

ASAP CONNECTIONS

Providing Research, Education and Support since 1988

“Pushing the Envelope”



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

Walk & Roll Brings National Awareness of Chiari and Syringomyelia

With seven walks this past year and more planned in 2012, volunteers are bringing awareness to the general public. Sharing information about the disorders with local businesses, neighbors, and friends is the first step of holding a local walk-a-thon. When news media gets involved the word spreads quickly. Those who thought they were alone in their fight soon find out there is support.

People like Laurie, Tami, Joseph, Lori, Stephen, Mary, Celeste, and Joe are stepping forward to go beyond their comfort zone to make a difference in the lives of those affected by CM and SM. If you too would like to get involved, an experienced team will guide and support you. For more information contact the ASAP office or Patrice Schaublin at Patrice_Schaublin@ASAP.org or 585-747-9651.

Join us July 18 – 21, 2012 ASAP's Chiari & Syringomyelia Conference Arlington, Virginia

ASAP's Chiari and Syringomyelia Conference will take place at the Key Bridge Marriott. This annual event draws the top specialists in the field who bring awareness to those affected by the disorders and to their colleagues. Events will start on Wednesday evening and run through Saturday night. During the four-day conference you will gain knowledge of symptoms, treatments and research. Experience a unique opportunity that will give you the power to improve your quality of life, make educated decisions about your medical care and help you take control.

ASAP has reserved a block of rooms at the Key Bridge Marriott, 1401 Lee Highway, Arlington, Virginia. A special guest room rate of \$109 has been negotiated. Attendees will be responsible for their room, tax and incidental charges. Make hotel reservations by phone or online:

- 1-800-266-9432
- www.ASAP.org/index.php/get-involved/conference/

Situated just across the Potomac River from Georgetown, the Key Bridge Marriott offers a panorama of the sights and sounds of the nation's capital. Ronald Reagan Washington National Airport, also located in Arlington, Virginia, saves you travel time to and from the conference.

Robert Keating, MD, Hosts ASAP Medical Conference



Robert Keating, MD, is the chief of neurosurgery at Children's National Medical Center. A world-renowned pediatric neurosurgeon, he is called upon by peers around the country and world to consult on best practices. He has authored two of the leading texts in the field as well as numerous research papers and abstracts. Areas of expertise include Chiari malformations, spina bifida, tethered cord, traumatic brain injuries and craniofacial anomalies. He leads one of the largest pediatric neurosurgery teams in the region and is professor of neurosurgery and pediatrics at George Washington University School of Medicine.

ASAP Profiles

Stamping Out Chiari



Nick and Gabby are only twelve and nine respectively but when they set their minds to something there is no halfway effort. After their father, Brad, passed away in 2007 due to complications associated with his Chiari diagnosis, they wanted to do something special in his memory.

The ASAP Stamp Project presented the perfect opportunity to bring awareness to their community. They created a tag line, *Stamping Out Chiari Malformation* and a poster. After talking with their principal, the flier was posted in their school newscast. They sent emails to friends and family and announced it on Facebook. Before long they were receiving stamps from scout troops, businesses and people around the world. In December they shipped five large boxes of neatly trimmed stamps to the ASAP office in Texas.

Their efforts have expanded over time. Soon after they began, they met three other families in their school community affected by Chiari. Nick and a friend, whose grandmother also has the disorder, recently completed a presentation for their science class about Chiari malformation.

Nick and Gabby are a part of a growing community of exceptional children who want to make a difference by spreading awareness. If you have a similar story that you want like to share, we would love to hear from you.

Contact information for submitting stories to ASAP *Connections* is available on page 8.

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

Outgoing Directors

Shortly after her diagnosis in 1997 Judy Hunt was invited to serve on the ASAP Board of Directors. During her tenure she served as secretary and then president for two terms after completing a partial term. For the past year, she served as immediate past president to assist the incoming president. A hands-on volunteer, Judy was instrumental in many organizational developments.

An avid supporter of ASAP founder Barbara White, Judy advocated Barbara's vision for the organization.

