

Providing Research, Education and Support since 1988

ASAP Chiari & Syringomyelia Conference July 25-28, 2018

Start making plans now to attend the ASAP Conference in Orlando, Florida this summer. ASAP will be celebrating 30 years of service to the Chiari & Syringomyelia community. The meeting will take place at the beautiful Gaylord Palms Resort in Kissimmee, Florida. Renowned for its magnificent atrium and “everything in one place,” the resort offers something for everyone. See page 4 for more information on making your reservation.

Conference Hosts



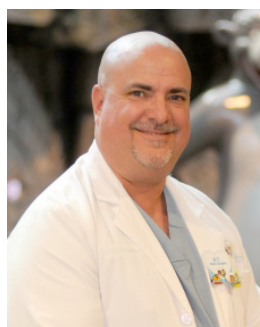
Ian M Heger, MD, FAAP, FACS is a board-certified pediatric neurosurgeon with a vast amount of experience in clinical practice and academia. He earned his doctor of medicine and served as a resident in neurosurgery at SUNY Downstate Medical Center in Brooklyn, New York. He was an ASAP fellowship recipient in 1996 under Dr Thomas Milhorat. He completed

his fellowship in pediatric neurosurgery at the Children’s Hospital of Philadelphia at the University of Pennsylvania.

Consumer’s Research Council of America named Dr Heger as one of America’s Top Surgeons in 2008, 2009 and 2012 as well as “Super Doctor” in the South Florida edition in 2008 and 2009. He serves on several prestigious healthcare committees and is a fellow of the American Association of Neurological Surgeons, American College of Surgeons, and American Academy of Pediatrics. He is also a member of the American Society of Pediatric Neurosurgeons.

Dr Heger is the section chief of pediatric neurosurgery at the Children’s Hospital of Georgia, and is an associate professor of neurosurgery at Augusta University/Medical College of Georgia in Augusta, Georgia. In addition to his clinical interests in Chiari malformation/Syringomyelia and related disorders, his expertise includes craniofacial and brain tumor surgery as well as general pediatric neurosurgery.

He serves on the ASAP Board of Directors and has also spoken at the ASAP conference.



Eric Trumble, MD, graduated with a degree in aerospace engineering from the University of Texas at Austin. Following graduation, he continued his research in neurosciences at the National Institutes of Health. After obtaining his medical degree at the University of Virginia, he served his residency at the Medical College of Virginia.

His formal training culminated with a pediatric neurosurgery fellowship at Children’s Medical Center of Dallas. Board-certified in both adult and pediatric neurosurgery, he has devoted his career to the treatment of congenital neurosurgical diseases. Dr Trumble is a highly respected expert in this area and has been published in countless pediatric and pediatric-neurosurgical journals as well as general neurosurgical publications. He has been awarded honors at every level of his training (Tau Beta Pi undergraduate, Alpha Omega Alpha medical).

Dr Trumble’s double-board certification (adult and pediatric neurosurgery) and clinical experience combine to improve treatment in patients with congenital neurosurgical diseases regardless of patient age. In his current position at Neurosurgeons for Kids, he and his fellow physicians provide comprehensive neurosurgery care, including skull/craniofacial anomalies, neuro-oncology, epilepsy, vascular malformations and congenital brain and spine malformations.

Dr Trumble has spoken at several ASAP conferences, sharing his expertise in the field of Chiari.

2017 Conference Lectures

Recordings from the 2017 conference in Long Island are now available for viewing on the ASAP YouTube channel.

We have currently posted a collection of 38 lectures representing a wide range of topics.

For a listing of available lectures go to www.ASAP.org, click on *Conditions* then *Online Video Library*. Look for 'To view videos from the 2017 ASAP Chiari & Syringomyelia Conference click here'.

If you have subscribed to *Chiari and Syringomyelia ASAP.org* YouTube channel you can receive notification when new videos are posted.



Teri's Run and Twilight Walk

Again this year Teri's Run helped raise awareness for Chiari malformation with Syringomyelia.

Austin Rodriguez is eight years old. He underwent decompression surgery at the age of five. For several years he has participated in the event to raise awareness and funds for research.

Thank you, Austin, for making a difference!

"As we go forward, remember to always live within your limitations, but without limits—because while you may live with these disorders, they do not define who you are. Our stories are not finished yet!"

**Eric J Berning
President
ASAP Board of Directors**

Special "Thank You" to Judy Hunt for her great proofing skills.

