ASAP
# Connections

Issue 5, 2008
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*"To Improve the Lives ...While We Find the Cure"*

Celebrating 20 Years of Excellence

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## Landmark Pain Care Policy

Press Statement attributable to: Will Rowe, Chief Executive Officer, American Pain Foundation

September 24, 2008—Today's Vote Represents Critical Step to Improving Pain Management in America

"The American Pain Foundation (APF) applauds the U.S. House of Representatives for taking a critical step in helping to improve pain care in America by passing the National Pain Care Policy Act of 2008 (HR 2994). The potential impact of this legislation on everyday lives cannot be overstated, nor can the tireless efforts of all of the individuals and organizations that have steadfastly joined forces to move this bill forward.

"Despite the fact that pain affects more than 76 million Americans—more than diabetes, heart disease and cancer combined—it remains woefully undertreated and misunderstood. All too common are stories of patients in the grip of pain, who are left to consult multiple care providers before their pain is properly diagnosed and managed, if it ever is. Not only is unmanaged pain emotionally and physically debilitating for patients, it also places a heavy burden on families and caregivers. The under-treatment of pain is also estimated to contribute to excessive healthcare costs and lost work productivity of approximately $100 billion every year.

"The present legislation authorizes an Institute of Medicine (IOM) conference on pain care, creates an interagency coordinating committee charged with identifying critical gaps in pain research, expands collaborative pain research across federal agencies and the private sector, and provides for a grant program to improve

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## Medically Fragile Children's Act

Press Release from Senator Hillary Rodham Clinton and Congresswoman Tammy Baldwin:

Senator Hillary Rodham Clinton (D-NY) and Congresswoman Tammy Baldwin (D-WI) have introduced companion legislation allowing states to create an all-inclusive care program for Medicaid-eligible children with the most intensive health care needs.

The Medically Fragile Children's Act (S. 3631/H.R. 7130) would ensure quality care with consistent coordination for children whose severe functional deficits require daily monitoring of their medical conditions. In the current Medicaid environment and in the healthcare system more broadly, care can be disjointed and duplicative, resulting in unnecessary hospitalization and diminished health outcomes, ultimately driving up healthcare costs.

"Families caring for children with the most difficult and complicated medical conditions have more than enough to handle without the added strain of a fragmented healthcare system that doesn't meet their needs. This legislation will take important steps to ensure consistent and coordinated care for those children who need it most, improving their quality of life and reducing costs," Senator Clinton said.

"Access to these programs will help restore respect and dignity to the health care of our most vulnerable youth," said Congresswoman Baldwin. "As I have seen in Wisconsin, with a comprehensive program of care, coordinated by a team of dedicated professionals, these children with special needs can achieve and maintain good health," Baldwin said.

Based on the pioneering model of care developed by a partnership between Palmetto Health of South Carolina, the Medical University of South Carolina, and

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## President's Letter

*by Judy Hunt*

Working Together: a World Without SM and CM

*Mackenzie had to stay home from school for the third day in a row. She knew from past absences that when she returned, her sixth grade classmates would joke how they wished they could trade places with her so they could miss a lot of school, too.*

*The pain was so bad that it hurt to lift her head up off the pillow, an excruciating pain where Mackenzie felt like everything was going to explode, a pain so intolerable that she just wanted to lash out at everything and everyone around because, well, just because, but no one would understand any of that. It didn't make sense. Nothing made sense.*

*Mackenzie's mom knew that her job was on the line if she called in sick at work another day, but going in was not an option today, not with her daughter home from school again. Nor was she looking forward to another screaming match with her husband about their daughter's condition today either.*

*More than anything, Mackenzie's dad just wanted a normal life. He never signed up for whatever it was that was wrong with his daughter. Maybe pretending a problem doesn't exist doesn't make it go away, but it makes it easier to deal with, that's for sure. Besides, someone has to be concerned with the realities of life, like making sure this family has a roof over its head and enough food to eat.*

Alone, no one knew what the other was thinking or doing. Independently, each person had one only set of resources to deal with each situation that came along.

