ASAP Chiari & Syringomyelia Conference
Meet Our 2015 Host

Cormac O Maher, MD is a neurosurgeon specializing in the care of children. Dr Maher’s major areas of clinical interest include the surgical treatment of arteriovenous malformations, Moyamoya disease, cavernous malformations, pediatric brain tumors, congenital malformations including cysts and Chiari malformation, spinal dysraphism, and hydrocephalus.

Dr Maher is a graduate of Georgetown University, where he obtained a Doctorate of Medicine and was elected to the Alpha Omega Alpha Medical Honor Society. He completed his surgical internship and neurosurgical residency at the Mayo Clinic in Rochester, Minnesota. Soon thereafter, he moved to Boston, Massachusetts for dedicated training in pediatric neurosurgery under the direction of R Michael Scott, MD of Harvard University and Boston Children’s Hospital. During his time in Boston, Dr Maher served as the Shillito Staff Associate in the Department of Pediatric Neurosurgery at Children’s Hospital Boston. After completion of his training in Boston, Dr Maher completed fellowship training in cerebrovascular neurosurgery under the direction of Arthur L. Day, MD of the Brigham and Women’s Hospital and Harvard University.

Dr Maher is an active clinician-investigator and has made over 100 presentations of his work at national medical meetings. He has published a large number of scientific articles as well as book chapters on a wide variety of neurosurgical topics. His work has appeared in many medical journals including the Journal of Neurosurgery, Stroke, Neurosurgery, and Neurology.

Dr Maher is a diplomat of both the American Board of Neurological Surgery as well as the American Board of Pediatric Neurosurgery. He is a member of the American Society for Pediatric Neurosurgery. He is a fellow of the American College of Surgeons, the American Association of Neurological Surgeons, and the American Academy of Pediatrics.

Dr Maher lives in Ann Arbor with his wife and three children.

ASAP Funds New Grant

Postoperative Syringomyelia Resolution in Canine Chiari-Like Malformation with principle investigator Lauren R Talarico, BS DVM DACVIM has been approved for funding. Lauren is a staff neurologist/neurosurgeon with VCA SouthPaws Veterinary Specialty and Emergency Center in Fairfax, Virginia. She is a member of the American Veterinary Medical Association, Diplomat-American College of Veterinary Internal Medicine and Northern Virginia Veterinary Medical Association.

The preferred therapeutic approach for treatment of Chiari-like malformation in dogs is a foramen magnum decompression (FMD). Based on the veterinary literature, short-term surgical success rates with FMD in dogs are approximately 80 percent. Similar to human reports, there appears to be a disease relapse rate ranging from 25-47 percent; most of these relapses are suspected to be due to excessive postoperative scar tissue formation at the FMD site. Cranioplasty and auto-grafting procedures have been adapted to discourage excessive postoperative scar tissue from recompressing the operative site.

The goal of this research project is to utilize objective postoperative MRI findings to determine if current surgical procedures are sufficient to help resolve syringomyelia and clinical signs. Ultimately, these findings may offer useful cross species information to help clarify the pathogenesis of Chiari malformation in humans. The project is scheduled to be completed by December 2015.
Volunteers Are the Heart of ASAP
by Patricia Maxwell

Volunteers come in all ages from many different walks of life for many different reasons. They know no boundaries. From the children who take part in KIDS For A Cure Club to the board members who govern the organization, they each have their unique contributions.

A famous saying, ‘it takes a village to raise a child’ could be transposed to say it takes a group of volunteers to elevate a non-profit. ASAP was started by a volunteer and has continued to develop for 26 years with the help of hundreds of volunteers. Some work behind the scenes while others take a very active role in development.

As 2014 nears its end it only seems fitting to recognize each individual. If I could I would properly recognize each and every one of you because you deserve that acknowledgment. Since that is not feasibly possible, please know that what you do is not only appreciated but making a difference in the lives of thousands.

Over the years I have worked with hundreds of volunteer; many have become close friends. They all have a very special place in my heart and are the heart of the organization.

Thank you!

ASAP History

In January 1995, ASAP added its 1,000th member. Today we have almost 11,000.

In 1995 the National Institutes of Health published a scientific summary as the result of a Syringomyelia Workshop spearheaded by ASAP Board and volunteers. The summary addressed pathophysiology, treatment and new areas for syringomyelia research.

The ASAP Conference that year was held in Chicago, Illinois with Dr Thomas Milhorat as keynote speaker.