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

Conference Scholarship

ASAP members can apply for a conference scholarship to help offset the cost of attending the 2018 conference. 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

Greetings to everyone,

My name is Eric Berning, and I am the new president of the American Syringomyelia & Chiari Alliance Project Board of Directors.

Before I introduce a little about my own background, I would like to express deep gratitude to our outgoing president, Patrice Schaublin, for her tireless efforts on behalf of ASAP. We have grown by leaps and bounds under her direction, and while we bid her a fond farewell as her term ends, we are certainly not saying goodbye. We all look forward to continuing ASAP's progress with Patrice by our side as an integral part of our organization and community. Please join me in thanking Patrice and wishing her all the best!

My personal story begins 15 years ago (although unbeknownst to me at the time, it really had been my entire life). I was diagnosed with Chiari and Syringomyelia in January 2003 and underwent decompression surgery in April of that year. Prior to my diagnosis, I had never heard of either of these conditions, even though I had suffered with unexplained symptoms since childhood. When my neurologist first told me what my MRIs revealed, I thought, "Oh great, how long do I have to live?" Fast-forward 15 years: I'm alive and well, and while I still experience chronic pain, tremors and the like, I understand these conditions better and how they affect each of us similarly yet so differently. I am a husband and father. I have been married almost 17 years to my lovely wife Jennifer, and we are parents of a 14-year-old high school freshman, Edward. My family is my rock, and they have been by my side through every learning process these conditions have thrown at us. Jenny was five months pregnant with Edward when I underwent decompression surgery and so much lay before me with upcoming fatherhood, let alone accompanied by a serious physical condition. I recall being wheeled to an emergency CAT-scan the night after my surgery due to swelling around my brain and telling my night nurse James to not let me die because I was going to be a dad. These are scary conditions with unknown outcomes, and I know that very well from my own personal journey.

In 2005 we relocated from Los Angeles to Houston. It was here that I found an ASAP support group and discovered this awesome organization. I am blessed to be able to maintain my "normal" lifestyle with some restrictions but the encouragement and camaraderie felt by touching base with others treading the same unsure waters was so comforting—I was not alone! At our meetings I had the great honor to meet a mother who did not have Chiari or Syringomyelia herself, but both of her two sons do. Her boys were very young, around the ages of 3 and 5. She was greatly concerned about the quality of life her children would have living with these disorders. As I listened to her, I thought about how I grew up with both of these conditions, completely unaware until the age of 37, and how many of my activities from my youth I would never consider doing again knowing what I

know now. But overall I led a pretty normal life as a child—and it is completely possible that her sons can as well, especially if they live within the reasonable limitations the medical community now provides as guidance for those of us with Chiari and Syringomyelia. That was when I realized that I can serve as an example of someone who lives within limitations, but without limits. I am someone who suffers pain and neurological issues related to these conditions, but they don't define me. My desire to share my story and encourage others facing these challenges led me to join the ASAP board. I have had an opportunity to meet and work with so many people within the Chiari/Syringomyelia community. It has been my pleasure to serve as secretary, to be on the Annual Conference Committee, and now to assume the position of the President of the Board of Directors. In each capacity I have undertaken, my ultimate desire and reward is to humbly serve my Chiari and Syringomyelia community.

As I take on this new role as president, I realize I have very big shoes to fill by following Patrice Schaublin. Her leadership has taken this organization to new heights, and as she hands off the reins to me in the new term, I share her same goals for ASAP to continue to grow and flourish. Patrice has been such an inspiration to me and others as she pushes through her own personal battles to give everything she has to make sure ASAP is strong and available for anyone who needs it. As they say, "the struggle is real," but together and beyond expectations, look what we can accomplish!

Last year, ASAP began collaborating with other Chiari and Syringomyelia groups in multiple countries to synergize the worldwide network of doctors and patients in an effort to continue the search for new treatments, discoveries, and eventually a cure. We will continue to seek to connect with other groups in order to strengthen our community, find and fund research, and provide support and awareness. Last July we held our largest conference ever in the history of ASAP, with attendees from across the United States and around the world. Over 80 physicians, specialists, and researchers from across the globe traveled to New York to participate, making it one of our best attended and most informative conferences yet. This summer will be a special milestone, as we host our 30th annual conference in lovely Orlando, Florida. We look forward to the celebration and hope to see many of you there.

