

# Connections

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



## A Sneak Peek at ASAP's Chiari & Syringomyelia Conference

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The ASAP Conference Committee has been working hard to ensure the conference not only meets but surpasses expectations. Our chosen site for this year—Madison, Wisconsin—is American's hometown and the perfect location for a family vacation. We encourage you to think of the conference as a family affair. We have special sessions for children and teens with Chiari, syringomyelia or related disorders as well as siblings and children whose parents are affected. When one member of the family is diagnosed, it affects everyone. The conference allows patients, family and friends to interact and share with others who understand their unique perspectives.

In this year's conference program, the organizers have made an effort to:

1. review the most current standards of diagnosis and treatment in Chiari malformations and syringomyelia and provide the essential definitions;
2. discuss the most salient controversial and complex issues;
3. provide a review of the most important research areas, both clinical and basic; and discuss various clinical problems such as pain and neurological deficits using standard and alternative therapies.

The program has been divided into eight modules:

- Module 1, Thursday 9:00 – 10:25 am: Basic concepts, definitions, and treatments of the Chiari malformations and syringomyelia (Drs. George, Iskandar, and Kula)
- Module 2, Thursday 10:40 am – noon: Associated clinical problems: Audio-Vestibular dysfunction, urological, neuropsychology, rehabilitation (Drs. Richmond, Kryger, Hermann, and Ward)

- Module 3, Friday 8:45 – 10:25 am: Complex and/or controversial problems: Tethered cord; Craniocervical fusion with Chiari I; Scoliosis; failed Chiari (Drs. Batzdorf, Oakes, Menezes, and McCarthy)
- Module 4, Friday 11:15 – 12:10 pm: Pain concepts and management (Pain experts Drs. Backonja and Mailis-Gagnon)
- Module 5, Friday 2:00 – 3:35 pm: Clinical research I: Abstracts from recent advances and publications (Drs. Bolognese, Wetjen, Frim, Rocque and Ashley-Koch)
- Module 6, Saturday 9:00 – 10:50 am: Pediatric Issues: Shunts; Incidental Chiari in children; Child's hospital experience (Drs. Albright, Keating and Struck, Child Life specialist Kaminski)
- Module 7, Saturday 11:00 am – 12:35 pm: Clinical research II: Reviews of Genetics, Radiology, Biomechanics and Pathophysiology (Drs. George, Iskandar, Haughton, Loth, Heiss and Bejjani)
- Module 8, Saturday 2:20 – 3:00 pm: Basic research on central nervous system healing: Stem Cells and CNS repair (Expert scientists Clark and Vemuganti)

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**American  
Syringomyelia  
& Chiari  
Alliance  
Project, Inc.**

501(c)(3)  
tax-exempt since  
1988

### Same People, Same Cause



American Syringomyelia Alliance Project will now be doing business under a name that more accurately reflects our community. ASAP now stands for the American Syringomyelia & Chiari Alliance Project, Inc. The name change reflects our ongoing commitment to education, research and awareness to the Chiari malformation with or without syringomyelia.

# ASAP

## Contact Us

### **ASAP**

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### **Knowledge is Power!**

**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.

### **ASAP is Going Green!**

What You Need to Know  
E-newsletters are EASY...

Bi-monthly eNEWSLETTER members will receive an email from ASAP notifying them that the newsletter is available for viewing. Simply click on the provided link or log on to [www.ASAP.org](http://www.ASAP.org).

E-Newsletters are ECONOMICAL...  
This FREE service is a great way to support the organization by helping us save time and save money.

E-newsletters are ECO-FRIENDLY...  
Signing up for E-newsletters is also a great way to save paper! You will be able to read your newsletter online or download at your convenience from your own personal computer. E-newsletters will be available for viewing online for an extended period of time.

**SIGN UP TODAY!**  
Contact the ASAP office and sign up to receive *ASAP Connections* online.

SAVE Time...SAVE Trees...with ASAP!

### **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. It 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 CEO

by Michael Scarpone, MS

### ***We are making a difference***

Over twenty years ago, Barbara White founded ASAP with the goal of bringing information and support to those who need it. We are realizing those goals in multiple ways.

### ***Research***

I am proud of our research accomplishments. ASAP has funded over \$700,000 in research studies during the past 10 years.

We are currently funding a two-year, \$220,000 study that will track different therapeutic treatment outcomes for people with syringomyelia and/or Chiari malformation. We expect this cutting edge project to provide a wealth of information about various treatment options.