A survey conducted with ASAP members provided significant familial component evidence for Duke University to conduct a pilot study that later developed into a large-scale effort to search for genes predisposing Chiari and syringomyelia. Also, the University of Wisconsin outcome study resulted from the information gained.

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.

ASAP Support Group Update

Lori Tutrow, ASAP Board member and support group leader of the Indy ASAP Chiari/Syringo support group, volunteered as Chapter Leader in September. Her duties will include working with existing groups and helping volunteers organize new groups. You can contact Lori via email at Lori_Tutrow@ASAP.org for assistance.

New groups recently formed:

**ASAP’s Marietta GA Chiari/Syringo Support Group**

Group Leader: Dee Mathewson
Marietta, GA
Phone: 770-696-3564
Email: dee.mathewson@ASAP.org

**ASAP’s Northwestern Pennsylvania Support Group**

Group Leader: Lisa Byers
Tidioute, PA
Phone: 814-706-2924
Email: NW_PA_support@ASAP.org

**ASAP’s Dakota Chiari/Syringo Support Group**

Group Leader: Halley Lee
Email: shlee@pie.midco.net

**ASAP’s Chattanooga Chiari/Syringo Support Group**

Group Leader: June Hyett
Hixson, TN
Phone: 423-240-5247
Email: TN_Support@ASAP.org

**ASAP’s Huntington WV Chiari/Syringo Support Group**

Group Leader: Angela Holley
Phone: 304-638-3432
Email: WV_support@ASAP.org

**ASAP’s Oshkosh Chiari/Syringo Support Group**

Group Leader: Stacey Blankinship
Oshkosh, WI
Phone: 920-267-8075
Email: Oshkosh_support@ASAP.org

Become An ASAP Volunteer

Submit an application at ASAP.org/index.php/volunteer/ or contact the ASAP office at 903-236-7079.
A Word From Our President

I can’t believe another year has passed and the holidays are upon us once again! It has been a busy year for ASAP. New board members, new head of research committee, new members and head of Medical Advisory Board, new research project, new support groups, new research fundraising initiatives, etc. Our 2014 annual conference was held in Princeton, New Jersey with Dr. Vez and planning has already begun for our next one in Ann Arbor, Michigan with Dr Cormac Maher.

This year our annual conference was attended by over 100 people. We are deeply grateful to our hosts, Dr Erol Veznadaroglu and Steffanie Archbald. Their compassion, presence and perseverance offered a unique experience to all in attendance. Thanks to their efforts, there was a wide array of subject matter presented by the top professionals in all fields represented.

2014 brought the beginning of the ASAP “Syringo-my-what?” Steps Across the States. This national initiative has enhanced our efforts to bring further awareness to SM. To that end we have designated May as syringomyelia awareness month. Although we will continue to raise awareness every month, we will use the month of May to emphasize awareness, educate and raise funds for continued research into this life-altering disorder. If you are interested in hosting a walk/gathering or run or spreading awareness by getting a proclamation for your state, please contact the office or email me (Patrice_Schaublin@ASAP.org).

In the near future, we will publish a video on our website updating our community on the most recent research funded by ASAP. This year we are funding a new project which you can read about in this issue. In short, ASAP in conjunction with Dr Robert Keating and Dr Lauren Talarico will be working together to help determine the underlying causes of these disorders. Chiari and syringomyelia affects many dog breeds, the most common being the King Charles Cavalier. In lesser numbers SM also affects many miniature breeds. With this study we hope to unlock new ways to treat these conditions in humans. We are optimistic that the crossover will provide new answers and new modes of treatment for both man and man’s best friend. To support this endeavor we are starting a new campaign named Kicks and Licks. If you are interested in helping please read the article on page 7.

On another note, as we come into this year’s holiday season, please remember ASAP. We are only able to continue through your generosity. Please take a minute to visit our website and make a donation or send your check today. No amount is too small; every dollar counts. Your tax deductible contribution makes a difference in the lives of so many who share your experience. As always, ASAP continues our mission in service to you, the CM/SM community. Thank you for your ongoing support.

Gentle hugs always,
Patrice

Medical Advisory Board Updates

Gerald Grant, MD FACS has accepted the position of Research Chair for the American Syringomyelia & Chiari Alliance Project. He has served on the Medical Advisory Board (MAB) since 2012. In 2013 he moved from Duke University in Durham, North Carolina to Stanford School of Medicine in California. Dr Grant is the Division Chief, Pediatric Neurosurgery.