I am absolutely honored to be a part of the leadership of this phenomenal organization; I look forward to working with everyone to expand awareness, develop treatments, fund research, and to find a cure. ASAP has had a significant impact on my life, and I want it to have a positive, fruitful impact on yours as well.

May you have a pain-free day,

Eric J. Berning

2018 ASAP Chiari & Syringomyelia Conference Registration Now Open

Conference registration fee of \$175 per person covers opening reception on Wednesday evening, three days of lectures, breakfast on Thursday, Friday and Saturday and the banquet on Saturday evening. Additional price options are available for one day, family of four and extra banquet. These are listed in the *Frequently Asked Questions* found in the *Annual Conference* side menu.

Make hotel reservations for the Gaylord Palms Resort with Marriott reservations at 877-491-0442. Tell them you are attending the ASAP Chiari & Syringomyelia Conference July 25-28.

Guest Room Rate: \$144.00++ per night plus resort fee \$22.00++. Resort fee is separate and distinct from the room rate and from taxes. These rates are negotiated rates for ASAP and resorts fees are non-negotiable. ASAP does not make any profit from these costs.

Resort Fee: In an effort to provide a wide range of quality amenities at a single packaged price, a “resort fee” of \$22.00 (plus applicable tax) will be added to the guest room rate per night, to include:

- High-speed Internet access in guest rooms
- Two bottled waters replenished daily in your guest room
- 24-hour access to Relâche Fitness Center

- Scheduled shuttle service to Walt Disney World® Theme Parks & Disney Springs®
- Local, toll-free and domestic long-distance telephone calls
- \$10 credit towards dry cleaning services
- One bucket of range balls at nearby Celebration Golf Club
- Private training session (15 min.) at Relâche Fitness Center. Limited sessions available Tues. – Sat. from 5 am – 12 pm, appointments required, please visit the fitness center to sign up.

Sun-drenched and spectacular, Gaylord Palms Resort offers world-class entertainment, restaurants and breathtaking Florida gardens under glass. Close to major theme parks and attractions with plenty of things to do while immersing you in the sights and sounds of the Sunshine State. Gaylord Palms Resort offers breathtaking environments with signature entertainment, dining and shopping – all under majestic atriums that ensure the ultimate Kissimmee vacation whatever the weather. Their lush, tropical atriums re-create three Florida environments that immerse you in the sights and sounds of the Sunshine State. From the rising mists of the Everglades and vibrant island revelry of Key West to the Spanish charm of St. Augustine, guests will appreciate all the resort has to offer.

Visit Orlando

Need more reasons to attend the ASAP Chiari & Syringomyelia Conference this July? Find unique experiences to ensure an unforgettable vacation. From spending time at the theme parks, to experiencing the destination’s many indoor and outdoor attractions, to hitting the golf course, an Orlando getaway is whatever you want it to be. You can also search for arts and culture, shopping, spas, golf, restaurants and dining shows, and nightlife to build your perfect itinerary. Speaking of which, *Visit Orlando* can help you maximize your time with trip-planning ideas, while their blog will keep you up-to-date on everything new in Orlando. They also have free apps available so you can personalize your experience.



Visit <http://www.visitorlando.com/> for more ideas on things to do, discount coupons, and tickets.

ASAP History

Together with his wife, Barbara, Don White founded ASAP in 1988. Frustrated by a lack of information and confusion after Barbara’s diagnosis of Syringomyelia and Chiari malformation, they vowed to bring awareness to these little known disorders. It was their dream that no person would face this diagnosis alone.

Although Barbara became quadriplegic and succumbed to complications that led to her death in 1991, Don remained committed to their mission. His devotion to ASAP was so strong that he continued to attend board meetings even while battling cancer. In 2008 Don lost his battle to cancer.

He once said, “There was no ASAP for Barbara and me, and we were determined to do something about it. We believed then and I still believe now that ASAP can and does make a difference in the lives of those affected by Syringomyelia and Chiari.”

Because of Don and Barbara’s efforts, Syringomyelia (SM) and Chiari (CM) became better recognized and awareness and understanding increased. They made a profound impact on the lives of many.

As we embark on our 30th year, the ASAP family is more committed than ever to seeing the organization carry on until the mission is fulfilled and a cure is found.

Spinal Cord Injury Research: Bonus Benefit to Activity-Based Training by University of Louisville

Activity-based training has resulted in unexpected benefits for individuals with severe spinal cord injury (SCI). Researchers in the Kentucky Spinal Cord Injury Research Center (KSCIRC) at the University of Louisville have discovered that the training designed to help individuals with SCI improve motor function also leads to improved bladder and bowel function and increased sexual desire.

