Attendees indulged in three days of information to help them ‘Navigate Chiari and Syringomyelia’. The Westin at Forrestal Village provided the perfect venue for ASAP’s Chiari and Syringomyelia Conference.

Dr Erol Veznedaroglu with the assistance of Steffanie Archbald provided local speakers who covered topics on genetics, diagnostics, associated disorders and surgery. The ASAP Medical Advisory Board along with Dr Andrew Ringer of Mayfield Clinic also enthralled the audience with their experience and knowledge in a variety of subjects. The ASAP research grant recipients updated everyone on their projects’ development and future plans. Videos of the conference will be available on the ASAP website at a later date.

But the conference is not all lectures; attendees participated in support group meetings, explored the area and relaxed at an elegant dinner while taking part in a silent auction.

Children were treated to their own conference under the guidance of Annie Chapman. They met Ben, a service dog, and his trainer, watched a magic show and learned a card trick. They also had the opportunity to ask questions of a neurosurgeon and neurologist. They explored their creative side by painting wind chimes when not playing games and making new friends.

The Conference Committee spent months strategically planning and preparing to provide an educational and social experience that both enlightened and supported those in attendance. Please join us in Ann Arbor, MI July 2015 with our host, Dr Cormac Maher.

Special thanks to Conference Committee Chair John Caemmerer for his leadership, and members: Kerry Chu, Annie Chapman, Shannane Hutter, Megan Jones, Patrice Schaublin, Laurie Swihart, Cathy Tufts and Lori Tutrow.

They all pitched in at the conference along with a number of other volunteers to ensure a smooth and successful event.
KIDS For A Cure Club

Over 15 children participated in the KIDS program during the annual conference held in Princeton, New Jersey. Ranging in age from 5 to 17, they learned about service dogs, asked questions of a neurologist and neurosurgeon plus practiced relaxation techniques.

Annie Chapman, who organized and oversaw the program, enhanced the event with a magic show put on by the Princeton Magic Club, arts and crafts and a pizza party.

Most of the children were a bit timid the first day but by the end of the day they were close friends and excited about getting together the following morning.

Join the fun in Ann Arbor, Michigan July 2015.

Kerry Chu Submits Resignation

Kerry Chu has served on the ASAP Board since 2011 and was elected as secretary in June 2012. She has been active with the organization for many years, first starting and running a support group in Long Island, New York and currently the Greater Houston Texas group.

Throughout her life, Kerry suffered from headaches. During her junior year in college, she had a bad fall out of her bunk-bed and slowly started experiencing additional symptoms: more intense headaches, loss of vision, floating black spots, intense tingling in her hands and feet, dizziness, vertigo, balance issues and difficulty focusing. The moments she remembers most of her college graduation weekend from Providence College were her continuous episodes of vertigo and weakness. After the usual battery of diagnostic tests and multiple doctor opinions, Kerry made the decision to have surgery in November of 2004.

It wasn’t until July of 2008 that she attended her first ASAP conference. That was when she met Patrice Schaublin (current board president). The next summer Patrice asked Kerry if she would be willing to lead a support group on Long Island. Kerry was thrilled to be given this opportunity as she knew how alone and scared she felt upon her own diagnosis. The group has since been meeting monthly.

During Kerry’s surgical recovery, she told her husband (then boyfriend), Bernard, “If I can survive brain surgery, I can run a marathon.” Since September of 2008 she has run six marathons and two half marathons including New York City in November of 2010. Kerry ran the NYC Marathon in honor of her Long Island support group and raised over $5,000 for ASAP.

Kerry tendered her resignation in July effective August 31. She wants to take time for her family but plans to return to the board in the future.

She will continue to lead the Greater Houston support group and support the organization. Kerry was an active member of the Board, chairing the Chapter Task Force, volunteering for several committees and handling the duties of secretary. She will be greatly missed but we wish her all the best and express our gratitude for her past, present and future involvement with the organization.

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.