Timothy George, MD FACS, FAAP has been involved with our organization for many years. Medical Director of Pediatric Neurosurgery at Dell Children’s Medical Center of Central Texas, he hosted the 2010 ASAP Chiari and Syringomyelia Conference. A native of Brooklyn, New York, Dr. George moved to Austin in 2006 from Durham, North Carolina where he was the Associate Professor of Neurosurgery, Pediatrics and Neurobiology at Duke University. While at Duke, Dr. George worked with Marcy Speer, PhD, on The Genetic Research of Chiari I and Syringomyelia, a multi-year study sponsored by the Bobby Jones Open and the American Syringomyelia & Chiari Alliance Project. He is coinvestigator with Dr Bermans Iskandar for the ASAP funded study Outcomes in Patients Undergoing Surgical Intervention for Chiari I Malformation with Syringomyelia.

Cormac Maher, MD will host the 2015 ASAP Chiari & Syringomyelia Conference in Ann Arbor, Michigan. He spoke at the conference in Los Angeles, California in 2013 and was scheduled to speak in 2014 but had to cancel due to a medical emergency. Read more about Dr Maher on page 1 of the newsletter.

Congratulations Dr Grant on your new position. Welcome Drs George and Maher to the Medical Advisory Board.
The U.S. Food and Drug Administration approved new labeling for Embeda (morphine sulfate and naltrexone hydrochloride) extended-release (ER) capsules, an opioid analgesic to treat pain severe enough to require daily, around-the-clock, long-term opioid treatment and for which alternative treatment options are inadequate. Embeda is the third ER opioid analgesic to be approved with labeling describing the product’s abuse-deterrent properties consistent with the FDA’s 2013 draft guidance, Abuse-Deterrent Opioids – Evaluation and Labeling. The new labeling includes a claim indicating that Embeda has properties that are expected to reduce oral abuse when the product is crushed.

Embeda has properties that are expected to reduce, but not totally prevent, abuse of the drug when crushed and taken orally or snorted. Embeda works by releasing only the morphine in the capsule when taken properly. When crushed, the naltrexone in Embeda blocks some of the euphoric effects of the morphine and can precipitate withdrawal in persons dependent on opioids.

When swallowed intact, however, Embeda can still be abused or misused because the naltrexone is not expected to substantially block the euphoric effects of the morphine. It is unknown whether the abuse-deterrent properties of Embeda will result in a reduction in abuse by the intravenous route until additional postmarketing data are available. Embeda can still be abused or misused by any of these routes, and such abuse or misuse can cause an overdose that may result in death. If abused, it can also cause withdrawal in people who are dependent on, or tolerant to, opioids.

“Preventing prescription opioid abuse and ensuring that patients have access to appropriate treatments for pain are both top public health priorities for the FDA,” said Sharon Hertz, M.D., acting director of the Division of Anesthesia, Analgesia, and Addiction Products in the FDA’s Center for Drug Evaluation and Research. “The science behind developing prescription opioids with abuse-deterrent properties is still evolving and these properties will not completely fix the problem. But they can be part of a comprehensive approach to combat the very serious problem of prescription drug abuse in the U.S.”

Embeda is not approved, and should not be used, for as-needed pain relief. Given Embeda’s risks for abuse, misuse, and addiction, it should only be prescribed to people for whom alternative treatment options are ineffective, not tolerated or would be otherwise inadequate to provide sufficient pain management.

Embeda was first approved on August 13, 2009, but was voluntarily withdrawn from the market in March 2011, due to testing that found stability concerns in the manufacturing process. The FDA confirmed that these issues were resolved with its approval of a manufacturing supplement in November 2013.

When Embeda was first approved, the drug was evaluated in a clinical trial of 547 osteoarthritis patients. Additional data from abuse liability studies conducted in laboratories and in people demonstrated the abuse-deterrent features of Embeda for certain types of abuse (oral and snorting), when the product was crushed. The abuse potential for the intravenous route was studied by simulating the amount of morphine and naltrexone that would be released upon crushing Embeda. This study demonstrated that Embeda was less attractive to abusers or less likely to produce a high (lower “Drug Liking” and “Drug High”) compared with morphine alone. However, it is unknown whether these results with simulated crushed Embeda predict a reduction in abuse by the intravenous route until additional postmarketing data are available.