For a moment, consider the untapped potential within these three individuals. Let's pool their resources so they work together toward a common goal of unity and understanding.

*Mackenzie teaches her dad that not only is his comfort enough to help her get through the darkest hours, it's the best fix she would ever want. His presence, his comfort, is the most important quality she needs to help her get through this crisis.*

*Knowing the physical exhaustion that goes along with caring for a child with chronic pain, Mackenzie's dad helps his wife realize that spending time away – taking a break – will be extremely beneficial. This time to rejuvenate will provide renewed energy, and in the long run, will afford the opportunity to be a better caregiver and parent.*

*Showing a side that her daughter never recognized, Mackenzie's mom stops hovering around, making room for dad. As she backs away, she demonstrates her ability to relinquish control, to be flexible as she adapts to the situation.*

Mackenzie and her parents are functioning on a different level now that they are communicating with each other. This same type of model applies to organizations like American Syringomyelia Alliance Project, Inc., our ASAP family.

When a number of groups work independent of each other, few of the groups, if any, know what the others are doing or planning. Individually, each group has to rely on its own internal resources, independently.

Yet when working together, these groups are able to move beyond their own resources. With more manpower, increased finances and improved endurance, we begin to function on a different level. Most importantly, we function as a communicating, cohesive unit. This family can continue to teach each other and learn from each other.

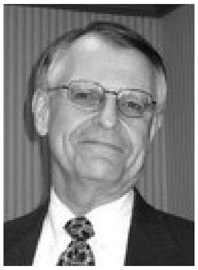
Given the target audience of this newsletter, surely every single person who reads this article will want to rid the world of the devastating effects of syringomyelia, Chiari malformation and related disorders. Individually, our wish *might* happen if we wish hard enough. Imagine, however, if instead, we pooled our resources and put all our energies together to make this happen.

As a 20-year organization, ASAP values its history and looks forward to watching it shape the future. Still, the crux of this organization is the people we serve. This family will continue to teach each other and learn from each other. Thank you.

**www.ASAP.org**

**1-800-ASAP-282**

## A Word from CEO Dick Hellner



Weathering the Economic Uncertainties

The news these days concerning the diminished strength of the dollar, the credit crunch and looming bank failures, the stock market's extreme downturn, looming business failures and rising unemployment is sufficiently scary for us all not to want to look or listen to the latest news.

Under these circumstances, we all have good reasons to choose to a more frugal way of living. Moreover, with higher costs for food, utilities, gasoline, healthcare and other necessities, the thought of that planned vacation, saving for a rainy day and even the occasional restaurant meal have been put on hold. To do otherwise might be seen as not acting responsibly or in the best interests of our families, community and indeed the country.

During this uncertainty, however, I hope you will keep in mind that our community—those with SM and CM, their families and friends—includes many who continue to need our help both now and in the future. They need our support and encouragement through participating on ASAP's message board and in support groups, getting the newest medical information through ASAP emails, telephone call-in programs and our web site or having an encouraging conversation with an ASAP volunteer or staff member.

Like you, ASAP is tightening its belt wherever possible. This extends to overhead and administrative costs that will not materially affect or diminish our community support programs in magnitude, frequency and effectiveness.

Also, please keep in mind that our community is growing all the time. The numbers of newly diagnosed individuals who seek our help continues to increase at over 100 people per month. Educating them and their families, getting them engaged in a support network and just being there for them during periods of stress increases weekly and stretches our limited human and financial resources all the more.

For all who participated in our recent annual membership appeal, you have my sincere thanks and admiration. The contributions are most helpful in keeping us going.

ASAP volunteers and staff are even now finalizing our end-of-the-year appeal. This is our "big campaign" in that the gifts we receive will determine the amount of reserch we will fund. Despite what uncertainties exist in the economy and in our homes, I sincerely hope that you will consider a generous year-end donation within your means. The needs of our community are by no means uncertain, nor is ASAP's desire to help.

## Coping Techniques

*by Patrice Schaublin*

During the peer support session at the 2008 conference we talked about pain management. A discussion of coping techniques people use to deal with their pain generated the following list.

