

*Providing Research, Education and Support since 1988*

## Elizabeth Michel Camak Counts

by Deborah Jacks Camak, MSN, RNC-MNN, FCN, C-EFM



Addison, age 14, was diagnosed at an early age with Syringomyelia.

This past year, she worked tirelessly to get Texas to recognize the month of May as Syringomyelia Awareness Month. She wrote several letters to the Governor of Texas, Greg Abbot. He and his wife accepted the request to get this accomplished.

The family has supported ASAP for many years and often request that family and friends make donations in Addison's honor to support programs and research.

Thank you Addison for going above and beyond to make a difference in the Chiari and Syringomyelia community.

**Today's youth are our future leaders.**

[Due to limited space the following is an abbreviated version of Elizabeth's story. Please read the detailed account of her experiences under 'Personal Stories' at ASAP.org.]

The prolific author Helen Keller once said, "Although the world is full of suffering, it is also full of the overcoming of it." This truly defines the life of my daughter, Elizabeth. Through many years of suffering, pain, living in a brace, enduring surgeries, and various therapies, she has rigidly withstood all with grace, truly exemplifying the overcoming of it. First diagnosed at the age of 5 years with idiopathic scoliosis, little did we know that it was just the beginning of a long, winding path that would lead through valleys of fear and mountains of joy.

By her 5th birthday, Elizabeth began to have days in which she would experience headaches, vomiting and nausea without explanation. During a routine medical office visit, it was discovered that Elizabeth had scoliosis with a 22-degree lumbar curve. Within months she was admitted to the services of the Greenville, South Carolina Shriners Hospital for Children.

For 7 years, she would spend 23 out of every 24 hours in a brace. Within 2 years, she began to develop a thoracic scoliosis curve in addition to the lumbar curve. After her 9th birthday, the physicians decided to try a Milwaukee brace since she now had 2 curves. Many of the children in Elizabeth's school avoided playing with her because of the brace. Even though she was treated with misunderstanding and prejudice, she continued to remain friendly and never retaliated toward them.

It was during this time that Elizabeth was also displaying the loss of her fine motor skills, pain in her arms and legs, some slurring of her words, balance difficulties, and expressed that she was having frequent headaches.

Within two weeks, during a visit with the physicians at the Shriners Hospital it was discovered that Elizabeth probably had a syringinx in addition to the scoliosis. Three weeks later it was confirmed. Elizabeth had Syringomyelia, Chiari and scoliosis. Seven days later, Elizabeth underwent her first surgery. Amazingly, she never cried nor complained during her surgery and was running through the Shriners Hospital playing with other children within 3 days postoperative. She was a real trooper!



Since graduating from high school, she has become a certified nurse assistant and a licensed esthetician. Elizabeth frequently shares her own story with her patients encouraging them with her experience. She uniquely understands their suffering and struggles since she has walked a similar path.

Again, as the author Helen Keller said, "Character cannot be developed in ease and quiet. Only through experience of trial and suffering can the soul be strengthened, ambition inspired, and success achieved."

## Chiari Awareness Month

For the past several years we have been celebrating Chiari Awareness during the month of September. Even if you missed this year you can create awareness all year long. Here are some ways you can participate.

- **Make a donation in honor of a family member diagnosed with Chiari.**
- **Request your governor to proclaim Chiari Awareness Month in your state for September. You can check your state website for more information on requesting proclamations.**
- **Share information about the disorder with friends, family, neighbors, etc.**
- **Hold an awareness event in your community.**
- **Participate in a local health fair. ASAP will provide brochure and bookmarks.**
- **Share the ASAP Fact Sheet with doctors, nurses, hospitals in your area. A PDF file is available for download at <http://asap.org/index.php/about-us/asap-fact-sheet/>**

## ASAP UNITES Cosponsors Scientific Meeting

In the interest of supporting the CM/SM community, ASAP will cosponsor the

### SM/CM/EDS

### Scientific/ Medical Meeting

June 2019

Hosted by Marcus Stoodley, MD, and Lynne Bilston, MD, this meeting will bring specialists together to challenge, have candid discussions, and share new ideas. This meeting will be cosponsored by COH, ASAP, Conquer Chiari and the Canadian EDS group, ILC Foundation. It will be held in Buffalo, New York.