Research participants receiving activity-based training conducted by KSCIRC at Frazier Rehab Institute initially reported improvements in bladder, bowel and sexual function anecdotally. Charles Hubscher, Ph.D., professor and researcher at KSCIRC, has documented those changes in research published January 31, 2018 in the journal PLOS ONE.

For individuals with severe spinal cord injury, bladder and bowel dysfunction are among the most detrimental factors to their quality of life, even more than the loss of independent mobility.

“Patients with spinal cord injury say they are most concerned by the problems associated with bladder function,” Hubscher said. “These issues contribute heavily to a decline in their quality of life and impacts overall health.”

Bladder dysfunction associated with SCI results in numerous health complications, requiring lifelong management and urological care in the form of catheterization, drug and surgical interventions, peripheral electrical stimulation and urethral stents. All of these therapies bring with them serious side effects and none substantially improves the basic functions.

To document changes in bladder, bowel and sexual function resulting from activity-based therapy, Hubscher and his colleagues performed urological testing (urodynamics) and asked research participants with severe spinal cord injury (SCI) to complete surveys about their bladder and other functions. Eight of the participants received activity-based training, which includes locomotor training, stepping on a treadmill with their body weight supported, and stand training in a specially designed frame. Four participants did not receive training.

The active participants’ functions following training were compared with their own condition prior to training and with individuals not receiving training. Following 80 daily sessions of locomotor training with or without stand training, the active individuals were found to store significantly more urine at safer pressures, reported fewer incidents of nighttime voiding and reduced general incontinence, as well as improved bowel functioning and increased sexual desire.

“Today’s published research indicates that activity-based training strengthens the neural circuits that control urogenital and bowel functions,” Hubscher said. “We hope to further

validate those findings by determining if the improvements can lead to elimination of related medications and/or long-term reduction in the number of daily catheterizations. In addition, we are evaluating the effects of spinal cord epidural stimulation on those circuitries.”

Susan Harkema, Ph.D., professor and associate director of KSCIRC and an author of the study, said the publication highlights the value of the research collaborations at UofL.

“This work showcases the exceptional environment for research at UofL, with basic scientists working in parallel with clinicians in rehabilitation and neurosurgery,” Harkema said. “There are relatively few researchers addressing bladder, bowel and sexual function both in animals and humans in chronic spinal cord injury. Dr. Hubscher’s work adds a unique and valuable aspect to our research.”

Epidural Stimulation Research

Researchers at KSCIRC are investigating the use of spinal cord epidural stimulation (scES) to facilitate the ability of SCI patients to stand, voluntarily control leg movements, and improve other functions. Spinal cord epidural stimulation involves the delivery of electrical signals to motor neurons in the spine by an implanted device.

In concert with this research, Hubscher is investigating the effects of scES on bladder, bowel and sexual function in SCI patients. Funded by a \$3.5 million grant from the National Institutes of Health, Hubscher has begun work to map the lumbosacral spinal cord for multiple aspects of bladder function. This work will identify locations on the spine and device configurations for using scES to improve bladder storage and voiding efficiency.

The funding is through the NIH Common Fund program Stimulating Peripheral Activity to Relieve Conditions (SPARC), which aims to increase the understanding of nerve-organ interactions and neuromodulation to advance treatment of diseases and conditions for which conventional therapies fall short.

Hubscher’s SPARC project has a three-year timeline and includes concurrent investigations in both animals and humans. His team will enlist six human research participants who have received scES devices and have completed the initial epidural stimulation study to assist with the development of device parameters, then test those parameters at home.

For the estimated 1,275,000 people in the United States who live with paralysis from SCI, therapies resulting from this research have the potential to increase their quality of life as well as reduce health-care costs.