Become An ASAP Volunteer

Submit an application at ASAP.org/index.php/volunteer/ or contact the ASAP office at 903-236-7079.
**2014 ASAP Conference Speakers**

[In alphabetical order]

<table>
<thead>
<tr>
<th>Name</th>
<th>Title and Affiliation</th>
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<tbody>
<tr>
<td><strong>Allison Ashley-Koch, PhD</strong></td>
<td>Associate Professor, Section of Medical Genetics, Department of Medicine, Duke University Medical Center, Durham, NC</td>
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<tr>
<td><strong>Mitra Assadi, MD</strong></td>
<td>Pediatric Neurology, Capital Institutes for Neuroscience, Pennington, NJ</td>
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<tr>
<td><strong>Mandy Binning, MD</strong></td>
<td>Director, Comprehensive Stroke Center, Capital Health, Stroke &amp; Cerebrovascular Center of New Jersey, Pennington, NJ</td>
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<tr>
<td><strong>Paolo Bolognese, MD</strong></td>
<td>Neurosurgeon, Associate Director, the Chiari Institute, Great Neck, NY</td>
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<tr>
<td><strong>Ricardo Cruciani, MD, PhD</strong></td>
<td>Neurology, Pain Medicine, Capital Institutes for Neuroscience, Pennington, NJ</td>
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<tr>
<td><strong>Debra Deluca, MD</strong></td>
<td>Clinical Neurophysiology, Neurology, Sleep Medicine, The Center for Sleep Medicine, Trenton, NJ</td>
</tr>
<tr>
<td><strong>G Peter Gliebus, MD</strong></td>
<td>Neurology, Capital Institutes for Neuroscience, Pennington, NJ</td>
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<tr>
<td><strong>Gerald Grant, MD</strong></td>
<td>ASAP Medical Advisory Board, Pediatric Neurosurgery, Stanford University Medical Center, San Francisco, CA</td>
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<tr>
<td><strong>Jacob Greenberg, BA, MD</strong></td>
<td>MD, MSCI Candidate, ASAP Research Grant Recipient, Washington University School of Medicine, St. Louis, MO</td>
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<tr>
<td><strong>John D Heiss, MD</strong></td>
<td>ASAP Medical Advisory Board, Head Clinical Unit, Surgical Neurology Branch, NINDS/ NIH, Bethesda, MD</td>
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<tr>
<td><strong>Bermans Iskandar, MD</strong></td>
<td>ASAP Medical Advisory Board, Director of the Pediatric Neurosurgery Program, University of WI, Madison, WI</td>
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<td><strong>Robert Keating, MD</strong></td>
<td>ASAP Medical Advisory Board, Chief of Neurosurgery, Children’s National Medical Center, Washington, DC</td>
</tr>
<tr>
<td><strong>Lance LaCerte, PSY D</strong></td>
<td>ASAP Medical Advisory Board, Behavioral Medicine, the Medical Center of Aurora’s Spine Center of Innovation, Aurora, CO</td>
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<tr>
<td><strong>Bryant Martin, PhD</strong></td>
<td>ASAP Research Grant Recipient, Director of the Chiari Research Center at the University of Akron, Akron, OH</td>
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<tr>
<td><strong>Esther Nimchinsky, MD</strong></td>
<td>Capital Institute of Neuroscience, Pennington, NJ</td>
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<tr>
<td><strong>Mark Quigley, PhD</strong></td>
<td>ASAP Research Grant Recipient, Children’s National Medical Center, Washington, DC</td>
</tr>
<tr>
<td><strong>Harold Rekate, MD</strong></td>
<td>Professor of Neurosurgery, North Shore Long Island Jewish Health System, Great Neck, NY</td>
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<tr>
<td><strong>Andrew Ringer, MD</strong></td>
<td>Neurosurgeon, Mayfield Clinic, Cincinnati, OH</td>
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<tr>
<td><strong>Harry Schwartz, MD</strong></td>
<td>Clinical Director, Spinal Cord Injury, Moss Rehab, Einstein Healthcare Network, Philadelphia, PA</td>
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<tr>
<td><strong>Alan Siu, MD</strong></td>
<td>ASAP Research Grant Recipient, George Washington University, Department of Neurological Surgery, Washington, DC</td>
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<tr>
<td><strong>Erol Veznedaroglu, MD, FACS, FAANS, FAHA</strong></td>
<td>ASAP Board of Directors, Director of the Capital Institute of Neuroscience, Chairman of the Department of Neurosurgery at Capital Health, Pennington, NJ</td>
</tr>
<tr>
<td><strong>Jennifer Yanoschak, MD</strong></td>
<td>Neuro Critical Care, Capital Institute of Neuroscience, Pennington, NJ</td>
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Dr Timothy George and Dr Cormac Maher who were scheduled to speak were unable to attend the conference this year due to extenuating circumstances.
Medical Advisory Board Updates

Dr Robert Keating was appointed Chair to replace Dr John Heiss who will stay on the Board.

Dr Erol Veznedaroglu moved from the Board of Directors to the Medical Advisory Board (MAB).