Please remember everyone is different and could have different reactions. For example, some find that applying an ice pack to a painfull area brings relief while other prefer warm moist heat. This list is a reproduction of what those present at the conference found helpful.

Ice
Exercise especially walking
Acupuncture (series of treatments)
Learn to say NO (Don't overdo!)
Hot tub/ whirlpool
Water aerobic class
Diet limitations
Pain pump
Guided imagery/ relaxation music
Massage
Cranial sacral therapy
Rest
Turbie towel
Spinal cord stimulator
Pace your day
Change positions often
Spin Spa in shower
Shoulder brace/back support
Delegating
Yoga (gentle)
Physical therapy
Cooler weather
Spiritual focus
Read a good book
Get a service dog/pet
Good friends
Heat wraps
Pilates
Support—being able to talk about illness
Breathing techniques
Sleep
Soft music
Aromatherapy
Microwaveable rice bags/cold packs

The information and products contained in this article are not intended to treat, cure, or prevent syringomyelia or Chiari malformation. You are advised to consult with a healthcare professional regarding the suggestions, recommendations, and products found above and before starting any diet, exercise, or supplementation program.

# Ask The Experts

## Question and Answer - Headaches after Decompression

**Q: Question** from audience: *My daughter was having tremors when she was younger and we wondered why. Every neurologist would say 'It's in your head'. So we went up to Seattle and we finally had an MRI and found she had the Chiari. She had surgery when she was 17, she's 22 now. She never had headaches but now she's getting headaches after the surgery.*

**Dr. Heiss:** Let me restate this. Your daughter had a Chiari decompression and since that she's had more headaches rather than less headaches. Has she had MRI follow up? Do you have a scan that shows what things look like now?

Q: *Yes and they said that it hasn't changed.*

**Dr. Heiss:** I think some people have surgical pain just from being operated on and in some patients it lasts a long time. We always have to make a diagnosis but sometimes we look for the common things like slumping of the cerebellum, where it falls down and it scars to the site where you did the surgery. You look for that but everyone has a little bit of that. So the question is, how far down does the cerebellum have to be? If it falls down, if it's stuck, if it's clear cut then other people like Dr. Batzdorf have written papers about re-elevating the cerebellum and taking away some of the scarring. You really have to see what the threshold is. Is the pain so bad that it interferes with the quality of life? If it does then you might consider going to someone that might think about a surgical option. If it doesn't and you just want to try something less aggressive then you would go to a neurologist and try some pain management.

Q: *We just started with Botox and a nose spray too. She gets two a week.*

**Dr. Ellenbogen:** Did her tremors get better?

Q: *No she still has them*.

**Dr. Heiss:** The other thing that you want to check is to make sure that you have stability of the spine. Dr. Menezes will talk about that. You have to make sure that everything's strong enough up there, that there hasn't been any weakening related to the surgery.

**Dr. Ellenbogen:** Roger, what about Botox? What's the role of Botox in this whole thing? Do you ever use it? Nate? Roger?

**Dr. Kula:** We have used it in a number of patients with cranial cervical fusions, we've given them intraoperatively, not exactly sure whether it's every single patient but I know on occasion we've done that. That's helped with some of the major complications of muscle spasm in the post-operative period, which extend up through six months. We use it primarily in those patients who—whether from a cranial cervical fusion, or from a posterior fossa decompression or revision—have muscle spasm as a major problem and usually pain management will do that. That's a significant problem which can exist even through the third, fourth and fifth month post-operatively. Some people I think have an anticipation that they're going to get better faster and don't stick with rehab efforts of muscle spasm which can be just as bad as the basics of post-surgical pain or the underlying Chiari pain as a symptom that may not be 100% relieved by a decompression surgery. I think it plays an important role. A lot of patients have difficulty getting it approved with their insurance. But it's only one component of a multifaceted approach to that which involves pain medication, muscle relaxants, physical therapy and a few other things.

