

# Connections

*"To Improve the Lives ... While We Find the Cure"*



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American  
Syringomyelia  
Alliance  
Project, Inc.

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## ASAP's Chiari / Syringomyelia Conference

### Quest for Understanding

The ASAP Board of Directors and Dr Bermans J Iskandar, host of the ASAP 21st annual conference, invite you to start making plans now to attend. The Sheraton Madison Hotel has been selected to accommodate this year's meeting. Please register early to assist us with plans for meeting room space and other activities.

### Our Host:

Bermans Iskandar, MD, is Director of Pediatric Neurosurgery and Associate Professor of Neurosurgery and Pediatrics at the University of Wisconsin Hospital and Clinics and the American Family Children's Hospital.

Dr Iskandar started his college studies majoring in Biology at the American University of Beirut. After receiving his college degree in Cell and Molecular Biology in 1985 from the California State University in Northridge, he received his medical degree in 1989 from the University of Pennsylvania School of Medicine. Dr Iskandar completed his neurosurgery residency at Duke University Medical Center in 1996. He followed his residency with a Fellowship in Pediatric Neurosurgery at Children's Hospital, Birmingham, Alabama. In 1997, he became Assistant Professor of Neurosurgery and Pediatrics at UW and in 2003 Associate Professor.

The author of over 70 publications, one book and numerous presentations/papers, Dr Iskandar has focused extensively on Chiari malformation, syringomyelia, and tethered cord in both adult and pediatric patients. A previous recipient of an ASAP research grant, he has been an ASAP Medical Alliance member since 2004 and a speaker at several ASAP conferences.

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## Top Ten Reasons Why You Should Attend the ASAP Conference

1. Hear the top physicians and specialists in the field of Chiari and syringomyelia.
2. Get answers to the questions everyone avoids!
3. Share coping strategies with people who face the same challenges as you.
4. Encounter charming ethnic enclaves, fascinating artistic communities and some of the state's most interesting tourist attractions during your stay in Madison.
5. Meet face-to-face with the people you've been chatting with online!
6. Interact with the physician panel during multiple *Question and Answer* sessions.
7. Special activities - including a pizza lunch - for kids ages 6 - 15.
8. Participate in workshops designed to address everyday issues people with Chiari / syringomyelia face.
9. Learn more about your organization and what you can do to help promote awareness.
10. Get inspired by cutting-edge research.

Bonus, discover you are not alone!

**ASAP's  
Chiari / Syringomyelia  
Conference  
Madison, WI  
July 15 - 18, 2009**

# ASAP

## Contact Us

### **ASAP**

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### **Save the Date**

**ASAP's Chiari / Syringomyelia Conference  
Quest for Understanding  
July 15 - 18, 2009**

**Sheraton Madison Hotel  
Madison, Wisconsin**

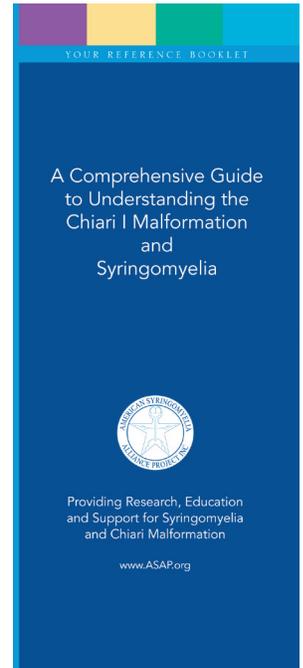
**Please Note:** Articles in this newsletter are not intended as a substitute for medical advice and do not necessarily represent the viewpoints of the editor, Medical Advisory Board or Board of Directors. Please contact your doctor before engaging in any new therapy or medication.

### **New ASAP Brochure Now Available**

ASAP has compiled the most up-to-date information in our newest 22-page booklet entitled "*A Comprehensive Guide to Understanding the Chiari I Malformation and Syringomyelia.*"

This free pamphlet is provided in all of our information packets, as well as in physician offices across the country in the hopes that every newly diagnosed patient will have access to accurate, up-to-date information as well as a place to find support.

Contact the office if you would like a copy.



### **Save Your Canceled Postage Stamps**

ASAP members began collecting canceled postage stamps as a fundraiser during the early 90s. They have enlisted the aid of local businesses, churches, social clubs, family and friends. The number of stamps donated has dramatically increased over the years.

This fundraising project is a favorite of many ASAP members. Although commemorative stamps such as the 'State' series bring in more money, the everyday 'flag' stamps are also of value. Since 1999, we have raised over \$6,000 through this project. So the next time you start to toss that envelope, take a few minutes to help ASAP.