ASAP research is peer reviewed which means that an independent committee decides the merits of the investigation. Research has always been an organizational core competency. Through these investigations we will find the key which unlocks the SM and CM mysteries.

### ***Educational outreach***

ASAP responds to more than 300 requests for information per month. As we continue to inform the public about the signs and symptoms of SM and CM, more people will be turning to ASAP for support. We have support groups established throughout the country. These groups continue to strengthen and grow.

This year's conference promises to be the best yet with interactive workshops, keynote lectures, sprinkled with a lot of fun. The conference allows patients, family and friends to interact and share with others who understand their unique perspectives.

### ***Our ability to raise much needed revenue***

We live in challenging economic times. However, those who are committed to our cause have the passion to overcome any obstacles. Their generosity is unwavering. Our stakeholders will continue to give because they know that ASAP will deliver on its commitment to fulfill its mission. We will continue to be stewards of integrity when it comes to donor dollars.

These highlights of ASAP's accomplishments and goals are examples of how we are making a difference. We have the ability to change the conversation around SM and CM from "We just don't understand" to "We have found the answers and are disseminating them around the world."

We will continue to fulfill Barbara's vision of bringing information and support to those who need it.



## ASAP Conference

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A new addition this year is the Thursday afternoon workshops. Nine workshops have been scheduled during three sessions. Attendees can choose one workshop per session.

### Session 1:

- Visual-guided Imagery and Biofeedback
- Brain/spine Anatomy
- Educational Plans

### Session 2:

- Social Security and Disability
- Physical and Occupational Therapy
- Injured Bystander

### Session 3:

- Acupuncture
- Volunteer Opportunities
- Dealing with a Chronic Illness

Our expanded Kids For A Cure Club program will give children between the ages of 6-16 the opportunity to participate in a variety of activities, such as violin lessons, drama, crafts, coping techniques, brain anatomy. In addition, Child Life specialists from the University of Wisconsin will work with attendees each day to answer questions.

The schedule will be enhanced by periodic presentations by patients in a peer-to-peer format. Questions from the membership will be collected in advance and organized into vignettes to be discussed by the experts throughout the program. Each module will be followed with a question and answer session.

The complete agenda is now available on our web site at [http://www.asap.org/2009\\_agenda.html](http://www.asap.org/2009_agenda.html) or by contacting the ASAP office.

## Quest for Understanding

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

## Ask The Experts

### Question and Answer



**Question:** The reason for my question is I've known a couple of people who the first manifestation of syringomyelia was urinary incontinence that was nonresponsive. I'm wondering at what point before you consider things like major surgery do you consider referral to some other specialty?

**Dr. Chai:** Like a neurologist or neurosurgeon? I think it gets back to that urodynamics tracing I showed. I purposely picked those two to give you the spectrum of what I call idiopathic detrusor over-activity, that's the formal name, it used to be called uninhibited bladder contractions, in a neurologically normal and a neurologically abnormal patient. So I do have some areas where I really do think there's something else going on then I will refer – and it's from the urodynamics testing.

**Question:** How frequently is that done by a urologist?

**Dr. Chai:** All the time I think, although I'm speaking for myself. I see a lot of referrals where I repeat all of the urodynamics myself because I don't think they're done. There are a lot of factors that go into urodynamics.

**Question:** So it would be the urodynamics that would give you the clue?

The problem with incontinence is it takes you by surprise. You can't leave the house.

**Dr. Chai:** Yes and I have referred patients to look and I have not, I haven't found a syringomyelia in patients I've referred but I haven't referred many. A lot of them actually come to me from neurologists, they've already gotten a diagnosis of a lesion and they have some sort of bladder problem. I have not yet seen a patient that had syringomyelia that I picked up.

**Response:** I've known a couple of the traumatic syringomyelia patients where the first manifestation of the syringomyelia was actually the incontinence.

**Dr. Chai:** So was that post-surgical?

**Response:** Post-traumatic, decades after a car crash.

**Dr. Chai:** Could it be just an injury that was managed conservatively? If the injury was severe and the person had spinal surgery, that to me triggers there's something neurologic going on. Are you referring to something that wasn't severe and one of the long term manifestations of syringomyelia?

Well I'm learning something too. I do take a history and I think about those things but I like to correlate other things. That's why I asked about the severity and if any surgery resulted in the spinal cord injury.

**Dr. Brockmeyer:** I think most neurologists would try to manage practically the incontinence, failure to store, failure to void issues themselves and then subsequently for the final resting place is really with the urologist if there needs to be a diverting, they can certainly manage the problem with surgical attempts.

