

ASAP CONNECTIONS

Providing Research, Education and Support since 1988

Ulrich Batzdorf, MD, Keynote Speaker

We are pleased to announce that Dr Ulrich Batzdorf, a pioneer in the modern treatment of Chiari (CM) and syringomyelia (SM), will be the keynote speaker for ASAP's Chiari & Syringomyelia Conference. The meeting will take place July 18-21 at the Key Bridge Marriott in Arlington, Virginia, located across the Potomac River from Washington, DC.

Professor and Executive Director of Spinal Neurosurgery, Dr Batzdorf's primary clinical and research focus is on the treatment of Chiari malformation and syringomyelia. One of the founding members of the ASAP Medical Advisory Board, Dr Batzdorf has been an attending physician at UCLA Medical Center since 1975. The author of multiple articles and books on CM/SM, he is considered a leader in the development of diagnosis and surgical treatment.

In addition to Dr Batzdorf, a host of specialists will present on a wide variety of topics. Start making plans now to attend ASAP's Chiari & Syringomyelia Conference by completing the registration form inserted in this newsletter.

ASAP's Chiari & Syringomyelia Conference Arlington, Virginia/Washington, DC July 18-21, 2012

by John Caemmerer

This year we will be "Pushing the Envelope" at the 24th annual conference. The event should prove to be one of the best ever!

Benefits of attendance start immediately with the first night's reception. Patients, family and caregivers meet in an informal setting that allow them to interact with others who face similar challenges to their own. They learn that they are part of a much larger community and they are not alone.

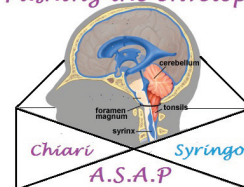
Thursday we begin three days of presentations that are sure to inform, enlighten and educate. Learn about the latest research, outcome studies, genetics, trends, surgical techniques, pediatric and adult approaches, alternative treatments and the list goes on. Presentations conclude Saturday afternoon, followed by the banquet that evening. Raffles, a silent auction and a live auction are just some of the activities that will complete this year's event, promising a fun-filled evening for all.

Dr Robert Keating has assembled a roster of speakers from around the country who are the best and brightest in their fields. Nowhere can our community find such elite and respected doctors and other professionals gathered in one place to share their knowledge and expertise. Dr Keating said, "I want this year's conference to be the best conference ever held by ASAP. Attendees will receive cutting-edge information delivered by the best and brightest from around the country. This is a 'must attend' for anyone affected by these devastating disorders."

ASAP is the only organization offering an event of this kind that is open to all persons of the CM/SM community and has been bringing it to you since 1989.

REGISTER NOW! We are expecting a large attendance and can only accommodate on a first-come, first-serve basis. For more information, visit ASAP.org or call 903-236-7079. We look forward to seeing you there!

Pushing the envelope



While we find the cure!

"Pushing the Envelope"



ASAP's Chiari & Syringomyelia Conference
July 18-21, 2012
Register online at ASAP.org

Stamp Project

by Patricia Maxwell



The Stamp Project has turned out to be more complex than I ever imagined. We first began collecting cancelled postage stamps in the early 90's. Over that time we have only had two people overseeing the project. They did such a good job, I never realized the time or experience involved. I just deposited the checks they sent.

After Maynard Guss passed away, we began looking for a volunteer to take over the project. We are still looking. We have had several people interested but so far no one has been willing to take over the project.

The requirement that seems to cause the biggest problem; you need a local stamp club with the ability to auction stamps to other collectors. It will also involve time to sort and 'clean' the stamps that have been donated. If you are interested we would love to hear from you.

We continue to receive boxes of stamps and sincerely appreciate everyone's contributions. Please continue to send stamps that are in good condition (attached to envelope and trimmed with 1/2 inch border around stamp) to the ASAP office.

ASAP Stamp Project

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.

Special Thanks ASAP Volunteers

by Patricia Maxwell

Have you ever heard the saying 'it takes a village to raise a child'? Well, the same is true for a non-profit.

Over the years, many have given of their time and talents to grow the organization and to make a difference in the lives of others. As the organization has developed so has the need for individuals to fill the gaps. Volunteers continue to play a vital role in ASAP. From our Board of Directors to the individual who supports others through social media. From those who organize fundraisers to those who participate. Every individual who shares their knowledge with friends and neighbors. Every doctor who speaks at an ASAP conference or support group meeting.