Cut stamp from envelope leaving a 1/4 inch border. They must be in good condition; damaged stamps are not usable.

**Please send stamps to:**  
Maynard Guss  
9593 NW 26th Place  
Sunrise FL 33322-2738



## Letter from our President

by Judy Hunt



With the end of our 20th year celebration and the arrival of spring, I have been thinking about our beginnings. When Barbara White was diagnosed with syringomyelia, resource organizations specific to the disorder did not exist nor did support groups. Syringomyelia was considered so rare, most thought starting an organization dedicated to those affected by the disorder an impossible dream. Not Barbara. It was worth whatever it took if she could help one other person.

This was a time before personal computers and the Internet. Barbara made endless calls to gather the limited amount of published information available. NORD and the Gazette International Networking Institute connected her with a few other people with SM. In addition to supporting others with her condition, Barbara wanted to share the information she found. With the help of some empathetic friends and her husband, Don, she took a leap of faith and started ASAP.

From those humble beginnings, ASAP has evolved into an internationally recognized non-profit organization with a strong financial record. Thanks to the foresight and preservation of Barbara and Don White, ASAP is the leading organization for those affected by syringomyelia and Chiari malformation.

Early programs provided by the organization have developed and grown over two decades from a handwritten list of networkers and a two-page newsletter typed on a manual typewriter. Newly diagnosed individuals can now find the latest information on our award-winning web site, attend yearly conferences where specialists share their knowledge and expertise, and support each other through our many networking groups.

As we continue to reach more and more people, ASAP sends hundreds of information packages each month, just for the asking.

So, this must cost some money, right? Where does ASAP get the funds for the materials, the postage, the support staff and the printing cost?

Let's recall ASAP's mission "*to improve the lives of persons affected by syringomyelia, Chiari malformation and related disorders while we find the cure.*" We often emphasize the second half of our mission, *while we find the cure*, the research aspect, but for this letter, I will concentrate on the first half, *to improve the lives of persons affected by syringomyelia, Chiari malformation and related disorders ...*

In 2003 the Barbara White Memorial Fund was initiated to help cover the cost of operations. Its success has allowed

us to continue established program and develop new ones. For example, Outreach, our newest brainchild, provides telephone support groups, webinars and educational teleconferences.

As you read this article, you should have already received your drive letter. Maybe you have already returned your donation. *Thank you!* Member participation is crucial to the success of the drive. Please give generously. If you are unable to contribute at this time, consider asking a family member or friend to give a gift in your honor. Each of us can make a difference.

We are excited that Michael Scarpone is back. He is developing a comprehensive financial plan that will cultivate ASAP's growth and foster new programs for our organization. Integral to that plan is the Barbara White Memorial Fund, an important financial resource for ASAP. It enables us to stand and work together on behalf of the rapidly growing numbers of men, women and children who are diagnosed each year with syringomyelia and Chiari malformation.

ASAP's Board of Directors is a composition of dedicated volunteers who take the integrity of this organization seriously. Our promise to you is that we will do everything within our power to insure that Barbara's dream and hard work will continue for as long as the need demands. But we cannot do it without your help. Thank you.



### Conference Scholarship

The Board of Directors and Conference Committee are proud to announce that we are once again offering a conference scholarship program this year. The scholarship helps defray some of the attendee's hotel cost in addition to waiving the registration fee for qualified applicants. A limited number of these scholarships are available and will be awarded on a first-come first-served basis to qualified applicants. If you are interested in applying for the scholarship, you should contact the ASAP office to request the guidelines and application. Deadline for application is May 31.

The scholarship fund is supplemented by donations from our membership. You can make it possible for those with limited incomes to attend this educational event and learn more about these disorders. To make a donation to the scholarship fund and help us increase the number of scholarships given each year, send your donation to the ASAP office in Longview. Please include a note that the donation is for the conference scholarship fund or use the registration form inserted in this newsletter.

## Ask The Experts

### Question and Answer

**Question:** Is there a difference between hydromyelia and syringomyelia?

**Dr Oró:** The terminology is a little bit confused and there are advocates one way or the other. In general hydromyelia was more often used for a wide dilation of the central spinal canal. Syringomyelia is the disruption of cerebral spinal fluid into the actual tissues themselves. We can call them all the same thing, realizing there may be different etiologies. I don't find hydromyelia that useful myself. The other term I will mention that is useful is a persistent central canal which gets confused sometimes with syringomyelia and it's very difficult to sort out. These are small thin cavities that are called fusiform. They taper at the top and the bottom. Some of us may have those naturally just because our central spinal canal never closed and it is not a true syrinx and it's not going to grow. I agree there's some debate when it gets to 5mm and 6mm cross section diameter, but if it's a thin fluid cavity in the cord itself some people get really frightened that they've all of a sudden now been diagnosed with syringomyelia. That may be what's called a persistent central canal that was there in all of us in fetal life. So I do like that term.