We are proud to join and contribute with other leaders in our community to better serve our community as a whole. Through greater partnerships we can achieve greater results. It is the ASAP Board of Director's belief that this investment in partnerships will have a positive impact far greater than each sponsor working separately - simply a case of the whole being greater than the sum of its parts. We look forward to sharing those results.

## Contact Information American Syringomyelia & Chiari Alliance Project

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**Laughter is the  
best  
medicine**

## 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](http://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

Hello everyone,

What a great conference we had in Florida in celebration of ASAP's 30th anniversary! It is exciting and rewarding to be part of a multi-faceted community dedicated to continuing the monumental work first initiated by Barbara and Don White back in 1988. We have come so far in the past three decades, yet there is much still to be done as we strive for a cure.

A key observation I took away from the conference was how tremendously important it is in this community to be present at and participate in activities that support and educate our members as well as raise global awareness of CM/SM and the accompanying issues and struggles we all experience. Common comments I heard were "I never knew," "I wish I understood before," and "How can I find out more?" Our goal is to reach more people around the world and be the go-to source for knowledge and support.

As I've said before, the best part of our annual conference is meeting others who care as deeply about Chiari and Syringomyelia as we do: patients, doctors, family members, caregivers, research teams, volunteers. Our great take-away is the knowledge that we are not alone. Many others share our experiences, pain, and fears, and there is comfort and encouragement found in knowing there are, indeed, resources available for us to learn more and receive support. As we see each year, there are a growing number of international professionals in medicine and science who have devoted their lives to understanding and pinpointing the best treatments for individuals with CM/SM, and ultimately discovering a cure. For these dedicated men and women, we are so grateful.

We truly exist because of the active participation of people like you. YOU are our bedrock! We ask—we need—you to continue to be active within our community. Create a support group (we have resources to help you!). Hold an awareness event (again, we have resources to help you!). Raise funds—again, we can help. Attend a conference—we have one every summer!

Keep in mind, you do not need to "reinvent the wheel" to spread awareness. Multiple organizations focus on Chiari and Syringomyelia and their related disorders, many of which originated from ASAP. We are working towards creating a more unified, responsive alliance, focused not on our differences, but on the common goals of our community. Our door is open to all who want to help and who are looking for a place to serve. Our contact information is listed on page 2.

Continue to fight the good fight and participate whenever, however, and wherever you can. You do not need to be an expert; sometimes it just takes being there for someone who needs some understanding.

Remember to always live within your limits, but live a life that is limitless!

## International Symposium for Syringomyelia-Chiari

July 17-20, John Heiss, MD, Paolo Bolognese, MD, and Patrice Schaublin attended the Syringomyelia - Chiari 2018 International Symposium in Birmingham, England. Hosted by Graham Flint, MD it was co-organized by the Ann Conroy Trust (ACT) and Aesculap Academia. The meeting was a follow-up to the international conference organized by ASAP and co-hosted by Paolo Bolognese, MD and Roger Kula, MD in July 2017 in New York. The next International Collaboration is scheduled for May 2019 in Milan, Italy with the help of the international support groups and Laura Valentini, MD.

The symposium started with an opening reception on Tuesday evening and provided attendees the opportunity to network and relax. Wednesday morning began with a welcome from Lynn Burton (Chairman of the Ann Conroy Trust). Over 50 speakers participated and included free paper presentations. Free papers are shorter presentations given by people active in the field, i.e., students, doctors, specialists. International physicians came from Italy, England, India, Germany, USA and Australia. Support organizations were invited to participate following the example of the US meeting for the continued development of the International Collaboration.