A few of her many accomplishments were the development of Circle of Friends, Faces and governance policies. As proofreader, she has ensured quality control for all ASAP publications. Many of the brochures and educational materials developed over the years carry her influence. She was heavily involved with the national conference working in a variety of areas. Judy brought a strong leadership that allowed ASAP to enhance its mission and goals.

She will continue to serve on the Governance Committee and play an active role in many aspects of the association.

Jo Prah and Donald Williams returned to the Board during the last year to assist with the transition. They provided new directors with the knowledge and skill from both their personal lives and past experience as Board members.

Jo served on the board from 2005-2008. She has been heavily involved with the Finance Committee helping ASAP to develop a strong financial stability. Her work experience and energetic personality provided a catalyst to energize the Board.

Don has been involved with ASAP for more than twenty years. He served on the Board from 2002-2008 and returned as president in 2011. ASAP benefits from his experiences as a corporate lawyer and businessman. Don continues to provide his services as needed.

ASAP is indebted to volunteers like Judy, Jo and Don.

A Letter

from our President



I would like to wish everyone a happy and healthy 2012. As ASAP's newly elected president, I look forward to interacting with you for the next three years. Your opinions are important to me and I value your input.

Having been involved with ASAP for 19 years, I still recall my first contact – a frightened call to the ASAP office and my conversation with Patricia Maxwell. I was never so grateful to have a listening, guiding ear on the other side of the phone.

One of the most important goals for the New Year is to increase our support and sense of community while we search for a cure. We can follow ASAP's mission "to improve the lives of persons affected by syringomyelia, Chiari malformation and related disorders while we find the cure" in many ways.

In helping to support the community, ASAP added a new points program so that the national conference could be attainable to all. The L.E.A.R.N! (Leadership, Education, Awareness, Research, Now!) Points Program fosters awareness through fundraising and gains monies which helps to continue our mission of education and support. Conference attendees hear about the latest research, gain support from others and meet world experts and pioneers who have developed new techniques. They learn coping techniques, alternative therapies, new procedures, pharmaceuticals being used, how to deal with pain, etc. New and updated ASAP programs are also introduced.

During this past year, we expanded our support programs, more than tripled our public awareness through national events, broadened our social media (Facebook, etc.), added more free webinars that were specifically requested and mailed thousands of information packets. Also, office staff and Board members personally answered hundreds of support calls.

We also completed Investigation of the Disease Progression of Pediatric Patients with Incidental Chiari I (Children's National Medical Center, Washington, DC).

This year we will pursue the Outcome Study aka Outcomes in Patients Undergoing Surgical Intervention for Chiari Type I Malformation with Syringomyelia (University of Wisconsin at Madison).

As one year ends and another begins, I thank all of you for your generous support of donations, fundraisers and time commitments. We could not do it alone. As you may know, ASAP has only two paid staff members; the rest of us are volunteers. We do our best to serve you, but know we cannot do it alone.

I extend my thanks to all Board members, volunteers and office staff (we could not do it without them). I would also like to thank those Board members whose terms have expired: Judy Hunt, Jo Prah and Don Williams. We are lucky that they will continue working on committees. They have been wonderful leaders and a great source of guidance to our community.

ASAP's year is not yet over as our fiscal year ends in May. I have challenged myself and a few others to help me reach a goal to raise \$200,000 by May. I invite you to join me in this challenge. If interested in this New Year pledge, please contact me at Patrice_Schaublin@ASAP.org or 585-747-9651. This can be done with a pledge, a fundraiser, a personal fundraising page, etc. All names will be added to the chart on our website as we grow in numbers. Join in and celebrate at our banquet in July!

Remember that you are not alone. We are here for you at ASAP. I have these disorders, too, and understand your chronic pain. I look forward to a better tomorrow for all of us.

With heartfelt thanks and gentle hugs,
Patrice Schaublin

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, etc.

Volunteers are also needed to write letters, make follow-up calls and collect items for the raffle. For more information contact the ASAP office.

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>

ASAP's L.E.A.R.N!

(Leadership, Education, Awareness, Research, Now!)
Points Program

Always seeking to remain true to our mission: to improve the lives of persons affected by syringomyelia, Chiari malformation and related disorders while we find the cure, ASAP is pleased to announce a new program. It is designed to make our national conference available to anyone interested in attending.