**Question:** Can you find Chiari with a regular MRI that's looking for MS? My son has terrible headaches and my granddaughter has terrible headaches. I've had migraines since I was a child. But basically the MRIs we get are the kind looking for MS. Would that show Chiari?

**Dr Brockmeyer:** Sure, it's an incidentally found condition in a percentage of cases, but you have to recognize it.

**Dr Menezes:** It's pretty evident on a MRI.

**Question:** In Dr. Oró's talk yesterday you were talking about syrinxes possibly being the remains of a tumor. Can you tell us about that?

The other question I have is what is happening to educate neurologists and neurosurgeons more about CM and SM. It is a real problem in my area. No one knows about it so I have to go elsewhere to try and find a doctor to treat me.

**Dr Oró:** As far as the syringomyelia just keep in mind that there are other causes. A high number of patients with a syrinx may have flow blocks due to hindbrain herniation or Chiari malformation that you've heard about. There are some other conditions within the spinal canal that can block flow that can lead to syringomyelia, those are quite rare.

Trauma is actually a common cause of syringomyelia. You've scarred the spinal canal and I think we'll hear more about that later on.

In a smaller group of people the fluid cavity could be due to fluid secreted by a tumor within the spinal cord itself. That's fortunately less common. Those people need a contrast scan that will light up the tumor. So that's a very different condition and has very different treatments; you've got to deal with the tumor to get rid of the cyst.

And then there are simply some syrinxes that we don't know where they come from.

*Only by working together, getting involved in whatever way you want can we eventually raise that blind spot.*

This question that you also raise is what do we do to educate the medical community. It's very difficult. I committed at a previous meeting that I would attempt to launch a blog talking to the

medical community, maybe on a weekly basis to raise some of these issues and spoon feed them on a reference list that if they have somebody with hearing problems it's there. We know that hearing can be affected, et cetera.

I think that the visibility of something like that is actually quite low but other than meetings, other than organizations championing, other than the federal government coming down and saying 'Hey we recognize that we've ignored this disorder,' this is a medical blind spot is the way I look at it nowadays. It's a blind spot that we've had. Only by working together, getting involved in whatever way you want can we eventually raise that blind spot.

**Question:** I was diagnosed with carpal tunnel. Then I found out I had CM and MS. My concern is that I live in North Carolina and the last neurosurgeon I spoke with in 2007 had provided me with the results of the MRI and indicated it was still elective surgery. He had suggested the bony operation. Some of the terminology that you use is really over my head.

My question is now what? The doctors I've seen in North Carolina are unfamiliar, so when and what stage do you know to have the operation? I don't have the headaches. I don't have a lot of the symptoms that I've heard so far.

**Dr Brockmeyer:** I think that obviously you're in a tough spot and we face this issue in Utah where people come from miles around to see us at the Children's Hospital. You need to find an experienced surgeon at a fairly high volume center, somebody who's used to seeing these kinds of problems and try to get an honest opinion. Sounds like you saw somebody, whether you trusted that opinion or not is up to you but getting to see somebody who this is routine for them, they see the issues, they see the complications and sees the whole picture, I think that's really important, but that's easier said than done. I can't fix that. I think that would be potentially a solution for you.

## Ask The Experts continued

**Dr Menezes:** You're in a pretty good location, it's just that you haven't matched up with somebody who's got the expertise. I could name people at Chapel Hill, Duke, Charlotte, who would be able to help you.

**Question:** I have a question about Chiari and tethered cord. It seems within the last few years we're hearing more about tethered cord and Chiari and I guess saying the chicken or the egg, which one came first? What are your thoughts on that, Dr. Oró? When you screen patients for Chiari and tethered cord, do you do the same? How do you proceed with that when the symptoms are so closely related now, or they seem to be?

**Dr Oró:** We can start by saying that Chiari malformation has been treated probably since about the 1950s. The treatment for over 50 years has been posterior fossa decompression. There are different variations and fortunately a relatively good outcome for people with posterior fossa decompression and for some a life changing outcome actually from what they were suffering before. So for many people it seems like posterior fossa decompression is the right approach.