Syringomyelia I think is much less common than multiple sclerosis but the problems urologically are fairly similar because they involve often times multiple levels of the spinal cord. We can manipulate the bladder function and sphincter function with a lot of medications; for instance there's some medications that may decrease the strength of the tressor contractions like baclofen. Things that we use for spasticity of the legs will often work for spasticity of the bladder and then there are other medications, as Dr. Chai mentioned that will increase the tone of the sphincter.

One of the problems with incontinence is it's not very manageable by the patient, it takes you by surprise, you can't leave the house. But if we can turn a patient with incontinence into someone who has retention, you can easily manage retention with straight catheterization. Many MS patients manage this easily under clean, not necessarily sterile, conditions, without complications for many years. If we can use medications that make you retain urine you can

control the process by self catheterization intermittently and remain continent with just the assistance of some medical therapeutics. If that fails at the end of the line then that's when we, as neurologists, get the urologist involved to do something really structural.

The only side issue is the issue of stress incontinence which often times is more of an issue in females than in males but there can certainly be some unique minimally invasive surgical procedures that can help with bladder lifts and some restriction of the perineal floor to aide in eliminating stress incontinence. Stress incontinence isn't a neurological or neurogenic problem it's a mechanical problem.

The first thing we try to approach is: is it a mechanical problem or is it really a neurological problem? Is it a neurogenic bladder or a mechanical issue?

[The preceding excerpts are from the 2008 ASAP Conference held in Arlington, VA.]

Toby Chai, MD, Professor of Surgery, Division of Urology, University of Maryland Medical School, Baltimore, Maryland

Douglas Brockmeyer, MD, Professor of Neurosurgery, University of Utah, Salt Lake City, Utah

A complete transcript of the 2008 ASAP Conference is available for sale (see page 10).]

## FDA Adopts Interim Plan to Avoid Shortage of Medically Necessary Opioid

On April 9, the U.S. Food and Drug Administration amended its March 30, 2009 action warning manufacturers to stop the production and distribution of certain unapproved prescription opioids; to allow the continued marketing and distribution of one particular type of opioid -- a high concentrate morphine sulfate oral solution -- on an interim basis.

The FDA took this action in response to concerns from patients and health care professionals in the palliative care community that the action taken on March 30 would cause a shortage of 20 mg/ml morphine sulfate oral solution. This product is widely used to alleviate pain in terminally-ill patients. The agency has determined that this dosage form is medically necessary and should remain on the market until an approved alternative becomes available to the patients who need it.

"While the FDA remains committed to ultimately ensuring that all prescription drugs on the market are FDA approved, we have to balance that goal with flexibility and compassion for patients who have few alternatives for the alleviation of their pain," said Douglas Throckmorton, M.D., deputy director, FDA's Center for Drug Evaluation and Research. "In light of the concerns raised by these patients and their healthcare providers, we have adjusted our actions with regard to these particular products."

To address the needs of palliative care patients, the FDA will allow companies that are currently manufacturing and distributing versions of this unapproved prescription product to continue to do so on an interim basis until an FDA-approved version of this product or another acceptable alternative therapy becomes available.

"The FDA appreciates the help we received from the palliative care community about how this drug is being used today to help patients," said Theresa Toigo, Director, FDA's Office of Special Health Issues. "We want to continue to talk to them as we move forward on this difficult issue."

This decision only affects the high concentrate morphine sulfate solution. Companies that received warning letters from the FDA on March 30 concerning other unapproved prescription opioid products will still be required to cease production and distribution of those products. The other products affected by the enforcement action are: immediate release tablets containing morphine sulfate, hydromorphone, and oxycodone.

The March 30 action is part of the FDA's Unapproved Drugs Initiative, which seeks to ensure that all drugs available on the U.S. market have met FDA's standards for safety, efficacy, and quality.

April 2009 News release provided courtesy of the U.S. Food & Drug Administration (FDA) · 5600 Fishers Lane · Rockville MD 20857 · 800-439-1420

## The Internet and Healthcare

*by Patricia Maxwell*

In a recent article published by Medscape, Dr Peter Yellowlees, professor of psychiatry at UC Davis, addresses the issue of the increasing role the Internet plays in the patient-doctor relationship. A role that he feels may not always be successful.