The FDA is requiring postmarketing studies of Embeda to further assess the effects of the abuse-deterrent features on the risk for abuse of Embeda and the consequences of that abuse. In addition, Embeda is part of the ER/LA Opioid Analgesics Risk Evaluation and Mitigation Strategy (REMS), which requires companies to make available to health care professionals educational programs on how to safely prescribe ER/LA opioid analgesics and to provide Medication Guides and patient counseling documents containing information on the safe use, storage, and disposal of ER/LA opioids.

Embeda is marketed by New York City-based Pfizer, Inc. The FDA, an agency within the U.S. Department of Health and Human Services, protects the public health by assuring the safety, effectiveness, and security of human and veterinary drugs, vaccines and other biological products for human use, and medical devices. The agency also is responsible for the safety and security of our nation’s food supply, cosmetics, dietary supplements, products that give off electronic radiation, and for regulating tobacco products.

FDA News Release October 17, 2014

ASAP Welcomes New Directors

Dee Mathewson
Dee.Mathewson@ASAP.org

Dee Mathewson resides in Marietta, Georgia with her husband. Her daughter who is studying for her bachelors degree lives close by. Dee likes to remain active at the gym or by hiking with her dog.

She was diagnosed with a syrinx after a car accident in 2009. A second accident resulted in the original syrinx doubling in length. Dee stumbled across ASAP while doing a search after being diagnosed. She was so relieved and grateful to have found such a great support.

Dee volunteered to organize the first Georgia support group and is eager and excited to help raise awareness.

She is looking forward to serving on the board.

Richard Simon
Richard.Simon@ASAP.org

Rich lives in Wyndmor, Pennsylvania where he works as a Juvenile Public Defender.

Born with spina bifida, Rich had surgery as a child which seemed to help. He enjoyed an active carefree childhood. Years later he learned he had hydrocephalus, Chiari and a syrinx. Surgery relieved many of the symptoms that developed during his adult years. Unfortunately neurological damage occurred resulting in chronic pain.

Several years ago, Rich served on the ASAP Finance Committee. He has been an ASAP member for many years and is dedicated to helping spread awareness about Chiari and syringomyelia in hopes we can find a cure.

Track Your Pain

We all know how important it is to track our daily routine when living with chronic pain to determine triggers and find solutions. But keeping a written journal may not always be feasible. With the widespread use of smart phones and tablets, many now have access to programs that make this much easier.

My Pain Diary is an iOS app that was developed to help patients with chronic pain keep a detailed record of all the information they need to share with their care professionals in order to better manage their pain and follow the evolution of their condition. What makes it especially useful is that it allows users to not only log the basic information (such as the location, type or trigger of the pain) but also to upload photo attachments. In addition, the application uses geo-localization to retrieve weather feeds, as in many cases variations of the weather can play a significant role in a person’s pain or mood. By collecting all these kinds of data in one dashboard, patients are able to compare their symptoms, see which factors affect their pain and send reports to their doctor. ($4.99 for both iPhone and Android)

Chronic Pain Tracker is available through iTunes for $6.99 (iPhone and iPad). Take the guesswork out of pain management and record your pain history with 19 unique health categories. Review a Summary Report with your doctor in the app, or export a PDF for printing/emailing. For less than typical insurance co-pay, you can improve the management of your pain.

Manage My Pain available through Google apps can help you track chronic pain. Create a personal profile and then input information about your symptoms into the daily trackers. The app can produce charts to show your family, friends, and doctors. This can help your doctor and loved ones better understand what you’re going through. Manage My Pain is free, but you can upgrade to a pro version for $3.99. The pro app offers backup information and has a more comprehensive tracking device.

WebMD Pain Coach™ offers a holistic approach to balancing lifestyle with chronic pain conditions to help inspire a better day. WebMD’s new app is a mobile companion to help you through daily health and wellness choices so you can better manage your chronic pain. Enjoy a personalized experience as physician-reviewed tips related to your specific condition are delivered daily to you. WebMD Pain Coach™ puts you in control of your lifestyle choices so you can review personal patterns to understand triggers, set goals, and easily share progress with your physician. It is available for free for both iPhone and Android.

These apps are based on their potential to aid people in dealing with chronic pain in a number of ways. Additional factors considered in selecting these apps include user ratings, affordability, accessibility, format, functionality, and relevance. Together, this collection represents the gamut of helpful iPhone and Android apps that are successfully designed to make chronic pain more manageable. (Prices may vary from those listed.)
Fundraising Events

Swing For The Cure

The 3rd annual golf tournament took place on June 20. The Kindlon and Sanders families hosted the awareness event raising over $17,500 for ASAP programs and research.