The question is could tethered cord play a role. We're beginning to look at that cautiously at our center. My own impression is that probably yes for some people with Chiari, the filum issues probably play a role but identifying those people, knowing how those people are going to do long term – we don't know. Other than a few individual cases.

I will also say we're looking at syringomyelia without other etiology, without other causes, no Chiari. Syringomyelia that seems to be symptomatic and significant. We are releasing the cord in those people with a minimally invasive procedure to section that band. What I would say is the results, and the numbers are small and the results I would say are encouraging but they're not 100%.

If you're undergoing a release of the filum for Chiari and syringomyelia, know that you're going to be in a new wave of patients. Hopefully this meeting itself in a few years will be able to give us some answers and some guidance.

[Transcript from the 2008 ASAP Conference, Arlington, VA.

John J. Oró, MD, is a neurosurgeon experienced in the treatment of Chiari I malformation. In 2005, he founded The Chiari Treatment Center in Aurora, Colorado.

Douglas Brockmeyer, MD, is the Professor of Neurosurgery at the University of Utah in Salt Lake City,

Arnold Menezes, MD, is Professor and Vice Chair of the Department of Neurosurgery at the University of Iowa in Iowa City.]

## Conference Auction and Raffle

It's that time of the year again and we are gearing up for the annual conference. We need your help to make our auction a success. Members donate some items while others are donated by local companies. Some of the handmade arts and crafts are chosen for the highly spirited auction.

The auction and raffle need our support to be a success! Please consider making a donation. If you are not attending the conference you can ship your donation to the ASAP office in Longview. (See mailing address on page 2.)

### Suggestions:

- Homemade Gifts (Afghans, Quilts, Cards, Paintings, etc)
- Theme Baskets (Italian, Pets, Teens, Beach, Garden, etc)
- DVDs/CDs, Electronics
- Candles/Lotions/etc.
- Children's Games/Toys
- Gift Cards
- Jewelry
- Re-gifts!
- Timeshares
- Ask local businesses for donations

### *Don't Forget!*

Send your items to our Longview office by June 30 or bring them to the conference



If you are interested in helping secure items or would like to donate to the event, contact Patrice Schaublin at 585-747-9651 or [Patrice\\_Schaublin@ASAP.org](mailto:Patrice_Schaublin@ASAP.org)

## Member Profile

by Lisa Vassallo

After a car accident in 1995 I was told I had whiplash, sent home to rest with muscle relaxers and scheduled for a few sessions of physical therapy. Over the years my neck pain would get worse and then fan out to my shoulder and back. With repeated trips to my orthopedic doctor my only advice was that arthritis had set in and to treat myself to a massage once a month.



As the years went by I started experiencing tingling and numbness in my fingers and toes and decided in 2007 to seek a second opinion. Working as a paraprofessional within our local school system my time was limited, so I waited until June to see another orthopedic doctor. After giving him my history and symptoms he ordered a cervical MRI. When the results came back he informed me I had some bone abnormalities and that this was out of his field, so he sent me to a neurosurgeon.

The first neurosurgeon commented that my brain was lying low and he would prefer for me to see someone else in the group and sent me for more x-rays. By now I am starting to get really scared by what they were not telling me. As soon as I got home I started researching anything I could find on the brain and the symptoms I was having.

At first I thought maybe this was MS, but then I remembered the comment the doctor made about my brain lying low. The more I researched, Chiari malformation kept coming up and the more I read I knew this is what I have! Other symptoms were listed that I had but never thought to relate to my neck pain and numbness. I remember telling my husband, I think I found what I have. He told me to stop reading the Internet because I was only getting myself worked up. I decided to call my PCP doctor because I always have everything sent to him. I asked if he could read me what the radiologist wrote on the report from the MRI. Sure enough 9mm cerebellum tonsils descended indicating Chiari malformation. Even though I suspected this, it was still hard to hear it confirmed.

I researched Chiari malformation before my next visit to the neurosurgeon. This time I had my husband come with me knowing it was serious. When the doctor came in he told us that he read that most of my pain is coming from my neck in the area of where my C3 and C4 vertebra were fused together from birth. He said arthritis had set in and that the bones rubbing together will cause pain. He recommended arthritis medicine, but never mentioned Chiari. So when I asked about the Chiari he said that it was insignificant because 9mm wasn't much and if it was causing symptoms they would be blurred vision and balance issues and nothing more. When I questioned him more he became agitated and

stated he was only here to deal with the matter at hand, my neck pain. It was at this very moment I knew that I had to become my own advocate.

For the next few weeks I read and researched all I could on Chiari. It was then I discovered ASAP and began reading story after story with the same issues from countless others with doctors dismissing Chiari as not a

big deal. The more I read and researched the angrier I became with the struggles we all had to go through within the medical field.