With the continual increase of adults using the Internet daily, it is believed that it will change the way much of medicine is practiced. Forces already making the practice of Internet healthcare advance rapidly include:

- increased consumer spending on health;
- patients taking responsibility for their healthcare;
- the fact that information technology in healthcare should reduce errors and mistakes;
- the increasing use of computers by physicians;
- the growth of the Internet as part of our daily lives.

Did you know that President Obama is implementing policies to increase the use of health information technology? It is national US health policy for all patients to have electronic health records within a few years. As a result more and more doctors and hospitals are implementing systems to support electronic health records now.

It is reported that at least 75 percent of Internet users in the United States utilize the web for health information and healthcare. Not surprisingly, individuals with chronic illnesses and those who have been recently diagnosed search for information about their symptoms, disorders and specialists who might provide the latest treatment options available. In recent years there has been a steady increase in patients being able to email their doctors, making communication easier for both.

For many years consumers have had the advantage of information and support through self-help web sites, listservs and Internet chat rooms. It is becoming common practice for doctors to communicate with one another through email. Blogs, webinars and streaming video are bringing information into the homes of many individuals who might not have access to it otherwise.

Widespread access to the Internet and email has enabled great improvements in clinical and health education practices worldwide. With the improvement doctor-patient communication with the use of the Internet it stands to reason that further improvements will follow.

## Member Profile

by Lori Tutrow

Last year saw both of my children having posterior fossa decompression surgeries. Keegan was 9 at the time, and he was the first of the two diagnosed with Chiari I malformation and syringomyelia. He was feeling really frustrated with the constant symptoms that were interfering with his participation in all the things that make the life of a 9-year-old boy fun.

He was feeling like the only child with these disorder despite our assuring him that he was not. It wasn't until we were able to meet his first Chiari friend a week before his surgery that he realized he was not alone. After meeting Aubrey, we began to see his acceptance of the surgery to come. We also had located some information about the annual ASAP conference. Children have their own special programming during most of the "grown up talk," and he was excited about the idea of being in a group of kids who know how he feels.

Keegan's surgery was just four weeks before the conference in Washington was to begin. He had a setback that nearly kept us from attending. After IV antibiotics and pain medications, he was feeling well enough for the trip. Truth be told, he was so looking forward to this that he would have wanted to go even if he wasn't feeling well! I can't put into words the relief I saw in him when he began meeting the other kids, and realizing there were a lot of kids who are traveling this journey too. I will never forget the first night at the conference. He was in the pool playing with another little boy about his age. Once his hair got wet, it was easy to see his scar, and the boy asked him what it was. I heard Keegan explain to him what it was, and that he'd just had surgery on his brain, and the little boy told him that it was weird. I held my breath. Keegan replied right back, "No it's not. If it was weird, there wouldn't have been so many other kids like me at the conference we went to today." The little boy nodded and off the two went to play some more. The conference gave Keegan a confidence that he wasn't alone, and that things would be fine, that we as his parents couldn't create for him on our own.

A child life specialist came for part of the kids' portion and taught them coping skills to get through pain and difficult procedures. Canine Companions did a presentation with therapeutic dogs. The kids were able to talk about their symptoms. Keegan is usually a big clam when it comes to anything related to feeling poorly, but he was able to share experiences when he was around other kids. My husband and I appreciated being able to learn from the



Keegan and Kaylee during their visit to DC

many neurosurgeons who came to present on a variety of topics. These were given in language that we could understand. It was helpful that each of them offered question and answer time. We learned some of the symptoms that Keegan had not had, but that Kaylee did. We also learned that these disorders do have a genetic link, and most siblings are encouraged to be seen if they begin displaying symptoms. When we returned from the conference, we had Kaylee tested, and she was also diagnosed with a Chiari I.

Kaylee, who was 11, had surgery in December 2008. She was able to return to school in January after the Christmas break, and was able to try out and play for her school's 6th grade basketball team just five weeks after her surgery.

We had hoped that the kids would be free of pain and symptoms after their surgeries, but they do still have good and bad times of symptoms. They both agree that the bad days aren't nearly as bad as before surgery. Keegan is getting ready for baseball season to start, and Kaylee is hoping to ride her Grandma's horse for 4-H. We were a very busy family before Keegan started feeling so poorly, too busy. As a family, we are still adjusting to their various symptoms and all that living with these disorders really entails. If it weren't for our faith in God, and the support and prayers from our family, friends, and those we've met along the way, this would be completely overwhelming.

We count ASAP as one of our blessings along this path, where we can find information from different neurosurgical perspectives, go to the annual conference, participate in the phone teleconferences, and talk with others on the message board.