A new Research Chair will be appointed by Dr Keating shortly.

Dr Timothy George, Medical Director of the Pediatric Neurosurgery Center of Central Texas and Dr Cormac Maher, Associate Professor of Neurosurgery at the University of Michigan Health System have joined the MAB. Watch for more details about our newest additions in future editions of ASAP Connections.

2014 ASAP Awards

Helping Hand Volunteers
Beth Brixius
Tabitha Peters
Lee Ann Clutter
Margaret Leisenheimer
Gina Huffman
Rain Deskins
Kaylee Lemmon
Staci Massi
Heather Leitner
Cat Becker

Visionary Awards
Michael “Yogi” Borys
Charyl Turner
Lauri Edwards
Megan Jones

Shining Star Volunteers
Amber Barnes
Jennifer Mucciacciaro
Sharon Sweeten
Jennifer Vasek

Key Volunteer Award
Shananne Hutter

Barbara White Award
Patricia Maxwell

Outgoing Board Members
John A Jane, Jr, MD
Medical Advisory Board
Renee Tobias
Board of Directors

A very special thank you to the many volunteers who work behind the scenes to provide programs for those affected by syringomyelia and Chiari malformation. Your efforts are offering hope, changing lives and making a difference! You are the foundation upon which the organization is built and stands.

Volunteers Respond

Renee Aulenbach Tobias - I received the award in the mail today. Thank you very much! I am honored and humbled to receive this award. I look forward to continuing my work with ASAP Organization and my support group once I am fully recovered.

Bridget Borys - Congratulations to the other winners as well! What a huge honor for you ALL!

Mike Yogi Borys - Congrats to Charyl, Lauri and Megan!! This is awesome! Another reason to help keep up the fight and spread awareness!

Tabitha Peters - looking forward to another 5k fundraiser in the spring!

Beth Brixius - Thank you so much! I had a great volunteering experience and can’t wait to do it again!

Heather Doty Leitner - This so made my day

ASAP’s Chiari & Syringomyelia Conference
Princeton, NJ

Presenting Level Sponsor

NSPC Neurological Surgery, P.C.
Comprehensive Brain and Spine Care

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Welcome Eric to the ASAP Board of Directors

Eric Berning lives in Houston, Texas, and was diagnosed with Chiari and syringomyelia in early 2003 at the age of 36. Despite chronic discomfort and intermittent loss of strength and function in his extremities since a young age, Eric’s condition went undiagnosed and misdiagnosed for many years, during which time he found himself living under the assumption that what he was experiencing must be “normal.” In late 2002, Eric’s chiropractor detected some neurological abnormalities which concerned him enough to not attempt manipulation of his cervical spine and instead insist upon referring him to a neurologist, even offering to make the appointment himself. Eric agreed to see the neurologist, and after a series of MRIs on his head, neck, and back, Eric was officially diagnosed with CM/SM and, in turn, referred to a neurosurgeon for immediate evaluation. In April 2003, by this time an expectant father, Eric underwent decompression surgery. While not a cure-all, much of Eric’s symptoms were halted from further degeneration—and while he continues to live with chronic pain, Eric also continues to live with the upbeat hope that ‘it won’t get much worse’. Eric likes to focus on the positives in his life: case in point, just months after his diagnosis and decompression surgery, Eric and his wife Jennifer welcomed their son Edward into the world—thus making 2003 truly a year of great blessings.

Eric continues to work full-time managing a contingent workforce program for a large corporation. A diehard Cleveland Browns fan, Eric does his best at keeping up with the activities of his now 11-year-old son, as well as being an active member of his community. He has served as the committee chairman of his son’s Cub Scout pack and is currently a committee member in his Boy Scout troop, has actively led fundraising teams for several charitable organizations, held deacon and elder positions at church, was elected to his HOA board, and has volunteered countless hours at his son’s school functions. Eric is hard to keep down—he may have to slow down at times, but he does not like to stop. He maintains a pleasant demeanor and positive attitude regardless of the issues he is physically dealing with at any given moment. In 2012, Eric began attending the local ASAP support group meetings in order to connect with others living with CM/SM, and to lend a voice of understanding and comfort to others facing the same challenges he does. He likes to remind those with these conditions, “While we may live with pain, it does not have to define who we are.” Eric is excited to join the Board to help raise awareness of CM/SM, to find opportunities to share his experiences in an effort to bring hope, understanding and guidance to those who need and seek it, and to ultimately see a cure that ends CM/SM once and for all.

Eric can be reached at Eric_Berning@ASAP.org.