I made the decision to go to a specialist in New York. Even this became a struggle with my insurance provider not covering out of network doctors. I didn't give up though and on my third appeal I won. But I still thought about all the other people that might be out there still struggling for answers. I knew something had to be done and that is when I called my State Representative to ask him to help me get a proclamation for Chiari Awareness month. A few weeks later I received a proclamation for the month of August from the Governor of Connecticut.

Now it was up to me to promote this. I called my local newspaper and had an article about the proclamation submitted. From that article another newspaper called and did an interview about Chiari. I also posted on ASAP to see if there were others in my state that would like to help me promote awareness. I received quite a few responses from the site and from people who had read the articles. I then realized there were a lot of us in Connecticut that really needed support too, so I started a support group. The group has been featured on a local news station to discuss Chiari, and our struggle to promote awareness.

I now have my State Representative helping us again to make September the permanent Chiari Awareness month in Connecticut. We wanted to be in sync with other states' Chiari month. We are also helping members in other states that are trying to get a national Chiari month. Currently we are working on a web site. I have also been asked to represent Chiari on a rare disease committee that has formed at our capital in Hartford. Every chance I get I try to make Chiari known to others and especially the medical field. I bring pamphlets of information to all my doctor's appointments and leave them with this literature. It is amazing how many doctors are not familiar with Chiari and only had a short mention of it in medical school.

If we all take part to help spread awareness maybe those countless stories will be stories of the past.

## Awareness and Fundraising

### Dodging for a Cause

by Emily Jarrett

At Lee's Summit North High School (LSN), the crowd was going wild. On the gym floor, the players ran, ducked, lunged and fought hard against each other, battling for the championship title. In the stands, friends and parents cheered on their favorite teammates, shouting encouragements and a little trash talking to the other players.

The teams weren't evenly matched, the uniforms weren't the same and the players ranged from 14 to 18 years old. One LSN student broke his nose during the game and many others limped off the court to the bench.

This wasn't a basketball game gone wrong; this was dodgeball.

"Dodgeball for Chiari" was the end of a semester-long project for DECA, an association of high school and college students studying marketing, management and entrepreneurship in business. Each semester, the DECA class at LSN divide into groups and create community service projects.

"Our group wanted to do something different," said Amanda Townend, a junior at LSN. "In the past DECA has done just about every sporting event, but no one had ever done dodgeball."

Townend and her group mates, Aleesha Ford and Pricilla Tulli, both seniors at LSN, said they had been working on "Dodgeball for Chiari" since the beginning of the semester.

The tournament pitted 10 teams against one another vying for the championship spot and bragging rights. Each team's members paid a \$20 entrance fee and prizes were raffled off to players and spectators.

"We knew all the money we made would be donated to a charity of our choice," Townend said. "And we knew we wanted to donate it to ASAP (the American Syringomyelia Alliance Project) because of Emily."

Emily is Emily Teasley, the older sister of Townend's classmate Zack Teasley. Emily was diagnosed with syringomyelia in December of 2007, tethered cord syndrome in May of 2008 and Chiari malformation in September of 2008.

In September, Emily underwent surgery to correct where her spinal cord was abnormally attached to her spine.

"I feel really good now," Emily said. "Before, my right foot was numb and I had trouble walking, but now it's better."

Emily said she was surprised when she heard about the dodgeball game, but "I thought it was really sweet they'd do that for a charity that no one has really heard of."

"I've known Emily and Zack forever, they're my neighbors," Townend said. "So when we had to pick a charity, we thought it should be ASAP. Chiari is a really rare disease and we wanted to get the message out about it."

Townend estimated her group raised \$1,000 through the game and raffle tickets to donate to ASAP.

"I'm glad so many people were interested in the tournament and bought raffle tickets," said Ford.

The group said they went to area businesses and asked them to donate services or coupons as prizes. Prizes ranged from a complementary treatment at Chiropractic Therapy, a free haircut at Salon Nuveo, microderm treatments at American Laser Center, a month-long free membership at the local YMCA and gift certificates to Platinum Tan, Benchwarmer's and Minsky's, to name a few.

"I know (Zack) Teasley but my mom was actually the one who told me about the game," said Daniel Fuchs, a LSN senior who was a member of Team Tank. "I thought it was for a good cause, to help out a charity and have fun too."

The Sunshine Boys, which included Zack Teasley as a member, went on to beat out the other dodgeball teams and were named champions.

"I think everyone had a great time tonight," Townend said. "The teams had fun but the most important thing was that it raised not only money but also awareness for Chiari."