Volunteerism maintains the programs offered through this organization for the thousands of people affected by syringomyelia and Chiari. We have been blessed to receive services provided by persons both directly and indirectly affected by these disorders. They initiate goals, run fundraisers, assist with development, govern and encourage. They have donated endless hours, tactical skills, and resources to develop an organization that is strong, principled and enduring.

Many never receive the appreciation they deserve yet they continue to offer their talents year after year. We would like to say a very special thank you to all our volunteers for your commitment, your talents, and your time.

Thank you for making a difference!

Social Media Networking

Join our organization's Facebook page at:
<http://www.facebook.com/#!/pages/American-Syringomyelia-Chiari-Alliance-Project/353050136431>

Join our group Facebook page at:
<http://www.facebook.com/groups/40685867222/>

Follow us on twitter:
<http://twitter.com/ASAPorg>

Melissa's Story

In September of 2000, at the age of 16, Melissa (Kindlon) Sanders was diagnosed with the neurological disorders of Chiari malformation (CM) and syringomyelia (SM). After being blind-sided in her car by a drunk driver, Melissa received emergency room medical attention and was released with no apparent health issues. Several weeks later she began to experience blinding headaches, nausea, dizziness, tingling and numbness in her hands and feet. After visits to several doctors, Melissa was referred to a Springfield neurologist who diagnosed the CM and SM. Although congenital, the diseases can be brought on by blunt trauma to the head, such as what occurred in Melissa's car accident.



After much research and consideration, Melissa had a decompression brain surgery at the Mayo Clinic in January 2001. Despite severe pain after surgery, Melissa's condition gradually improved. Several months later fluid started leaking from the back of her surgery incision. The fluid was cerebrospinal fluid (CSF) and presented a serious problem that had to be addressed with more surgeries. As a result of the leaking spinal fluid, Melissa contracted spinal meningitis.

According to her New York doctors, she was alive only because her mom had urged that she be put on antibiotics as a precaution.

Fast forward four years and Melissa has now had four more brain surgeries, a plate put in her head, a shunt to help the spinal fluid flow and numerous spinal taps. After all this the last surgeon to treat her said, "Melissa is a failed Chiari patient." This meant that nothing surgically could be done to relieve



Recovering From First Surgery

her pain. Her only treatment option to help with the chronic pain and nausea was the prescribed use of narcotics such as fentanyl, oxycodone, morphine and zofran for nausea. The narcotics minimized the pain but left her feeling lethargic and not able to enjoy life. Proms, graduation and other milestones in her teenage life were all missed as a consequence of the disease she lives with daily.



**Trying Something New
(It didn't work!)**

Many Chiari patients like Melissa appear normal on the outside not reflecting the severe pain and discomfort that they live with on a daily basis. There are also those that are confined to wheelchairs and hospital beds.

Melissa weaned herself off all narcotics so she could lead a normal life as a mother, wife and teacher. She lives in Chatham with her husband Scott and two year old son Caleb and they are expecting their second child in October.

Melissa never complains and rarely shows the severe pain and discomfort she lives with daily. Today she treats her condition only through physical therapy and Advil. There is no cure for CM and SM and pain management is restricted primarily to the use of drugs.

Money is needed to raise awareness of the disease, fund research to help find a cure and make living with the disease more tolerable. We have no celebrity spokesperson, just concerned people like you to help us.

Melissa organized *Swing Fore the Cure*, a charity golf tournament to bring awareness to the disorders and raise needed funds.

Conference Auction and Raffle

We hope you can attend the conference in person. If not, you can still be a part by donating to the raffle and auction.

Contribute your hand-made crafts, unused gifts, theme baskets, toys, frequent flyer miles (35,000 or more), hotel and resort packages, golf course packages, sports memorabilia, theme park vouchers, designer items, autographed books, unique trips (offshore fishing, white water rafting, etc.), condos & time shares, electronics (ipads, iphone, ipods, xbox 360s), tickets to events (professional

sports, Broadway plays, concerts, etc.), jewelry, specialty liquor/wine connoisseur items, artwork and photography, gift certificates for national restaurants/stores, health & fitness items.