During the symposium, ACT had a Memorial Lecture for Edward Oldfield, MD, Bernard Williams, MD and Ann Conroy. On the final evening of the conference, a dinner was held at the Birmingham Museum & Art Gallery, ending a wonderful event.

Many thanks to Dr Flint and his team. We look forward to working with our new international partners and are excited to see what the future brings to our community. Together we will gain access to funding opportunities (government and Fortune 500 companies). Our scientific goal will be to facilitate and legitimize the common efforts of specialists from around the globe. Two goals already developing are an annual international meeting and a redefinition of Chiari I.





## ASAP Chiari & Syringomyelia Conference

Try to imagine a hotel that encloses the outdoors under an atrium. While walking from your guest room to the meeting room, you pass shops, a fort, the everglades (with alligators) and walking trails. Imagine a space that holds multiple restaurants, one of them includes a sailboat surrounded by a fish-filled pond as part of the seating area. That is the Gaylord Palms Resort. The venue allowed us to enjoy the outdoors in a climate-controlled setting making it the perfect place to celebrate ASAP's 30th anniversary.



It was good to see friends who have attended past conferences and make new friends whom we hope to see at future meetings.

The event began on Wednesday evening with an opening reception and banquet in the fort. Attendees later broke into smaller groups for an hour of peer support. Thursday morning everyone looked forward to

a full day of presentations. We learned that one of our hosts, Dr Eric Trumble, had accepted a position in Sioux Falls, South Dakota and would be moving within the week. This will be welcome news to those in the Dakotas and surrounding area.

The day's presentations included:

- Decision Tree for Treatment of Chiari – Erol Veznedaroglu, MD
- The Nuances of Management of "Uncomplicated" Chiari I Malformations - Eric Trumble, MD
- Craniocervical Morphometrics and Chiari – Cormac Maher, MD
- Disorders of CSF Circulation – Herbert Fuchs, MD
- Chiari I and Dysautonomia: Occipitocervical Instability – Hal ReKate, MD
- Occult Tethered Cord – Holly Gilmer, MD
- Arachnoid Cysts, Arachnoiditis, and Syringomyelia – John Heiss, MD
- Neurologic and Neurosurgical Manifestations of EDS – Paolo Bolognese, MD
- Chiari I: Surgical Principles & Avoiding Treatment Failure John Oro, MD

We expect to have all the presentations edited and available for viewing on our YouTube channel later this year.

Friday was another full day and included lectures from doctors Barth Green, Miami; Mark Cheat, Orlando; Roger Kula, Lake Success; Jeffrey Greenfield, New York; Arnold Menezes, Brian Dlouchy and Saul Wilson, all from Iowa City; and John Oro, Aurora. Everyone took a short afternoon break to enjoy a slice of cake to celebrate ASAP's 30th anniversary.

By Saturday, everyone was exhausted but with another lineup

of great speakers and presentations, no one wanted to stop. Special thanks to Roger Kula MD and John Orom MD who pulled double duty to present on Chiari & Pregnancy and Neuroinflammation: The Gut-Brain Axis respectively. Doctors Ian Heger and Jacob Eichenberger of Augusta and Michael Westerveld, MD of Orlando spoke in-depth about Chiari and pain management while

Suzanne Oro gave a presentation on Taking Chiari and Related Disorders to School. Dr Carl Barr local to Orlando talked about CMI and Osteopathic Manipulation. Dr David Limbrick of St. Louis brought everyone up-to-date on the ASAP and PCORI-Supported Clinical Trial: Posterior Fossa Decompression with or without Duroplasty for Chiari Type I Malformation. Petra Klinge, MD who flew in from Providence, Rhode Island gave a talk on Chiari and Cognition- Fiction or Reality. The final presentation of the day included Barbara Lichtenstein, Rich Simon, Annie Chapman, Sarah Jenks and Stevie Collier who spoke about their various experiences and how Chiari / Syringomyelia has affected their lives.