**ASAP sends out monthly eBlasts to keep members informed about breaking news, upcoming events and much more.**

**Don't miss important updates!**

**Add the domain name ASAP.org to your safe sender list.**

## Awareness and Fundraising

### Project Chiari

by Patricia Maxwell

Brittany Vanek, an 8th grader from Indiana, is a member of the National Junior Honor Society. Her mom, Cyndi, has Chiari malformation and syringomyelia. So when Brittany considered her NJHS community service hours, she chose to raise awareness about Chiari. She said, "My mom does so much for others; I wanted to help in some way. I am trying to bring awareness to Chiari so that a cure can be found."

Cyndi, a former ICU nurse, had never heard of Chiari before being diagnosed. Neither had many of the doctors she worked with at the hospital. Brittany was only 4 years old when her mom first learned what was causing her headaches, clumsiness, numbness and the strange buzzing that traveled down her arms. In 1998, Cyndi underwent decompression surgery to correct the malformation. Over the next ten years she would go through multiple surgeries.

Last September, Brittany developed a web site to promote awareness and raise funds for research. Cyndi wrote, "When my daughter showed me what she had created, I was both proud and humbled that out of so much heartache, she found a way to help others and spread the word about Chiari in such a unique way." The web site tells the family's story from Brittany's viewpoint, and uses photos to help others not just read about Chiari, but understand



what people with Chiari and their families go through.

When Brittany showed her brother, Eddie, the web site, he drew two designs for a Chiari pin. The family liked them so much that they had a company make pins and charms which

Brittany placed on her site for sale. She has also designed bracelets, necklaces, key chains and bookmarks which are featured in the gallery. At present there have been over 2000 page views on Project Chiari. At the end of 2008, they forwarded 100% of the money that was brought in through the sale of these exclusive items to ASAP.

Cyndi said, "After seeing what my kids were able to do with creating awareness through Brittany's web site. They became my inspiration for creating our support group in Northwest Indiana to help others." The group holds monthly meetings the 1st Monday of the month, 7 pm, at the Center for Advanced Clinical Studies, 200 East 89th Avenue, Merrillville, IN. They are also planning a Chiari Walk fundraiser this September.

To view Brittany's web site, visit  
<http://betajournal.comcast.net/Project-chiari/>

For more information on the Indiana support group or the Chiari Walk, please contact Cyndi at [vanek4@comcast.net](mailto:vanek4@comcast.net)

### Join ASAP's Summer Campaign for the Cure!

As ASAP launches its Summer Campaign for the Cure, supporters will find a new way to get involved with fundraising. You will have the opportunity to tell your personal story on your own web page. We will provide the place for you to share your story in words, photos, even videos.

ASAP has joined with Firstgiving for safe and effective results. The site is secure for your donors, and even allows you to track your progress toward your fundraising goal. Studies show that online fundraising raises significantly more money than traditional means. Many people find it less intimidating to ask for money online than in person.

Okay, enough talk. How do I get started?

Just follow these simple steps:

1. Visit: <http://www.firstgiving.com/cmsm>
2. Click **Get Started**

3. Select **Summer Campaign for the Cure** or create your own unique event, such as in memory or in honor of a loved one.
4. If you've used Firstgiving before, log in to your account  
If not, enter your email and click **Continue**
5. Fill out your account details and click **Continue**
6. Choose your web address and click **Create Your Page**

To tell your personal story, add photos and set a fundraising target, click Personalize and share your page. Once you've edited it, click **Save and continue**.

Now click **Email your friends** to share your fundraising page with everyone you know who might want to help you reach your fundraising goal! It's that easy, and it works! Try it and see. You can log on to your account at any time and send email updates to your donors.

For help or questions, contact [support@firstgiving.com](mailto:support@firstgiving.com)

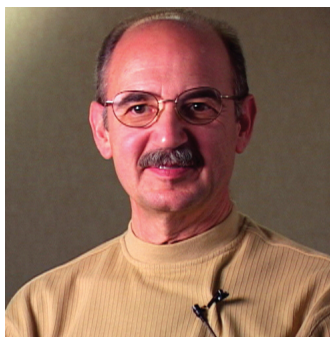
## Meet the Medical Advisory Board

### John J Oró, MD

A nationally recognized leader in the treatment of Chiari I malformation, Dr John J Oró was born in Lerida, Spain in 1950. Eight years later his family moved to the United States where he later became a naturalized citizen. After obtaining his undergraduate education in Houston, Texas, he completed his medical education and post-graduate surgical training at the University of Texas Medical Branch in Galveston and his neurosurgical residency training at the University of Missouri, in Columbia. Dr. Oró stayed on in the community as part of the University faculty.

