Ferguson

Jeff & Kelley Degraffenreid

Karen Putnam

Janice Knox

Linda Siders

Marsha Hill

Ellie McCallum

Lee Miller

Judy Hunt

Guy & Marlene Petersen

Gwen Miske

Cynthia Hendricks

Rebecca Galloway

Dan Lean

Danette Kane

Gary Seccomb

Jim & Becky Sprunger family

Esta Swartz

Holly Ann Correia

2018 Conference Speakers

Gaylord Palms Resort

Kissimmee, FL

July 25-28

Host:

Dr Ian Heger - Augusta University Medical College of Georgia

Dr Eric Trumble - Congenital Neurosurgery,

www.pedneurosurgery.net

Speakers:

Dr Carl Barr - Florida Hospital for Children, Orlando

Dr Paolo Bolognese - Chiari Neurosurgical Center at NSPC, New York

Dr Jacob Eichenberger - Augusta University Medical College of Georgia

Dr Brian Dlouhy - University of Iowa Hospitals, Iowa City

Dr Herbert Fuchs - Duke University Hospital, Durham, North Carolina

Dr Tim George - Dell Children's Hospital, Austin, Texas

Dr Holly Gilmer - Michigan Head & Spine Institute, Beaumont

Dr Gerald Grant - Stanford Medical Center, Stanford, California

Dr Barth Green - University of Miami Florida

Dr Jeffrey Greenfield - Weill Cornell Brain and Spine Center, New York

Dr John Heiss - NINDS/National Institutes of Health, Bethesda, MD

Dr Roger Kula - Chiari Neurosurgical Center at NSPC, New York

Dr Cormac Maher - University of Michigan Health Systems, Ann Arbor

Dr Arnold Menezes - University of Iowa Hospitals, Iowa City

Dr John Oro - Colorado Chiari Institute, Aurora

Dr Hal Rekate - Chiari Institute, Great Neck, New York

Dr Michael Westerveld - Florida Hospital for Children, Orlando

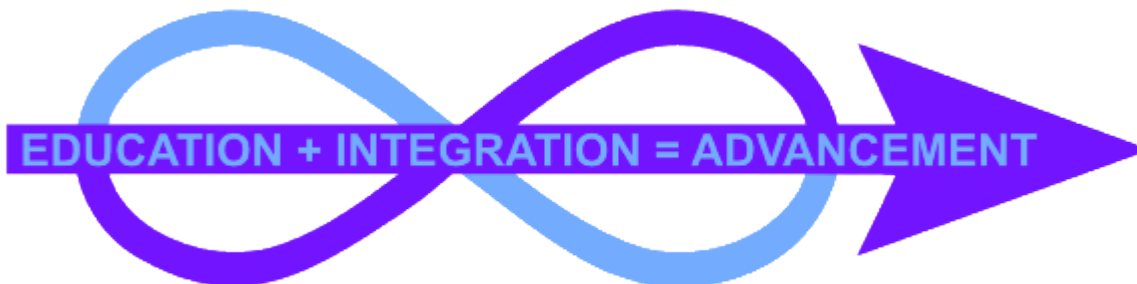
Dr Saul Wilson - University of Iowa Hospitals, Iowa City

Dr Erol Veznedaroglu - Drexel Neuroscience Institute, Philadelphia, PA

Dr Justin Virojanapa - Northwell Health, New York



2018 ASAP Syringomyelia & Chiari Conference





KICKS & LICKS 2018

Two Feet, Four Paws....One Cause!

ON
May 5, 2018 @ 10am

AT
Blumont Park, 601 N Manchester St,
Arlington, VA 22203

WITH
Agility Course • Relaxed Leash Lesson
Paw Painting Activity • Medical Discussion
Silent Auction • Pet Photography
Pack Walk @ 11am • Raffles
Food & Family Fun!



American Syringomyelia
& Chiari Alliance Project



www.ASAP.kintera.org/kicksandlicks2018

Special thanks to
Jen Sadrak for hosting
this year's Kicks & Licks.

Our Sponsors:
Gold Sponsor



Brass Sponsor



Friends of ASAP



Yogi's 3rd Annual Community Fund Day

May 20, 2018
Seneca Falls Elks Lodge - River Rd
11 AM - 4 PM

BBQ provided by Waterfalls Catering (chicken, baked beans, mac salad and roll), Always loads of fun for the entire family.

Special thanks:

- To the Seneca Falls Police Department for taking pictures of kids/people dressed up in a uniform and inside of the police cruisers.
- Two Barn Farm for fun their animals and the pony/horse rides.



B98.5 Bottle Drop

B98.5, Central Maine's country music radio, hosted a bottle drive in April at Damon's Beverage Mart (in Augusta) and Damon's Beverage (in Waterville). Damon's donates 6 cents per bottle or can to ASAP.

On Saturday, April 21, Sarah Dyer broadcast live at the Augusta location from 9am - 11am and the Waterville location 12pm - 2pm. The radio station provided give-a-ways which included some great concert tickets.

Sarah, a DJ for the station, was diagnosed with Chiari and is spreading awareness in Maine. She also attended a health fair in March where she and Lisa Dunton-Roy, support group coordinator for Maine, shared information about Chiari and Syringomyelia.

Sarah has also been soliciting items for the conference auction and raffle. We will have lots of great items including heated neck wraps, a Thomas Kinkadee print, instant pot pressure cooker, and many more.

**Today, wherever you go,
spread awareness!**



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

ASAP Board of Directors

Eric J Berning, President
Patrice Schaublin, Past President
Cathy Tufts, Vice-President
Annie Chapman, Treasurer
Richard Simon, Secretary
Paolo Bolognese, MD
John Caemmerer
Ian Heger, MD
Molly Lichtenstein
Bridget Maher
Gerald Grant, MD FACS
Robert Keating, MD

ASAP Medical Advisory Board

Robert Keating, MD - Chair
Children's National Medical Center
Ann Berger, MD
National Institutes of Health
Timothy George, MD
Dell Children's
Gerald Grant, MD - Research Chair
Stanford Medical Center
John Heiss, MD
NIH/NINDS
Bermans Iskandar, MD
University of Wisconsin-Madison
Roger Kula, MD
North Shore Univ Hospital
Cormac Maher, MD
Univ of Michigan Health Systems
Arnold Menezes, MD
Univ Iowa Hospitals & Clinics
John Oro, MD
Colorado Chiari Institute
Erol Veznedaroglu, MD
Drexel Neuroscience Institute



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.

Email: Patricia_Maxwell@ASAP.org

Mail: *ASAP Connections*
PO Box 1586
Longview, TX 75606

ASAP Connections Editor: Patricia Maxwell