Then it was time to relax, enjoy a cocktail, a delicious meal, an improv performance and help raise funds by bidding on silent auction items. Special thanks to Sara Dyer who solicited various companies for some great items and the attendees who donated special pieces. Awards were presented to our hosts, Dr Ian Heger and Dr Eric Trumble, in appreciation of an outstanding job organizing our conference, promoting awareness and developing education. Barbara Lichtenstein received an award for Key Volunteer and Patrice Schaublin was surprised with the Barbara White Award. We recognized doctors Roger Kula and John Heiss for 20 years of service on the Medical Advisory Board. Michele Ray, Ronda Hoover, Mike Borys and Sharon Sweeten are our Helping Hand Volunteers for 2018. Ann Humphreys and Jen Sadrak will receive certificates for Visionary and Key Volunteers respectfully. Shining Star volunteers for 2018 are Lisa Dunton-Roy and Sara Dyer.

As usual saying good-bye was hard. In some ways, the conference goes by excessively fast. You are exhausted but wish you had more time just to sit and visit. But we always look forward to the next year and anticipate seeing each other again.



## Members Share Their Conference Experiences

Thank you for all that the Board, volunteers, and doctors do to put on these annual conferences.

I had not been to one in 13 years. I had multiple, (to put it mildly), surgeries between 1998 and 2005, and was lucky enough to attend a few conferences during that time.

After my last surgery in 2005, I just wanted to put as much of my “Chiari life” behind me as I could. I was very lucky to meet and fall in love with an amazing man, who saw behind my debilitating headaches and depression. He helped me to see that I could have a life beyond Chiari. We were married in 2007, had our first child in 2009, and our second in 2012. My family is the center of my universe. I still have headaches, but the days when I just can’t get out of bed are much fewer, thanks in large part to Botox, getting off of narcotics (rebound headaches), & the love and support of my husband and kids. On days when I would normally have just stayed in bed and rested all day, I am now able to “push through” for them, (most of the time.)

My husband and I really enjoyed the ASAP Conference. We learned a lot about the latest information on Chiari. My husband, especially, learned so much. He really had his eyes opened as to how much people with Chiari and SM go through. He made a comment about how all of the people there were just as strong and resilient as I am. He was impressed.

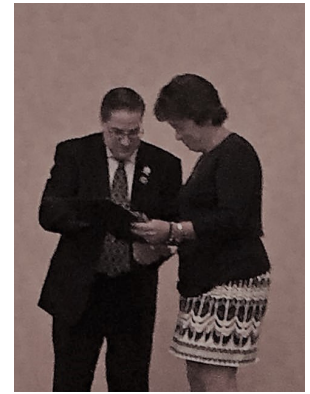
We also got to meet many other people who are going through, or have gone through, a lot of the same things that we have dealt with. There is a true sense of camaraderie amongst Chiari patients and their families, and it’s always nice to make those connections.

Another reason for us to return to “The World of Chiari” at this point in time is the fairly recent diagnosis of our 9 year-old son. He was actually diagnosed a couple of years ago, but the herniation was minimal, as were his symptoms. In the last few months, his headaches have increased, so we did another MRI, & his herniation has expanded. We are still not at the point of considering surgery, but we want to get him under the care of a Chiari Specialist BEFORE we get to that point. We wanted to ask around, and get some advice on who we should see, now that Dr. Trumble is leaving. We got some great advice, and made some great connections.

The ONLY complaint I have at all, is that the chairs were a little uncomfortable for those of us with neck issues to sit in all day, (for 3 days in a row). High-backed chairs would be helpful. Otherwise, an amazing job was done by all involved! Thank you again for all of your hard work! It is much-appreciated!