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

Alana Wolfe Ficco

Becky Jo Keys

April Roy

Joan Vileno

Austin Rodriguez

Foxfield Veterinary Services
Teri's Run Foundation

Bob Hoover

David Heinsohn
Members of the Indian Div
of the National Model
Railroaders Assoc.
Jim Senese

Brenda Jarmon

Charles & Dianne Michael

Bridget LaSelva

Penny LaSelva

C Scappa

Heather Scappa

Claire Mockler

Rita Fitzpatrick

Debra Cacace

Christopher Cacace

Edith & Aaron Kaufman

Stephen and Arlene Sharkey

Family & Friends

Timothy and Barbara
Sutherland

Guy Petersen

Douglas & Martha Leerssen

Kathie Hall

Judy Dragiewicz

In Honor of

Donor

My Mother Beth

Phillip LaPlante

Patrice Schaublin

Maureen Purcell

Patty Gary

Kenneth Gary

Robert K Elliott

John Elliott

Sandra Forsberg

Daniel Forsberg

Sean J McCarthy

Melinda McCarthy

Stephen & Arlene Sharkey

Aaron & Edith Kaufman

Lance Bowman

Margaret Ptopst

Lauren Foland

Priscilla McDaniel

Lisa Underhill

Michael Monroce

Lynn Marotta

Eric Marotta

Mike Kirlin

Gwen Kirlin

Dennis & Diane Kirlin

Jacqueline Babitts

Steven and Rosa Babitts

Kevin Claver

Robert Claver

Steve Cole

Thomas and Evelyn White

Sydney Lee

Steven Lee

In Memory of

Donor

Ann Priester

Aiden Faulkner
Michaela Faulkner
Giuliana Rayno

Donalda Wolfe

Donald Loucks
John & Kimberly Mulvay
Lori Kaczmarek
Patricia Bertone
Peg Rosky
William & Susan Coyne
Christine Tomsey

Elaine Attell

Stephen and Arlene Sharkey

Fred "Jake" Jacobeit

Maurie Jacobeit
Mrs. Julia Shuldt
D Max & Linda Geldean
Charles & Mary Hussman
Dale & Carolyn Kern
Donald & Virginia Alexander
Harriet Thomas
Richard & Bonnie Gesling
Rose Olsar
Linda DeLost
Stan & Deanna Woerner
Ted & Vicki Lawrence
Michael & Mary Ellen Harris
D & P Buckman
D & C Boock
J & N Wessenforf
Barbara Jacobeit

Christian Barthol

Maria Nork
Marilyn Burney

In Memory of

Donor

Giorgina Fornero

Sarah Ashley & Dr. Bolognese's
patients
Riklan Resources LLC

Jim McCallum

Ellie McCallum

Karl O'Connor

Alan Hecht
Barbara Watson
Brian Shaffery
Danielle Cratch
Harriet Kazarian
Jennifer Cheifetz
Joanne Millman
John, Karen, Marcus & Peter
Hammel
Lois Kane
Maren Enghauser
Peter Quintiliani
Elaine Kalinoski Granoff
Margaret O'Leary

Marjarie Tray

Stephen and Arlene Sharkey

Maxine Leske

Vernon & Roberta Jelle

Maynard Guss

David Kalish

My son, Richard Kloss

Lawrence & Sharon Kloss

Teola Sutherland

Ted Pounders

Wilbur Chapman DuBois III

Robert DuBois

Carol Nelson

Pamela Angelakis

Kids For A Cure

The conference is a great time for children to get together. They learn about the disorders, engage in fun projects and get to meet others who share their unique experience. The program is for those who have the disorders, have a sibling or parent diagnosed or want to support a friend. Sessions are organized and managed by an ASAP volunteer with assistance from a child life specialist.

This is an opportunity for the next generation of ASAP leaders to learn more about the organization.

Think Positive Thoughts

Research has shown a positive outlook may boost your overall physical health. And if you do become ill, that attitude may help you deal with it and have a better quality of life. Research also shows that optimists may be more likely to accept their illnesses and try to find the humor in difficult situations. Choose to think positive thoughts that elevate your mood, throw a more constructive light on difficult situations, and generally color your day with brighter, more hopeful approaches to the things you do.

My Chiari Story **by Shane C 2017 BJO Scholar**

My mother has a picture of me playing hockey when I was seven. Underneath it resides the following quote “You can’t be brave if you’ve only had wonderful things happen to you.”

When I was seven, I was diagnosed with Chiari malformation, a condition caused by a portion of the brain—the cerebellar tonsils—extending beyond the base of the skull and into the spinal column. The end portion of my young brain descended twenty millimeters into my spinal cord, which compressed the brainstem and nearly caused a stoppage of spinal fluid to the brain. Only through decompression surgery would we be able to relieve this pressure and reopen passageways.