Q: *She started getting the headaches after three years.*

**Dr. Kula:** I think the issue is that we have to relook at that. Is there trauma involved? Did she have a slip, a fall, or a motor vehicle accident? The question is why is there a headache? Could there be instability, as Dr. Heiss said? Could there be CSF leakage for some reason? There's an interesting abstract that appeared as a result of an interest in patients that have what's called Whiplash Associated Disorder, which is persistence of neck pain and headache more than three months following a whiplash injury. There is a group of Japanese rehab and neurosurgical people who looked at this group of patients and found—what I thought was quite surprising—that about 50% of the patients had lumbar CSF leaks. Some of whom improved significantly with just blood patches. The idea was that craniocervical impact or chest impact or motor vehicle accident might have generated CSF leaks that certainly might be a major cause of why Chiari patients present a lot after minor, or somewhat less than minor, head injuries.

[Transcript from the 2007 ASAP Conference, Seattle, WA.

John D Heiss, MD, Head, Clinical Unit, Surgical Neurology Branch, NINDS/NIH, Bethesda, MD

Richard G Ellenbogen, MD, Professor of Neurological Surgery, University of Washington

Roger W Kula, MD, Medical Director of the Chiari Institute, Great Neck, NY]

## Landmark Pain Care Policy

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health professionals' understanding and ability to assess and treat pain. It also requires the Secretary of Health and Human Services (HHS) to develop and implement a national outreach and awareness campaign to educate patients and caregivers on the significance of pain as a public health problem.

"The companion measure (S3387) was introduced by Senators Orin Hatch (R-UT) and Christopher Dodd (D-CT) this summer. We urge members of the U.S. Senate to consider the millions of Americans who needlessly suffer with debilitating pain—whether it's post-operative pain, pain from an injury or the result of well-known chronic diseases, such as cancer, diabetes and arthritis—when they cast their votes on this important issue.

"Congressional action to provide strong and effective direction and resources to advance pain medicine has been long overdue. **Too many lives have been shattered by untreated or improperly treated pain,** which can negatively impact almost every aspect of a person's life including sleep, work, and social and sexual relations. People in pain have a right to timely, appropriate pain care.

"Since its inception, APF has been at the forefront of advocating for people living with pain and their caregivers. APF, along with a dedicated and extensive grassroots network of advocates and national partnering organizations, has been steadfast in its efforts to move this legislation forward. A basic tenet of medicine is to do no harm and to alleviate suffering. This legislation helps uphold the standard of medical care that every American deserves, and that which we should not falter to provide."

[Editor's Note: Reprinted by permission from the American Pain Foundation (APF). For more information, visit www.painfoundation.org.]

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## Medically Fragile Children's Act

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that state's Medicaid and Social Services programs, this bill will allow states to tailor programs to meet the needs of their most medically complex children. If enacted, this legislation would also support several innovative programs in New York and the successful medical partnership model pioneered by the Medical College of Wisconsin and the Children's Hospital of Wisconsin, which established the medical benefits of care coordination and family support for medically fragile children.

Jim Kaufman, Vice President for Public Policy for the National Association of Children's Hospitals (NACH), added his support by saying, "NACH has recognized the Medically Fragile Children's Program as an innovative partnership between the state of South Carolina and the Medical University of South Carolina Children's Hospital that provides coordinated, high quality and cost-effective health care to children with special health care needs. We commend the introduction of this legislation, which allows other states to implement similar programs incorporating family choice and access to program services up to age 25."

A study of the South Carolina program by the National Association of Children's Hospitals found significant per child savings for Medicaid over a less-coordinated delivery system and a reduction in emergency room visits by 50 percent for children served by the program. In addition, 55 percent of program enrollees exceeded clinical expectations.

In authoring this legislation, Senator Clinton and Congresswoman Baldwin were joined by Reps. Henry Brown (R-SC) and John Spratt (D-SC).

## Awareness and Fundraising

Special thanks to the following:

Connie Moeller invited residents from the Twin Cities and surrounding area to the Mall of America for the Chiari Malformation & Syringomyelia Walk for a Cure on September 20.

Chiari People of PA held a Mall Walk-a-thon and Auction on September 21.