If you have items you would like to donate to the event, please contact Barbara_Banick@ASAP.org or the ASAP office at 903-236-7079. Contact the ASAP office for directions on shipping items to the meeting. Thank you for any assistance you are able to provide to enhance the raffle and auction.

ASAP Chapters Update

An American Syringomyelia & Chiari Alliance Project (ASAP) Chapter is made up of individuals concerned with ASAP, Chiari malformation (CM) syringomyelia (SM) and is initially formed to meet their mutual needs: learning about CM/SM, offering support and sharing coping techniques.

- Education and mutual support of the group members through such means as video presentations, discussions and presentations by professionals.
- Increasing public awareness of ASAP, CM and SM through articles in local newspapers and magazines, local radio and television presentations and presentations to local organizations.
- Promoting awareness of ASAP, CM and SM in the medical and educational communities by video presentations and distribution of literature.
- Responding to inquiries about ASAP, CM and SM: providing information to individuals, professionals and public service agencies.
- Providing advocacy information to the families of people with CM and SM.
- Fundraising in support of ASAP.

Our ASAP Chapters continue to grow, providing monthly support groups throughout the country. However, we still need **your help** in many states.

Here is a list of our active Chapters.

- AZ Syringo & Chiari Support Group – Phoenix, AZ
- Colorado Brains Connected – Evergreen, CO
- ASAP's Eastern Iowa Chiari/Syringo Support Group - Cedar Rapids, IA
- ASAP's Indy Chiari/Syringo Support Group – Greenfield, IN
- ASAP's Tampa Support Group – Tampa, FL
- Midwest ASAP Connection – Blaine, MN
- Durham, NC Support Group – Durham, NC
- ASAP's Long Island, NY Support Group – Garden City, NY
- North Jersey Arnold Chiari & Syringomyelia Alliance – Boonton, NJ
- ASAP's Butler, PA Chiarians – Butler, PA
- Chiari People of PA – Mohnnton, PA
- ASAP's Charleston Area Chiari/Syringo Support Group – Charleston, SC
- ASAP's Central Houston Chiari/Syringo Support Group – Houston, TX
- ASAP's North Houston Chiari/Syringo Support Group – Cypress, TX
- Edmonds, WA Support Group – Edmonds, WA
- ASAP's Madison, WI Chiari/Syringo Support Group – Madison, WI

If you do not see a support group on this list near you and are interesting in starting one in your area, please contact Kerry Chu at kerry_chu@asap.org or contact the ASAP office at 903-236-7079.

Spring Fundraising Events



Sugar Land, Texas, April 28
Walk host Cathy Tufts & Laurie Swilhart



Colorado Springs, Colorado, May 5
Walk host Tamra & Chad Allgood



Greenfield, Indiana, May 5
Walk host Lori Tutrow

Utica, New York Walk, March 31
Walk host Celeste Wilson Ramseur

Cure Chiari ASAP, May 6
5 Boro Bike Tour
Agata & Cathy Piraino, Laura Sottile

Clyde's Chiari Awareness Walk, May 25
Middletown, Ohio
Karen & Anna Tannreuther

2nd Summerville Walk, May 26
Summerville, South Carolina
Laurie Yeh & Patrice Schaublin

ASAP Welcomes New Board Members



Annie resides in Pearland, TX, a suburb of Houston, with her two sons, Jacob and Ethan. She obtained her Bachelors of Business Administration, with a concentration in Accounting, from Houston Baptist University and currently is the Financial Controller for an international chemical company.

Annie's symptoms began in her early 20's but it was not until her late 30's that she was diagnosed with Chiari malformation and syringomyelia, both in the summer of 2010. Her initial diagnosis indicated she did not have Chiari but did have a substantial syrinx. She visited several neurosurgeons afterwards and each of them confirmed she did indeed have a fairly severe Chiari malformation. After observing the symptoms for a year (numbness, chronic pain, balance issues, short term memory loss, etc) Annie decided to proceed with the decompression surgery in May 2011. One year after her surgery, the tonsillar descent has retreated. A long but thin syrinx is still present.

Annie traveled to Denver to attend ASAP's annual convention in July 2011. It was the first time she'd met another Chiarian! She soon embraced the second family she found in ASAP. Through ASAP and referrals from other Chiarian's Annie offers support to others preparing for decompression surgery. She understands what it is like to feel isolated and scared when faced with the reality of this rare condition. She continues to share her own success story with others struggling with Chiari and/or syringomyelia.