[Editor's Note: Emily Jarrett is an education reporter for the Lee Summit Journal.]

The Facebook logo, consisting of the word "facebook" in white lowercase letters on a blue rectangular background.

New friends are waiting! Find ASAP on Facebook under both Causes and Groups and meet other members. When you become a member, don't forget to invite your friends to join by using the "Invite people to join" link.

## Things To Do and See in Madison

What the heck do you do in Madison?

Every day, visitors are discovering all of the wonderful attractions that Madison has to offer. From the family-friendly Henry Vilas Zoo and Madison Children's Museum to the historic University of Wisconsin - Madison campus to the natural beauty of Olbrich Botanical Gardens and the UW-Arboretum, there is something for everyone. But that's only part of the picture!

Venture out in any direction from Madison and, amid the rolling green landscapes, you'll encounter charming ethnic enclaves, fascinating artistic communities and some of the state's most interesting tourist attractions.

**The American Players Theater:** Spring Green: shows July 17, at 6 pm Furthermore...and Then and Fat Jack's Barbecue on July 19 at 4 pm

**Farmers' Market:** the USA's biggest farmers' market

**Memorial Union:** the student union on Lake Mendota: Ice cream, brats, boats, and nightly live music.

**State Street:** The heart of downtown Madison, a unique place alive with activity every day of the week

**Veterans Museum:** (Capitol Square): Information on Wisconsin veterans

**Maxwell Street Days:** Madison's oldest and largest sidewalk sale event

**Cave of the Mounds:** (30-minute drive): Magnificent caverns, with their jewel-like stalactites and stalagmites

**Olbrich Gardens:** (10-15 minute drive): An oasis of beauty on the shores of Lake Monona

**Harry Villas Zoo:** A wide variety of exciting attractions, including animal exhibits, picnic areas and playgrounds in the park, swimming and more

**Washburn Observatory:** Come see the stars

**Monona Terrace:** Designed by Frank Lloyd and built in the late 1990's

Other attractions you will want to check out: Chazen Museum, Dane County Fair, Tour of the Capitol, Museum of Modern Art, The Overture Center, and the Wednesday evening concert on the square

[For more information on things to see and do in Madison visit [www.visitmadison.com](http://www.visitmadison.com) or contact the Madison visitor's bureau toll-free 800-373-6376]

## Meet the Medical Advisory Board John Heiss, MD



John D Heiss, MD, is Head of the Clinical Unit of the Surgical Neurology Branch, National Institute of Neurological Diseases and Stroke (NINDS), National Institutes of Health (NIH), in Bethesda, Maryland. Board certified in neurological surgery, he performs neurosurgical procedures for adult patients with syringomyelia who are participating in clinical research protocols at the NIH. He has special expertise in brain tumor surgery in the Intraoperative MRI Suite at the NIH. He also performs surgery for patients with the type of epilepsy that cannot be controlled by medication. His surgery and clinical research are performed at the Clinical Research Center, a seven-story hospital on the main campus of the National Institutes of Health. His research is supported by the Intramural Research Program at the NIH.

Dr Heiss spent his childhood in St. Clair, Michigan, a small town 50 miles north of Detroit where he attended public school. He received a degree in Biomedical Sciences in 1977 and his medical degree in 1980 from the University of Michigan. Seven years later, his neurosurgery residency at the University of Cincinnati College of Medicine was completed. As an Assistant Clinical Professor of Neurosurgery at the University of Cincinnati, he was also a member of the Mayfield Neurological Institute.

In 1991 Dr Heiss joined the National Institutes of Health staff. A year later he and his mentor, Edward Oldfield, MD designed a clinical study to better understand the mechanism involved in the development of syringomyelia in patients with Chiari I malformation. This study resulted in a series of papers that helped to explain the process. He subsequently developed research protocols to study syringomyelia not associated with the Chiari I malformation and to study the genetics of Chiari I malformation. Dr. Heiss joined the Institutional Review Board (IRB) of the NINDS in 1998 and became Vice-Chairman in 2002. In 2007, Dr Heiss became Head of the Clinical Unit of the Surgical Neurology Branch. He also has the rank of Clinical Professor of Neurosurgery at George Washington University Medical School.

A frequent speaker at ASAP conferences, Dr Heiss has served on the ASAP Medical Advisory Board since 2006. He hosted the ASAP 20th Annual Conference, serves as Chair of the Research Committee and holds a seat on the ASAP Board of Directors.