Hearing from past attendees and recognizing that cost has been a prohibitive factor for many attending the conference, this new program is designed to allow everyone the opportunity to participate in our conference. Over the years, ASAP's national conference has been instrumental in sharing the latest *research*, providing *education* for patients, caregivers, and professionals alike, and raising *awareness* of these disorders for thousands of people.

We are pleased to invite you to participate in this program, and urge you join us in our mission.

- This program is available to all ASAP members. Membership is free and available to anyone interested in joining our cause.
- Interested parties will set up a personal fundraising page through ASAP.org. If you want to participate and you do not have a computer or internet access, please contact our office.
- Participants will receive one point for each dollar donated to their personal fundraising page. For those participants running fundraising events (walks, dinners, etc.), points will be awarded for the NET contribution (gross less expenses). Individuals or teams participating in these events agree to donate 10% of points awarded to the event organizer. Event organizers will be responsible for submitting an accurate accounting of donations/expenses, to be verified by ASAP.
- For every 5000 points earned, participants in this program will receive a complimentary package to the ASAP national conference. This package will include tuition for the event, hotel room (one per family), and travel allowance (airfare to \$350 r/t or mileage credit of .40/mile up to \$250).
- Program will run retroactively from June 1, 2011 until May 31, 2012.

For more information visit www.ASAP.org or contact the ASAP office.

Volunteers Needed

We are looking for volunteers to assist the Board and staff. In order to continue to provide quality in what we offer we need your help.

Please consider joining one of the committees listed below. Your help is invaluable in continuing our mission. You can fill out a volunteer form on our website at www.ASAP.org/index.php/volunteer/ or contact the ASAP office. Thank you.

1. Finance Committee - supervise organization funds, work with committees on budget, monitor fiscal year budget, etc.
2. Revenue Generation Committee - plan fundraising, help develop annual budget, establish task forces, etc.
3. Research Committee - actively seek out quality biomedical research according to ASAP policy, monitor ongoing research, develop budget, etc.
4. Information Technology Committee - evaluate current technology use, develop budget for IT, make sure website is properly maintained, etc.
5. Marketing/Communication Committee - recommend marketing plans, approve public documents: newsletters, brochures, etc.
6. Awareness Committee - develop ways to get the word out about CM, SM and ASAP.
7. Conference Committee - help plan our national conference. This committee is now working on the 2012 conference to be held July 18-21 in Arlington, Virginia. If you are interested in helping please let us know ASAP.
8. Support Groups Task Force - maintain existing groups and implement new groups.
9. Lobbying - lobby local, state and federal government to further our cause.
10. Circle of Friends - send cards to members who are having surgery, had a family death, etc.
11. Kids For A Cure Club - make cards for children in the hospital, make bracelets, etc.

This is a sampling of our volunteer opportunities and a few of the things the committees do. For more information please contact the ASAP office.

Fusion

Question: What is a possible reason for a sub-optimal cranial cervical fusion that needs to be re-fused? What can be done to prevent needing a re-fusion?

Dr. Menezes: What makes a good fusion? One is indication factors such as age and how many operations the patient has had. What are we left with? This is called substrate.

What are the limitations?

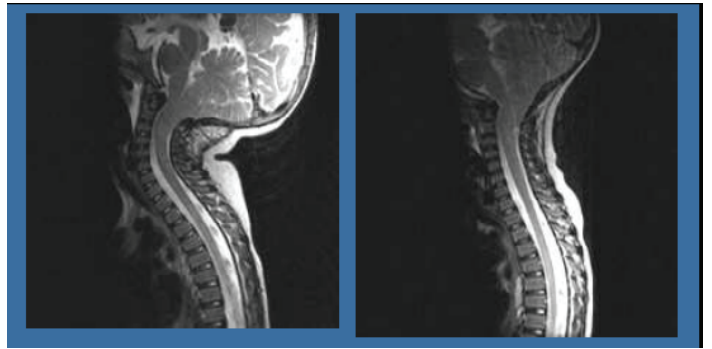
I talked about how in children below the age of 7 or 8 we use strictly bone and then after that it's different forms of instrumentation. We try to make sure the patient still maintains as much motion as possible.