In 2011, Annie joined ASAP's finance committee and in 2012 she was elected to the Board of Directors. She hopes to use her business and finance background, along with her compassion, to help ASAP continue on their goal to fulfill their mission.



Lori Tutrow lives in Greenfield, Indiana with her husband, Dan, and two children, Kaylee and Keegan. She graduated from Indiana State University and currently works as a Case Manager for adults and children with developmental disabilities.

Lori learned about ASAP in 2007 shortly after her son was diagnosed with Chiari and syringomyelia. Lori received tremendous support and informational resources from ASAP and its volunteers. In 2008, both her son and daughter had decompression surgeries. Lori has been an active volunteer with ASAP since that time to help raise awareness and important dollars for research by facilitating a local support group and hosting fundraising walks.

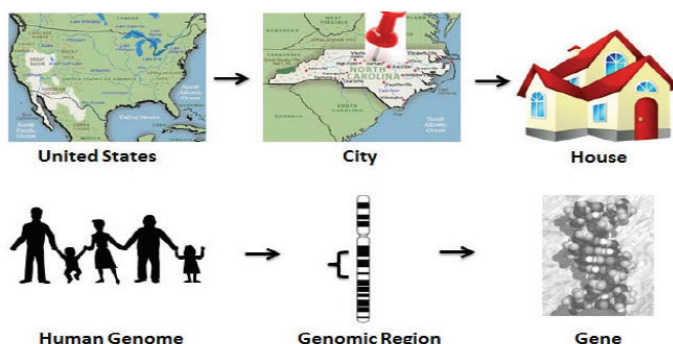
Lori is excited about joining the Board of Directors to help improve the lives of all those effected by Chiari, syringomyelia and related disorders.

Chiari Whole Genome Linkage Screen Completed

The human genome (all the DNA in a human) contains roughly 22,000 different genes. Genes can be thought of as instructions or recipes for how our bodies develop and function. Genetic disorders are caused by changes in a gene or genes, preventing the gene(s) from performing their proper function.

Whole genome linkage analysis (a genome screen) is performed in an effort to locate specific regions of the genome that may contain genes that cause or contribute to Chiari type 1 malformation (CM1). A whole genome screen is a bit like searching the United States (the genome) for a single house (a gene) without an address. A linkage screen allows us to identify the city (region) that the house is in and we use other methods to locate the house.

We recently completed a whole genome linkage screen of 375 individuals in 67 CM1 multiplex families (families with two or more members diagnosed with CM1). We found several regions of interest and have already begun investigating candidate genes (genes we think may be involved in causing CM1) within these regions. One gene of particular interest is currently being sequenced (read) in individuals diagnosed with CM1 in order to find changes within the gene that are not found or rarely found in individuals without CM1.



Chiari Study Enrollment Update

We have collected DNA samples from 1,350 individuals in 277 families from across the United States. Of these 277 families, 217 families (78%) are multiplex families, meaning there are two or more individuals diagnosed with Chiari type 1 malformation (CM1) in the family.

Thank you to all who contributed a sample since 1994 when the study began. Research toward a better understanding of the causes of CM1 would not be possible without your help. We continue to enroll additional families with two or more members diagnosed with CM1.

[Reported from: Duke Center for Human Genetics, News About Chiari Type 1 Malformation Research, Spring 2012]

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

Agata Piraino

Cathy Piraino

Blair Hagelgans

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Dawn Aftanis

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Jacquelyn Smith

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Joanne Thompson

Richard Dietz

Ashley Dietz

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L Williams Payne Crest

Linda Frissom

Melvin Bonds

Karin Maeys

Patricia Augustine

Michael Oppeau

Grissom Family

Dan & Sharon Pierce

Robert & Tina Samuelson

Michael Graynar

Stephen and Arlene Sharkey

Wayne Stokes

Guy and Marlene Petersen

ASAP Logo



The ASAP logo was designed by founder Barbara White in 1988. The emblem was created to represent both her home and her diagnosis. The center star denotes the State of Texas. The innermost design embodies the brain, spine and nervous system.

The ASAP acronym signifies the need for information, awareness and a cure as soon as possible.