His distinguished career at the University of Missouri included his appointment as Program Director of the Neurological Surgery Residency Training Program and as Chief of the Division of Neurological Surgery, a position he held until his move to Colorado in 2005. He founded The Chiari Treatment Center, located on The Medical Center of Aurora campus, where he continues to pioneer advances and refinements in the treatment of this disorder.

Board certified by the American Board of Neurological Surgeons in 1989, Dr Oró has focused on a variety of neurosurgical areas including tumors of the brain and spine, skull base surgery, surgery for brain aneurysms and vascular malformations, and spinal surgery.



Dr Oró has been actively involved in hospital, state and national committees including serving on the Board of Directors of the American Association of Neurological Surgeons. He has published over 60 medical articles and book chapters and has received many teaching and physician recognition

awards. He has been listed among the Best Doctors in America since 2001, and listed among America's Top Surgeons in 2007. Beyond being an excellent surgeon, he has held numerous appointments, serving on boards and committees at the state and national levels.

Dr. Oró's commitment to advancing Chiari care developed during his tenure as Professor and Chief of Neurosurgery at the University of Missouri. "In 1998, I developed a special interest in Chiari I malformation because I saw that many people were not receiving adequate evaluation and treatment." Since his initial interest, his commitment to providing the best surgical procedures and patient care has increased and in 2005 he moved his practice to Colorado to further advance the care of persons with Chiari and/or syringomyelia.

Currently, Dr. Oró is involved in ongoing research into Chiari I malformation and syringomyelia, and continues to present his results and perspectives at national meetings and in published texts and materials.



## ASAP Welcomes New Medical Advisory Board Members

ASAP is honored to announce the appointment of Robert Keating, MD; John Jane, Jr., MD; Ann Berger, MD and W. Jerry Oakes, MD to the Medical Advisory Board.

Dr. Robert Keating, Chief of Neurosurgery at Children's National Medical Center in Washington, DC, said, "I am impressed by the dedication and role in educating the public that ASAP has undertaken and hope to be able to add in a measurable way to your organization." He was a speaker at the 2008 conference in Arlington Virginia, he will speak at our 2009 conference in Madison. You can catch his lecture, *Incidental Chiari I in Children*, on Saturday, July 18.

Dr. John Jane, Jr. is the Director of the Division of Pediatric Neurosurgery at the University of Virginia. He has published over 60 peer reviewed articles and chapters. One of Virginia's top neurosurgeon, we are eager to work with this pioneering pediatric specialist.

Dr. Ann Berger is the Chief of Pain and Palliative Care Service at the National Institutes of Health. Recipient of numerous awards, she is the senior editor of a major textbook in pain and palliative care. Dr. Berger is the first pain specialist to serve on ASAP's Medical Advisory Board. We are looking forward to the important contributions her expertise will bring to the SM/CM community.

Dr. W. Jerry Oakes is Professor of Pediatrics and Neurosurgery at Children's Hospital of Alabama. He has published extensively on Chiari, syringomyelia and related disorders. We are honored to have him serve on our Medical Advisory Board and look forward to learning from him.

[Watch for indepth articles about these members of the Medical Advisory Board in future editions of *ASAP Connections*.]

## Restrictions on Institutional Review Board

The U.S. Food and Drug Administration announced that Coast IRB, LLC of Colorado Springs, Colorado, has agreed to voluntarily halt some aspects of its clinical trial oversight operations due to serious concerns about the company's ability to protect human subjects participating in clinical trials.

According to the company's records, these actions may involve approximately 300 active human research studies conducted by some 3,000 clinical investigators.

Until further notice, Coast IRB [institutional review board] has agreed to stop reviewing new FDA-regulated studies. Also, Coast IRB will direct clinical investigators in on-going FDA-regulated studies approved by Coast IRB to halt new subject enrollment. FDA has issued a warning letter to Coast IRB outlining its concerns and FDA will continue to actively monitor the company and take appropriate action as necessary. These restrictions will remain in effect until the FDA is satisfied that Coast IRB has taken necessary corrective actions that bring it into compliance with FDA regulations designed to protect human research subjects.