Sincerely,

Jeni A



### The most beneficial aspects of the conference:

- Speaking with other delegates and exchanging information, seeing the passion of the doctors, validation of symptoms and realizing I am not alone. - Erin
- Learning how to help my daughter, hearing the doctors speak about topics like Chiari and pregnancy, Taking Chiari to School, pain management options, surgical options, networking and meeting doctors and parents/families - Kristina
- Case studies, opportunity to be involved and support - Linda
- I totally needed this. It helped me feel like I am not alone in this struggle. - Vicki
- Learning more about advances in treatments, networking and empathizing with those who are experiencing effects of disease - Ruth
- Knowing there are others like me and we do not have to suffer alone. Learning that happiness improves health - Glenda





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

##### Addison Mims

Carmen Lathrop  
Randy Begier

##### Jacqueline Babitts

Steven & Rosa Babitts

##### Sharon's MS Graduation

Loralee Uhlenhake

##### Ruth Williams

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#### In Memory of

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## ASAP KIDS

Several years ago, Annette Johnson solicited for a donation from Kohl's. ASAP received a large supply of stuffed toys and books which we share with our KIDS. We have also sent boxes to several children's hospitals around the country. Here are a few of our recent recipients.



30th Anniversary

**Thank you to all the volunteers who have made it possible to serve the Chiari and Syringomyelia community for 30 years.**

**Our children are our future.  
We need to fight harder to find a cure.**

## ***"Thank You for Supporting ASAP!"***

Let us hear from you, update your contact information.

Name \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

Email \_\_\_\_\_ Phone # \_\_\_\_\_

☐ Yes, I would like to continue receiving the newsletter.

☐ No, please remove me from your mailing list.

\*\*\*\*\*

Your support makes a difference in the lives of thousands. Please help us to continue our programs and research funding with a donation today. Every dollar counts!

☐ Check enclosed payable to ASAP, Inc. – You can also make your donation online at ASAP.org

Credit Card ☐ MasterCard ☐ Visa ☐ Discover ☐ American Express

Card # \_\_\_\_\_

Name of Cardholder \_\_\_\_\_

Signature \_\_\_\_\_

Expiration Date \_\_\_\_\_ Security Code \_\_\_\_\_ Amount \$ \_\_\_\_\_

Return form to: ASAP, Inc., PO Box 1586, Longview TX 75606-1586

### **Chiari Patients and Families!**

Get involved in a NIH-sponsored study at Yale University now expanding to explore the MOLECULAR GENETICS of Chiari malformation.

You don't have to live near Yale or even the U.S., and even if you don't have a family history, we are still interested in your participation! It's free and easy.

For more information contact us at:

- [chiari.genetics@yale.edu](mailto:chiari.genetics@yale.edu) or (203)903-2820

THANK YOU to the over 95 families who have participated so far!

Help us learn about what genes might contribute to Chiari Malformation.

Kristopher Kahle, M.D., Ph.D.  
Yale School of Medicine  
Yale-NIH Centers for Mendelian Genomics

### **Alternative Therapy**

#### **Healthy Living**

Many factors affect your health. Some you cannot control, such as your genetic makeup or your age. But you can make changes to your lifestyle. By taking steps toward healthy living, you can help reduce your risk of heart disease, cancer, stroke and other serious diseases.

- Get the screening tests you need.
- Maintain a healthy weight.
- Eat a variety of healthy foods, and limit calories and saturated fat.
- Be physically active.
- Control your blood pressure and cholesterol.
- Don't smoke.
- Protect yourself from too much sun.
- Drink alcohol in moderation, or don't drink at all.
- Get enough sleep every day.

But its not just about hygiene, diet and exercise. It is also about your mental well-being. Focus on the positive, enjoy those around you, laugh often and experience the best quality of life possible.

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

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## ASAP Connections

The American Syringomyelia & Chiari Alliance Project (ASAP) is a tax-exempt 501(c)(3) organization. Our goals include providing a clearinghouse for information on Syringomyelia (SM), Chiari malformation (CM), and related conditions.

We offer a supportive network of programs and services and fund research to find better therapies and cures. ASAP is supported by tax deductible donations.

*ASAP Connections* is published quarterly for ASAP members. Your contributions of articles, letters, and photos are encouraged. The editor reserves the right to edit any article in order to accommodate space.

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