**Don't miss important updates**

**Add ASAP.org to your safe sender list**

## FDA Warns About Risk of Wearing Medicated Patches During MRIs

Certain adhesive patches that deliver medication through the skin have been found to be a risk to patient safety. The patches, if worn while undergoing magnetic resonance imaging scans or MRIs, can cause skin burns, says the U.S. Food and Drug Administration.

The patches of concern include both brand name and generic products and patches purchased over the counter without a prescription.

The FDA issued the Public Health Advisory on transdermal drug patches after learning that a warning was missing on some patches that contain aluminum or other metals in their non-adhesive backing. The backing is the portion of the patch not in direct contact with the skin. While not attracted to the magnetic field of the MRI, the metal can conduct electricity, generating heat which can cause burns. Users of the patches reported receiving skin burns at their patch site when wearing the patch during an MRI scan.

“The risk of using a metallic patch during an MRI has been well-established, but the FDA recently discovered that not all manufacturers include a safety warning with their patches,” said Janet Woodcock, M.D., director of the FDA’s Center for Drug Evaluation and Research. “Because the metal in these patches may not be visible and the product labeling may not disclose the presence of metal, patients should tell both their health care professional and their MRI facility that they wear a medicated adhesive patch.”

The FDA was alerted to the missing MRI warning on Teva Pharmaceutical’s fentanyl transdermal system in January. The FDA investigated and found that a similar warning was also missing on a variety of skin, or transdermal, patches delivering medications.

The FDA is reviewing the labeling and composition of all medicated patches to ensure that those made with materials containing metal provide a warning to patients undergoing an MRI and will alert the public when this information has been added. Until then, the agency recommends that people wearing medicated skin patches, including nicotine patches, talk to a health care professional about their patch at the time they receive their MRI referral. The professional will advise the patient about when to remove the patch before the procedure and about replacing it after the procedure.

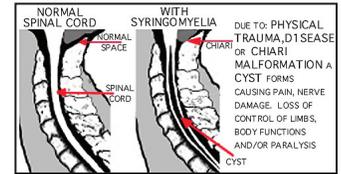
Patients should also tell their MRI facility that they are using a patch when they call to schedule their appointment and should repeat this information when filling out their health history questionnaire after arriving for their appointment.

[U S Food and Drug Administration press release issued March 5, 2009]

## Spread Awareness with an ASAP Business Card

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

Jerry Lindner, an ASAP member, designed the cards. He prints them on his home computer and makes them available to others for a small fee to cover the cost of stock and ink.



To place an order, include the information you would like on the front of the card; it may also be left blank. Enclose a self-addressed stamped (one stamp) envelope with \$3.00 for 20 cards. Enclose a self-addressed stamped (two stamps) envelope with \$6.00 for 40 cards.

**Mail to:** Jerry Lindner  
5855 Muir St.  
Simi Valley, CA 93063

If you have questions: call 805-581-1344, or Email [jlindner99@sbcglobal.net](mailto:jlindner99@sbcglobal.net)



## Make the Most of Medical Appointments

**Speak Up:** Let your doctor know what is wrong.

**Prepare:** Make a list of symptoms and questions you have for the doctor. Take time before your visit to determine what you need to tell your doctor.

**Bring a health buddy:** Have a friend or family member go with you. They can help you to remember what the doctor says.

**Know the goal:** Ask what is expected to be accomplished and when.

**Plan ahead:** Carry a list of current medications and dosage, medical conditions and allergies with you. This information could be extremely important if you are involved in an accident.

Remember ASAP...

## When It's Time to Remember Loved Ones

Our appreciation to everyone who made a recent donation to ASAP on behalf of their friends / loved ones.

### In Honor of

Donor  
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> Learn more at:  
[www.iGive.com/SM](http://www.iGive.com/SM)

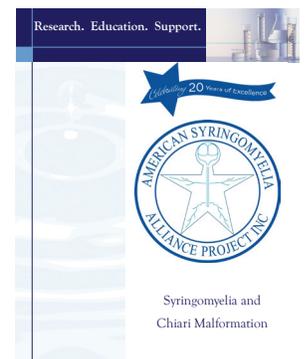
## Order Your Copy Today

The Syringomyelia and Chiari Malformation resource book contains 164 pages of professionally transcribed presentations from the 2008 Annual Medical Conference.

With 18 presentations and five Question and Answer sessions, this spiral bound manuscript covers everything from diagnosis to research. The full color slides enhance each chapter helping the reader to visualize the speaker's lecture.

The beauty of this resource is that you can pour through all the information that is pertinent at any given time, and then days, weeks or perhaps even months later, you may seek completely different information and find it.