Under current federal law, clinical research involving human subjects and FDA-regulated products, such as drugs, biologics or medical devices, must have the review and approval of an "institutional review board" (IRB). An IRB is a panel of doctors, scientists and non-scientists charged with reviewing the clinical research to protect the rights and welfare of the subjects participating in the study.

This action follows a recent undercover operation by the U.S. Government Accountability Office (GAO). The GAO submitted to Coast IRB for review a fictitious research study involving a purportedly FDA-cleared medical device. Although no human subjects were involved, the GAO operation heightened FDA's concerns about Coast IRB's ability to protect the rights and welfare of human research subjects.

In evaluating the information provided by the GAO investigators, FDA determined that Coast IRB committed several violations of the laws and regulations intended to protect the rights and welfare of human research subjects in clinical trials and that the company failed to perform the robust review needed to approve a study.

The FDA's action is precautionary. Because of the potential risk to enrolled subjects and disruption to the research if on-going studies were abruptly terminated, studies that Coast IRB has already approved will be permitted to continue. However, no new subjects will be permitted to enroll in these studies until there is assurance that the research has undergone adequate review.

April 2009 News release provided courtesy of the U.S. Food & Drug Administration (FDA) · 5600 Fishers Lane · Rockville MD 20857 · 800-439-1420

## The Facts about Pain

Pain is complex and frequently misunderstood by the public. The issue of pain is riddled with myths and misperceptions, which makes the task of informing and educating people about pain and its management that much more challenging.

Some common misconceptions about pain:

- Pain is 'all in your head.' Although this is partially true because we need our brains for the perception of pain, that does not mean pain is imaginary when the source of pain is not well understood. Pain is all too real to the person who lives with it day in and out.
- Pain is just something one has to live with—an inevitable part of a disease or condition. The fact is most pain can be relieved with proper pain management.
- Pain is a natural part of growing older. While pain is more common as we age because conditions that cause pain (e.g. arthritis, degenerative joint disease, cancer, shingles, and osteoporosis) are more frequent in older adults, it should not be something people have to struggle with.
- The best judge of pain is the physician or nurse. Studies have shown that there is little correlation between what a physician or nurse might 'guess' about someone's actual pain. The person with pain is the authority on the existence and severity of his/her pain. The self-report is the most reliable indicator.
- Seeking medical care for pain is a sign of weakness. Pain carries a stigma and many people hesitate talking about their pain and how it affects their daily life, they also don't want to be considered a bad patient.
- Use of strong pain medication leads to addiction. Many people living with pain and even some healthcare providers falsely believe opioids (strong pain medicines) are universally addictive. Studies have shown that the risk of addiction is small when these medicines are properly prescribed and taken as directed. As with any medication there are risks, but these risks can be managed.

[Information provided by the American Pain Foundation, *A Reporter's Guide: Covering Pain and Its Management*.]

**Visit us on the Web**  
**[www.ASAP.org](http://www.ASAP.org)**

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.

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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

## In Memory of Chip Vierow

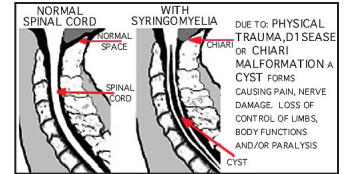
The founder of WACMA, Chip Vierow, passed away on November 6, 2008. He had been fighting a courageous battle with a liver disease called nonalcoholic steatohepatitis (which is not associated with Chiari). He spent the last few weeks in the intensive care unit awaiting a liver transplant, but became too sick before a liver became available.


Chip's legacy was a vision of how to help other Chiarians: to provide a place to seek support, a great place for information about Chiari, and a forum to encourage the members to make the same choice daily that he did, which was to: "Always Think Positive and Never Lose Your Sense of Humor."

## 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.



 Your Name  
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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.

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Email [jlindner99@sbcglobal.net](mailto:jlindner99@sbcglobal.net)

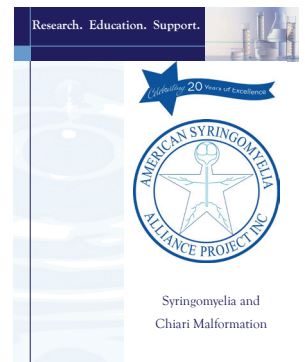
## Order Your Copy Today

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

With 18 presentations and 5 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.