What's a fusion and what should it accomplish?

To put it simply, first you must know what are you fusing. What motion takes place at that level? At the cranial cervical region it's flexion and extension; there's an arc of about 90°. Lateral neck rotation that can be 90° but the first 35-40° is between the first and second bone. Therefore if you lock the first and second bone up you're going to lose that. Do you have a choice? If the correct indication was there you don't have a choice.

The last is side to side bending. Each one of these takes place at different levels in your spine in the cranial cervical region. If that area is closed then you lose that. Permanently, if you're an adult, yes. If you're a child, you're able to make compensation at lower levels that allow you to still have motion.

Ultimately it is not metal alone. It is metal and bone if someone has used it. It is bone to bone that needs to be maintained. If that finally takes place then you've got a successful fusion then postoperative bracing doesn't need to be maintained.



How do you prevent having to go back to re-fuse? By doing it correctly in all the ways that we just talked about.

Dr. Kula: I'd just like to make a few additional comments. I agree with Dr. Menezes. Certainly if the indications aren't there initially then the symptoms might not be improved and that would be a reason for a failure. The fusion has to be done under the right circumstances.

The other issue is the inter-body fusions between the vertebral bodies are in close proximity and relatively easy. The big jump is between C1 and C2 and the occiput. Failure for that fusion to take place I think is probably there's not enough bony fusion material between that big jump and that's a long space. The other thing that we've been interested in, the issues dealing primarily with an adult population, is the presence of osteoporosis and osteopenia and a more recently recognized problem with the widespread presence of Vitamin D deficiency. In our population about 80% of patients are Vitamin D deficient, probably on a dietary basis. So we've been paying close attention to that. A successful fusion requires good bone metabolism and good bony substrate.

[Arnold Menezes, MD - Professor and Vice Chairman, Department of Neurosurgery, University of IA, Iowa City, Iowa]

Roger Kula, MD - Medical Director of the Chiari Institute, Great Neck, New York]

Urbanathlon Fundraiser

In October 2011, Jay Tysoski tackled the Men's Health Urbanathlon in Chicago, Illinois to raise awareness and funds for Chiari malformation.

An avid fitness trainer, Jay lives in Ontario, Canada with his wife Alison who was diagnosed with Chiari in 2009. Jay said, "In response to her bravery as well as others and a passion to find a cure, I have decided to train and run in the Men's Health Urbanathlon." Jay was also driven to accomplish the undertaking in memory of his mother who passed away from cancer in 2010.

The urbanathlon is not your standard road race. It is an obstacle-ridden, nine-mile road race with some infamous obstacles that include: a tire pit; a tour bus climb; jumping over taxi cabs; and running the stairs in Soldier Stadium, home to the NFL's Chicago Bears.

Jay finished in the top 13 percent out of 5,000 participants. ASAP was proudly represented on the back of his t-shirt.

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

Alicia Roden

Allen Alberson

John Myseros, MD

Rofman Family

Danielle

Anthony Cannavo, Jr.