Order your copy today from our ASAP online store or directly from the ASAP office for just \$70 which includes shipping and handling.



You can honor a loved one or a friend through a gift to ASAP. An acknowledgement card will be sent in your name to the person honored or the family of a deceased friend or loved one for a donation of \$5 or more. When making a gift, please send your name and address as well as the name and address of the person or family to whom the card should be sent. Remember to include the name of the individual you wish to honor or remember.

## ASAP Conference

continued from page 1

### Program:

Chiari malformation and syringomyelia experts are gearing up to present the latest treatment options, alternatives in symptom management, and advancements in research. Ambassadors will be available to offer support, guidance and encouragement during the four-day event. With multiple opportunities to speak with the presenters, ask questions and learn from specialists, the conference provides an opportunity to the newly diagnosed and veteran alike that is not available elsewhere.

A full preliminary schedule of speakers will be posted on our web site and appear in an upcoming issue of *ASAP Connections*. Workshops for parents, caregivers, spouses, teens and adults will be new to the program this year. Back by popular demand, Kids For A Cure Club events will take place daily.

Ever wonder what there is to do in Madison, Wisconsin? Come find out! We've given you a headstart with *Things to do and see in Madison* on page 8. So plan a few extra days to explore this capital city with scenic areas, historic places, and fine museums.

### Registration:

- Adults: \$160 each
- Children ages 6 - 15: \$85 (5 & under no charge)
- Family pack: two adults and two children: \$450
- Refunds will be given on cancellations made before July 1, minus a \$25 handling fee.
- The fees include: all lectures and workshops, Wednesday night refreshments, continental breakfast Thursday, Friday & Saturday, and Saturday evening banquet meal.
- After July 1 individuals will be able to register at the conference for \$185 per person, child registration will remain the same.

### Hotel:

Sheraton Madison Hotel  
706 John Nolen Drive  
Madison, WI  
Telephone 608-251-2300

### Airport:

Madison is served by the Dane County Regional Airport located minutes from downtown. Offering more than 100 commercial flights daily, Dane County Airport offers direct non-stop service to many cities across the United States..



### Ground Transportation:

The Sheraton Madison Hotel provides complimentary transportation to and from the Dade County Airport. If you will need wheelchair accessible transportation, please make arrangements with the hotel in advance at 608-251-2300.

There is bus service from the Chicago airports and Amtrak station to Madison. The service is offered by the Van Galder Bus Company. Details can be obtained and tickets purchased at <http://www.coachusa.com/vangalder/>. The round-trip fare from O'Hare is \$54. Union Cab of Madison Cooperative, Inc., (608) 242-2000 is a licensed wheelchair accessible company.

### Hotel Room Rate:

\$115 plus 14.5% room tax per day. Attendees will make their own reservations by calling the Sheraton reservation line at 1-800-325-3535 or 608-251-2300. Let them know you are attending the ASAP conference to receive this rate, which will be extended three days before and three days after the conference. **To receive the discounted rate, room reservations must be made by June 17, 2009.**

### Local Members:

Your family and friends are welcome to attend the conference and see for themselves why ASAP is so important to you. If they can't make the conference, please invite them to join us for the closing banquet at a cost of \$65 per person.

**If You Can't Attend...** but would like to offset the cost of the conference by making a donation or send an item for the raffle, we extend our grateful appreciation. Please send either to the ASAP office. (Note: raffle items must be received by June 30.)

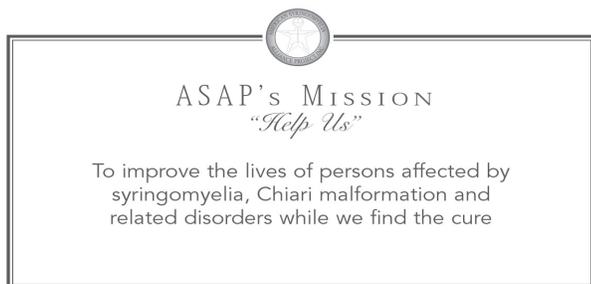
[Special thanks to Fred Parker for compiling our conference announcement.]

**[www.ASAP.org](http://www.ASAP.org)**

The American Syringomyelia 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 articles, letters to the editor, etc. are encouraged. The deadlines for these submissions are the 1st of February, April, June, August, October and December. The editor reserves the right to edit any article in order to accommodate space. Please send newsletter suggestions to: [Patricia\\_Maxwell@ASAP.org](mailto:Patricia_Maxwell@ASAP.org) or ASAP, PO Box 1586, Longview TX 75606

**Patricia Maxwell** Editor, *ASAP Connections*



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