After a painful recovery from my surgery, I went shopping with my mom at the Paper Store. While walking around the store, I picked up a book. It had a bright blue cover with a picture of a snowman on it. My mom saw me reading the book and said she would buy it for me. As I walked towards the register, I told her that the kids in the hospital would really like this book. Without another word, my mom bought every single book at every single Paper Store within the Greater Boston area and *Share with Shane* was born. For the past ten years, the program has provided gifts to countless young patients at Boston Children’s Hospital during the holiday season and it has allowed me to give back to the hospital that has given me so much more. My goal every year is to bring a smile to the face of each patient that gets a gift. I know that it is not easy for them to smile during such a terrible period in their young lives. But if a stuffed animal or a toy truck can make them smile for even a minute, my goal is achieved. For me, that is what *Share with Shane* is all about: helping people through traumatic times by comforting them and putting smiles on their faces.

When I think back, I still remember my parents sitting me down to tell me I was going to need to have surgery. They explained to me a little about the surgery, talking about my head and neck, not really mentioning my brain. They were honest, saying it would be painful, but they would take care of me. Painful it was. Having to go through an experience as intense as brain surgery taught me that I could conquer anything. Marcus Luttrell, a Navy Seal and the author of New York Times Best-seller *Lone Survivor*, once said “No matter how much it hurts, how dark it gets, or how far you fall. You are never out of the fight.” I have fallen far and felt intolerable pain but I now use this experience to fuel the fire inside of me. I persevered through the pain, the complications, four years of physical and occupational therapy. I was able to play at recess again and eventually hockey and baseball. I compensated for the things the Chiari took from me and I made adjustments accordingly with school and sports. I am at the top of my life journey succeeding and competing. But, I still know that every time I take another step forward I am blessed to have that opportunity.

Chiari malformation does not define me. However, my journey with Chiari has most definitely shaped the person I have become in a positive way. Bobby Jones was known, despite his illness, to always carry himself with character and perseverance both on and off the golf course. I take pride carrying myself with these traits. Therefore, being a recipient of the Bobby Jones Open Scholarship is a great honor and I appreciate the generous support towards my academics. My family and I are thankful for the mission of the American Syringomyelia & Chiari Alliance Project in research, education, and support. Families and patients rely on this support as they continue to fight their battles against Chiari malformation and Syringomyelia.

ASAP INSTALLS NEW OFFICERS

New leadership pledges continuity

Longview, TX February 7, 2018 - The American Syringomyelia and Chiari Alliance Project Board of Directors is pleased to announce election and installation of its new officers. Pursuant to its bylaws, new officers were elected in December 2017. Installation took place during the meeting of the board February 7, 2018, to be effective immediately. Elected to three-year terms are President of the Board Eric Berning, Vice President Cathy Tufts and Secretary Rich Simon. Annie Chapman will continue in her role as Treasurer until such time that a suitable replacement can be found. Immediate past-president Patrice Schaublin will remain with the organization in the role of Executive Director.

Incoming president Eric Berning first discovered ASAP in 2005 when he attended a support group meeting in Houston, Texas. In 2014, after several years of volunteer service, Eric was invited to join the board of directors. He has served on the board first as a member-at-large, then as secretary, before being elected president. “I realized through my own diagnosis and journey that I could serve as an example to others, that these conditions would have an impact on my life but not define my life,” says Berning. He adds, “I look forward to what the future holds for ASAP in our quest to fulfill our mission statement, as well as being instrumental in our continued success.” Outgoing President Patrice Schaublin says, “We look forward to Eric’s

leadership; he brings new skills and optimism to our organization. Serving as president is not an easy task. We are deeply grateful to Eric for his past and continued service.”

Incoming Vice President Cathy Tufts first began her service to ASAP with a series of successful fundraising walks. Being the mother of children affected by these disorders, Cathy had the strong desire to better serve the community, and joined the board of directors in 2014. “We have accomplished so much as an organization, but there is still so much more to do,” says Tufts. “I look forward to serving ASAP in my new role as vice president and being instrumental in having a positive impact on all those affected and the families so desperately seeking answers.”

Newly elected secretary Rich Simon has served on the board of directors since 2014. “This is such a fantastic group,” says Simon. “It is truly my pleasure to serve this organization to the best of my ability. I look forward to being part of our continued success.”

Patrice Schaublin will continue to serve ASAP in her new role as Executive Director. “It has been an honor to serve ASAP over these past many years. I am excited to begin a new era and support our new officers in continued service to our community,” states Schaublin. “Please join me in welcoming the new leadership and offering them best wishes for the continued success of ASAP.”

ASAP®

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, ED
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
Duke 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
Erol Veznedaroglu, MD
Drexel



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