Heidi Diven

Arnold & Nancy Manseth

Michael Kirlin

Dennis & Diane Kirlin

Barbara Gemmell

Jim & Marcia Kirlin

Gail Agalotis

Gwen Kirlin

Tony & Carol Smith

Grace Taylor

Bishop Donahue High School

Holly & Hope Patterson

Stuart & Sara Patterson

Eva Nagymihaly

Lawrence Moore

Cynthia Moore

Alexis Grant

Mary Young

Christa Truchan

Guy Petersen

Doug & Martha Leerssen

Lyndon & Teresa Larson

Vince & Ruth Ann Mocini

Mike & Mary Sutherland

Jim & Victoria Sutherland

Dick & Lori Sutherland

Dan & Nancy Sutherland

Patricia O'Connor

Bill & Juliette Piercy

Timothy & Barbara Sutherland

Steve Cole

Thomas & Evelyn White

Jacqueline Babitts

Steven & Rosa Babitts

Claver Family

Robert Claver

In Honor of

Donor

Rephia Mitchell

Bobby Mitchell

Claire Mockler

Rita Fitzpatrick

Marianne Mockler

Pamela Dorsey

Cybil Martin

Brad Laventure

Roy L Spring

Sandra Forsberg

Daniel Forsberg

Michaela Miranto

Mrs. Beth McDonough, MPAC

Kimberly & Stephanie McFarland

Phil & Elizabeth McFarland Family

Christopher Spagnuolo

George Collins

Gordon & Lindy Shafer

Melissa Preece

Peg Curtacci

Family & Friends

Blair Hagelgans

Holly Fokin

Michael Jagoe

Heidi Jagoe

Marsha Stein

Jerry Stein

Alison Tysoski

Jay Tysoski

April Roy

Joan Vileno

Lynn Marotta

Eric Marotta

Kathryn Wilson

Nancy Wilson

Lee Miller

Rick Ellsworth

Jane Wortas Maze

Lauren Mitchell

Fellow CM/SM peers

Lisa Simmons

In Memory of

Donor

Maynard Guss

David Kalish

Matthew Volkay

Franklin Pediatrics

Preston Moore

John Mebane

Gerald Lyman

Mrs. Gerald Lyman

Cecilia Banyai

David Otterstatter

John Weldele

Zoe Brink

Guy & Marlene Petersen

Brenda VanLaarhoven

Greg & Jill Moe

Bob Mohar

Janet Maki

Jill Maki

Bernie Miller

Lee Miller

Alexa

Lisa Simmons

Megan Reynolds

Mairead Reynolds

Wilbur C DuBois III

Robert DuBois

Kirk Bailey

Thelma Banks

Mary Emanuel

Virginia Jennings

Theresa Kenworthy

Patsy Bailey

Robert Carlson

Shelley Norris

Nancy Maraccini

Shelley Norris

Kathy Hall

Eddie Cohen

Muriel Greenspan

Stephen & Arlene Sharkey

Theodore Smolenski, Sr.

William Schultz

ASAP Logo



The ASAP logo was designed by founder Barbara White in 1988. The emblem was designed 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 signified 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

We Would Love to Hear From You!

After the last newsletter a few of our members returned their "I want to make a difference!" form to let us know they are receiving their newsletters. But we still need to hear from thousands more. We want to make sure we do not remove anyone fighting the battle against Chiari and/ or syringomyelia from our database.

We are not asking for a donation. We just want to hear from you! Just fill in the contact information on the form on page 7 and return to ASAP. As always we welcome your comments, suggestions and updates.

If you would like to help reduce printing and mailing cost, please consider signing up for E-Connections, same newsletter, faster delivery.

“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

1/2012

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!

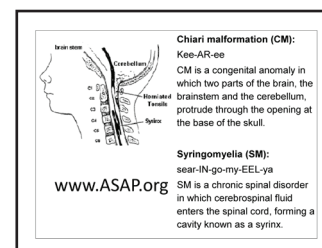
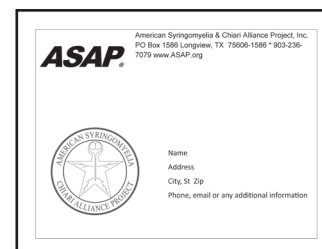
Order personalized ASAP business cards with a brief description of Chiari and syringomyelia on the back.

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.

ASAP Board of Directors

Patrice Schaublin, President
Bill Hagelgans, Treasurer
Karen McFarland, Secretary
Barbara Banick
John Caemmerer
Kerry Chu
John Heiss, MD
Robert Keating, MD
Erol Veznedaroglu, MD



ASAP Medical Advisory Board

John Heiss, MD
NIH/NINDS
Ann Berger, MD
National Institutes of Health
Bermans Iskandar, MD
University of Wisconsin-Madison
John Jane, Jr, MD
University of Virginia
Robert Keating, MD
Children's National Medical Center
Roger Kula, MD
North Shore Univ Hospital
Arnold Menezes, MD
Univ Iowa Hospitals & Clinics
John Oro', MD
Neurosurgery Center of Colorado

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