Oklahoma City ASAP Walk & Roll

Amber Barnes, walk coordinator, worked for months holding ‘local night out’ events and securing sponsors to raise over $13,000. Approximately 300 people attended the walk & roll. They were treated to various activities including face painting, a live DJ, popcorn, raffle and auction.

West Virginia 5K Walk Run & Roll

Angela Holley hosted a 5K on September 27 in Huntington, West Virginia. About 60 participants took part.

Thank You!
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 / loved ones.

In Honor of
Donor

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Shop the ASAP Store for Unique Holiday Gifts that Spread Awareness
www.ASAP.org/index.php/store/

Kicks and Licks
New campaign to fund research

This new event is a walk/run or gathering for humans and dogs. You can host one with or without the dogs. It’s a chance to get together for a cause we have in common. The word “Kicks” is another name for sneakers and “Licks” are of course the unconditional love that dogs provide to us. So, grab your sneakers and your leashes and join us. Over 15 breeds have the disorders and most commonly the King Charles Cavalier spaniel. We are tied together for a cause.

I believe that working with the canine community will help provide more awareness and, ultimately, this research will help further treatments that could potentially impact humans as well as man’s best friend. Let me know if your vet wants to get involved with this project.

To book your walk or gathering please email Patrice Schaublin (Patrice_Schaublin@ASAP.org). May is also awareness month for syringomyelia. If you would like to get your state’s proclamation and need some help or plan a gathering or walk, please let us know and we will be more than glad to help.

Conference 2015
by Patrice Schaublin

We receive many calls asking about attending the conference. Families have expenses and even though our costs are minimal compared to other nonprofit conferences, we still have people who say they NEED to go but can’t.

We have a scholarship which can help defray the costs. We also have a L.E.A.R.N. Program, a fundraising project where you earn points to attend the conference. It will cover your hotel room, conference fee and reimbursement toward travel. You can earn points in different ways, (walks, personal fundraising page, write-a-thon, dinner, sponsorships, etc.) Please check it out on our website for the rules. EVERYONE can go and WE can help you but now is the time to START. [Go to www.ASAP.org, on the bottom of the page under Great Expectations, click on ASAP’s L.E.A.R.N. Program]
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.

Email: Patricia_Maxwell@ASAP.org
Mail: ASAP Connections
PO Box 1586
Longview TX  75606

ASAP Connections Editor: Patricia Maxwell
It is almost the end of the year, a fact starkly apparent in the minds of many college-bound seniors. I’m with you. You’ve got essays to write, applications to fill out, and scholarships to search for. Not to mention your normal school work. All in all, it can be very overwhelming, especially for the chronically ill senior. I have some tips to help you through your last year of high school and into your college career.

- **Plan everything out** and avoid the stress of last minute deadlines. Get a calendar, write everything down (tests, homework, college deadlines, activities), and stick to it! Make sure to count in ‘sick days’ when you might not be up for work.

- **Contact the college’s disability services department.** Every school has one, and it will be important to hear from them exactly which accommodations they will be willing to give you. College is different than high school; they are not required to give you certain accommodations.

- **Talk about your struggles,** and more specifically how you overcame them, when it seems appropriate in application essays. Your story is unique, share it! Make sure you are positive and realistic about your situation.

- **Visit campuses,** but it may be easier to do this on your own depending on how well you tolerate activity. Official tours can be long and taxing, so it may be helpful to determine what help you might need in getting through one before arriving on campus. Be sure to speak with the admissions office if you will need assistance on your tour.

- **Ask about credits** and how many are required to maintain scholarships. Make sure to keep in mind that you will have times when you are sicker and may not be able to take a full load the first semester when scheduling classes.

- **Most importantly, find support!** We all need support to get through the tough times, including those in college.

  I’d like to hear what you think about college! Email me at kidsclub2@asap.org!

  Kaylee

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We need your help to figure out what this says! I’ll give you a clue: It is a special slogan for ASAP! Use the secret code below to figure out where the letters go! Once you have used your amazing powers to solve this puzzle, you can shout it out! We will give you a free letter to start- GOOD LUCK😊-Dan

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A B C D E F G H I J K L M N O P Q R S T U V W X Y Z

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& = N 5 = I \() = T \[ = Y
% = J 8 = O \) = T