## **SAMHSA and FDA Join to Educate the Public on the Safe Use of Methadone**

The U.S. Substance Abuse and Mental Health Services Administration (SAMHSA) and the U.S. Food and Drug Administration (FDA) today [April 28, 2009] launched an initiative to help ensure the safe use of methadone. A prescription drug best known as a treatment for addiction and dependence on heroin and other narcotic pain medicines, methadone is also prescribed to treat moderate-to-severe chronic pain patients. The campaign responds to concerns about an escalating number of poisoning deaths linked to the improper use of this medication.

The public outreach effort, *Follow Directions: How to Use Methadone Safely*, is designed to inform consumers, health care professionals and treatment clinics about the safe use and misuse of the drug for both pain relief and drug addiction treatment.

Methadone is a synthetic opioid that has been used for decades to reduce drug withdrawal symptoms. Recently, it has been increasingly prescribed as a pain reliever for patients whose moderate-to-severe chronic pain does not respond to non-narcotic pain medications.

The percentage of all poisoning deaths linked to methadone has tripled in recent years, increasing from 4 percent in 1999 to 14 percent in 2004, according to the Centers for Disease Control and Prevention. Moreover, the number of poisoning deaths linked to methadone is rising faster than the number of poisoning deaths from any other narcotic drug.

Methadone may be best known for use as an addiction treatment medication, but the bigger problem and concern has been with the more recent use as an analgesic. The risk of methadone overdose is partly due to the way the drug metabolizes in the body. People who take methadone normally feel relief within four to eight hours. However, unlike other narcotic pain relievers, a single dose of methadone can remain in the body anywhere from 8 to 59 hours. As a result, the drug builds up to toxic levels if it is taken too often, in too high an amount, or with other medications.

"The methadone safety campaign materials provide simple instructions on how to use the medication correctly to either manage pain or treat drug addiction," said H. Westley Clark, M.D., J.D., M.P.H., C.A.S., F.A.S.A.M., Director of SAMHSA's Center for Substance Abuse Treatment. "Our goal for this training is to support the safe use of methadone by all patients and prescribing healthcare professionals."

Methadone, when used for the treatment of narcotic addiction, must be dispensed by a program/clinic that is certified by SAMHSA and registered with the Drug Enforcement Administration (DEA). But when used as an analgesic, methadone may be prescribed by any healthcare professional registered to prescribe Schedule II controlled substances, and can be dispensed by any licensed and DEA-registered pharmacy.

"Methadone is an important and beneficial drug when prescribed and used properly," said Douglas Throckmorton, M.D., Deputy Director of the FDA's Center for Drug Evaluation and Research. "Educational efforts like the one we are announcing today can help prevent the tragedies that occur when methadone is used improperly."

Outreach materials about methadone for the public and health care professionals include a brochure, a poster and a fact sheet, in English and Spanish. In addition, a point-of-sale information sheet will be distributed in pharmacies where methadone is dispensed to pain management patients.

SAMHSA and the FDA will continue to work collaboratively with other federal agencies, states, health professional societies, patient advocacy groups, and other interested parties to develop and implement practical steps to reduce avoidable methadone-associated deaths.

To learn more information about the campaign, visit **[www.dpt.samhsa.gov/methadonesafety](http://www.dpt.samhsa.gov/methadonesafety)** or call 240-276-2700.

### **Frequently Asked Questions about the ASAP Syringomyelia / Chiari Conference**

#### **What is the last day to reserve a room?**

Time is running out, Be sure to reserve your room at the Sheraton Madison before June 16 to receive the discounted room rate of \$115 +tax per day. Call 1-800-325-3535.

#### **Who should attend the conference?**

Anyone who is interested in learning more about Chiari malformation, syringomyelia, their symptoms, treatment

and research. The majority are people diagnosed with one or more of the disorders. Caregivers, parents, doctors, and family members find the conference beneficial by obtaining a greater understanding of the disorders and how their role of advocate can help their loved ones.

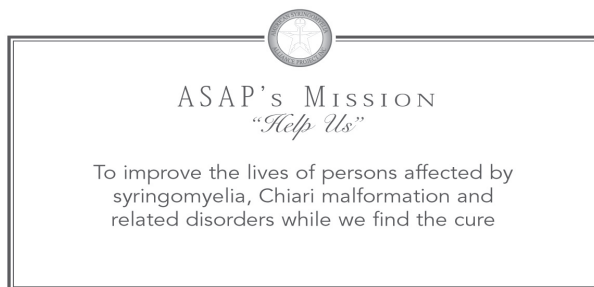
#### **When is the last day to register?**

You can register online, by phone, or through the mail until July 1, 2009. After that date, you may still register on site.

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 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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