New Merchandise Now Available

- 7 inch car magnet ribbon with removable center refrigerator magnet
  - $5.00
- Lanyards let you show off your dedication to spreading awareness
- Screen-print on woven band
- Detachable key chain
- Available in purple for Chiari malformation awareness
- Available in blue for syringomyelia awareness
  - $5.00 each

Removable window decal free with every order during the month of September

Check out the new merchandise now available through the ASAP Store. www.ASAP.org/index.php/store/  

Don’t want to order online? Call 903-236-7079.
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

Dan
  Michael Isikow
Halee Fishman
  Linda Konchel
Jacqueline Babits
  Steven & Rosa Babitts
Melissa Zimmerman
  Elizabeth Pray
Michael Kirlin
  Gwen Kirlin
Sunshine Matthews
  Donald Tabor
Michael McDaniel
  Deborah Longtime

In Memory of
Donor

Ann Priester
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Mayur Patel
  Parth Patel
Jack Leiberman
  Stephen & Arlene Sharkey
Lola Kliewer
  Bobby & Peggy Kirksey
LG Patterson
  Molly McMahon
Megan Reynolds
  Family & Friends
John Hartnett
  Donna Sherman
  Elena Robles
  Regina Luisi
Richard French
  Shirley French
  Kenneth & Judith Jasinski
  Mr. & Mrs. Buchanan
Roberta “Bert” Davis
  Gerald Davis
  Glenn Davis
  Michael & Katherine Lewis
  Richard Davis

ASA History

To strengthen the ties between ASAP and the research community, the ASAP Board of Directors voted to establish a Medical Advisory Board in January 1996. With the help of this Medical Advisory Board, ASAP is able to better evaluate the merits of research projects, encourage awareness of syringomyelia and Chiari among medical professionals, promote fundraising and encourage government sponsorship of projects. Dr Thomas Milhorat chaired the first Medical Advisory Board. Other members included doctors Henry Joseph Barnett, Ulrich Batzdorf, Arnold Menezes, Richard Ellenbogen, Robert Stanton, and Marcy Speer.

In November 1996, ASAP announced its first sponsorship of a Research Fellow, Dr Ian Heger at the SUNY Health Science Center at Brooklyn. Dr Heger worked in Dr Milhorat’s laboratory and focused on developing experimental models of non-communicating syringomyelia.

2014 Annual Conference Sponsors

We recognize the many individuals and companies for their generous donations to our welcome bags, raffle and auction, including but not limited to the following.

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Email:  info@ASAP.org
       Patricia_Maxwell@ASAP.org
       Jamie_Mayhan@ASAP.org
Conference Attendees Share Their Thoughts

Annette from Colorado attended her first ASAP Conference and wrote: Everyone was amazing from the meet and greet to the last break out session. There was such a willingness from so many individuals to assist others, the presenters, staff, and volunteers were always available. The amount of information I took away from this conference is insurmountable. The camaraderie among everyone shows this really is a family oriented organization.

I may not have CM/SM, but my brother-in-law does. I came here for a few reasons, yet the best part of my experience is that I came to the conference with so many questions and before I left a large majority of the questions were answered and the ones that were not I was provided with information to locate the information.

Tyson from New Jersey wrote: In my opinion, the conference was excellent and I rate it at 5 out of 5. I gained more helpful information and insights into Syringomyelia in a couple of days than I had received in the last sixty years or so; thank you!

Bonnie from Pennsylvania also rated the conference a 5. I could not believe all the specialists that were there. The panel discussions were great. I still can’t believe we were able to ask any and all the questions we wanted.

The hotel was awesome. I truly felt like a princess.

I have never met any one with CM / SM before. Just being with others who truly understood how I feel was both a blessing and an unforgettable experience.

Thank You for all your hard work. God Bless you all for helping so many others to improve their lives.

Anonymous: This only being my second conference, I once again learned a lot of information that I had not known before. I was able to follow up on studies that were now completed. Also it is always amazing to not feel alone, since everyone knows what you are talking about when you say ‘my head hurts’. People understanding what it’s like to have to not overdo as well as always having to carry a ton of medication everywhere you go.

Suggestions: I truly enjoyed the conference but the price is just too much for the average charian or syringo to attend. I would hope for more support group times as well as more advanced talks that delve deeper into more complex issues. Having more specialized talks would be amazing.

I attended the conference as a person with only syringomyelia. I felt most of it was geared towards Chiari malformation. I would like to see more topics about syrinx not related to Chiari malformation.
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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