Contact Information American Syringomyelia & Chiari Alliance Project

Physical Address: 300 North Green Street, Suite 412
Longview, Texas 75601

Phone: 903-236-7079

Fax: 903-757-7456

Toll-free: 800-ASAP-282 (800-272-7282)

Staff: Patricia Maxwell & Jamie Mayhan

Email: info@ASAP.org
Patricia_Maxwell@ASAP.org
Jamie_Mayhan@ASAP.org



Register for the ASAP
Chiari & Syringomyelia
Conference Today

www.ASAP.org

“Yes, I want to make a difference!”

I support the work of the American Syringomyelia and Chiari Alliance Project, Inc.

Name _____

Address _____

City _____ State _____ Zip _____

Email _____ Phone # _____

Circle your choice: E-Connections or mail delivery.

You must provide a valid email address for E-Connections.

I would like to make a tax-deductible donation to support ASAP programs & research.

☐ 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

6/2012

AWARENESS AND FUNDRAISING

Share your ideas and experiences:

Short stories may be published either in *Connections* or on our website. Submissions should be sent to the ASAP office. In addition to typed essays we also accept legible handwritten articles.

Fundraising made easy:

Interested in hosting a fundraiser to support ASAP programs and research? We are here to help and guide you to ensure a positive experience. You can also develop your own personal fundraising page to encourage family and friends to donate to ASAP.

Awareness items:

ASAP has items available to help with spreading awareness in your community. Bookmarks, postcards and brochures explain the disorders in varying detail allowing an easy and convenient way to let others know about Chiari and syringomyelia. Supply your physician's office with brochures. Hand out bookmarks to neighbors and friends. Include awareness cards when sending holiday cards. Please contact the ASAP office to request items.

SPREAD AWARENESS with an ASAP Business Card

Don't Just Tell People About CM/SM... Show Them!

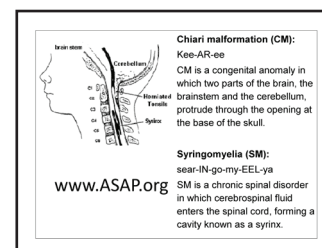
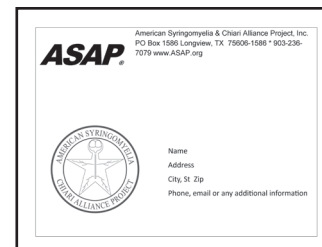
Order personalized ASAP business cards with a brief description of Chiari and syringomyelia on the back.

To place an order, include the information (i.e., name, address, phone, email) you would like on the front of the card; it may also be left blank.

20 cards - \$5.00
40 cards - \$10.00

Mail to: ASAP
PO Box 1586
Longview TX 75606

If you have questions: call 903-236-7079
or email info@ASAP.org



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 bimonthly 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

ASAP's Chiari & Syringomyelia Conference

July 18 – 21, 2012

Registration Form

Contact Information

Name: _____

Address: _____

Phone: _____ Email: _____

Additional Attendees

Please add contact information if different from above, including ages of children.

Name: _____

Name: _____

List additional attendees and contact information if needed on back.

Fees

Number

Sub-total

Adult registration by July 7 (includes banquet): _____ x \$160.00 _____

Children's registration: ages 6 - 15 (includes banquet): _____ x \$ 85.00 _____

Additional closing banquet tickets: _____ x \$ 65.00 _____

Family pack: 2 adults, 2 children (ages 6-15) _____ x \$450.00 _____

(Includes banquet)

Number of vegetarian entrees banquet: _____

Special diet request: _____

Note: By submitting this form and/or attending the conference, you agree to allow ASAP to use photographs and/or videos taken of you in ASAP's promotional materials. You understand that ASAP will not publish or record any personally identifiable information without your express written consent.

Payment Information

I want to make a donation. Scholarship Fund \$ _____ Conference Sponsor \$ _____

Payment Type: ☐ Check ☐ Credit Card Total Amount Enclosed (see sub-total above): \$ _____

Credit Card Type: ☐ Visa ☐ MasterCard ☐ Discover ☐ American Express

Cardholder Name (please print): _____

Credit Card Number: _____ Expiration Date: _____

Cardholder Signature: _____

Mail to:
ASAP Conference Registration
PO Box 1586
Longview TX 75606