Joyce Jordan solicited funds through an email-a-thon to support the PA walk.

Christine Marchesano and the ASAP South Jersey Chiari Awareness Initiative Support Group held a spaghetti dinner and auction on October 3.

## Member Profile

### A Family Affair

My name is Jennifer. I was diagnosed with Chiari malformation (CM) after 20 years of being told I was crazy. I was devastated but also pleased that my decades of complaints were finally validated. After my diagnosis, I was stunned by the noticeable lack of knowledge in the medical community about these conditions. I learned that unless I did my own research and enlightened many of my physicians, I'd just be dismissed in the same way I had been during the 20 years prior to my diagnosis—only now—they were dismissing me in spite of my brain hanging out of my skull!

I am the mother of 3 beautiful children who have recently been dealt the same diagnosis. Along with Chiari, they also have syringomyelia (SM), tethered cord syndrome, Ehlers Danlos syndrome and a variety of bony anomalies often found with CM.

I tried over the years to educate my family, friends and doctors, but my fight was a tiring, lackluster one. All that changed once my children were diagnosed. It's one thing to accept that there is little understanding about CM and SM when it was my own diagnosis, but I refuse to accept this lack of knowledge when my children's health is at stake. This is why I joined ASAP. They provided a wealth of information, along with tremendous support from other families afflicted with these conditions. I have great respect for the physicians on their advisory board and those associated with the organization.

On the journey for answers about CM and SM, I've discovered how easily the seriousness of these conditions can be dismissed. It's one thing if such dismissal only caused hurt feelings and a few more months or years of discomfort, but such is not the case—especially when it comes to syringomyelia. This condition can be a progressive, *gradually worsening* disorder that needs to be carefully followed by a specialist. It can destroy the spinal cord and cause damage to the nerve fibers. This is something that should not be taken lightly by anyone.

After I was diagnosed, I asked if I should worry about my children having it too. I was told that the familial incidence was very low and that unless they showed classic signs of CM, they needn't be tested. I've always instinctively suspected that the kids had CM too, but they never showed clear signs of it. They each had many of their own subtle signs, but none that screamed "Chiari!" I tried to ignore my instincts and have faith that they were okay.

It wasn't until I read a few medical articles that mentioned a possible connection between CM and tethered cord that my alarms sounded. I discovered that my children had very classic signs of a tethered spinal cord. Surely this wasn't a coincidence. Getting a prescription from the pediatrician for MRIs based on my suspicions (with only vague medical journal documentation of familial occurrences) was no easy task. I won't go into details about how everything unfolded, but the point needs to be driven home that there needs to be a much greater understanding of Chiari (by the pediatric and the medical community in general). Along with ASAP, I'd like to champion that campaign.

Chiari malformation and syringomyelia should get the serious research emphases they deserve. It is becoming abundantly clear that these conditions are not as rare as originally reported. Between the greater use of MRI and the understanding about the relationships between these disorders, more and more people are finally getting properly diagnosed. It needs to be understood that once a patient is diagnosed with a Chiari malformation, it's imperative that the entire spinal cord be scanned (MRI) to look for syringomyelia.

My daughter has a dangerously large syrinx in her cervical and thoracic spinal cord. I cannot help but ask myself how long it had been there and if she'd have less cord damage if we found it sooner. If left to our pediatricians, her spinal cord wouldn't have been scanned at all unless she had become severely and overtly symptomatic. If I didn't do my homework and be my children's advocate, they would be walking around this very day with cysts destroying the inside of their spinal cords—and no one would know it.

Too many doctors don't know, or understand the signs and symptoms of CM and SM. Too little is understood about the genetics behind these conditions. The 8-12% familial incident rate needs to be looked at more closely. I would bet my titanium cranial plate that this number is hugely underestimated. While I know 8-12% is the actual percentage found among patient populations, I challenge how hard they're looking at their patients' families. All too often I hear symptomatic patients referred to as having "incidental asymptomatic Chiari" simply because doctors don't understand the wide array of symptoms associated with Chiari. This has gone on for too long. It's 2008, we deserve the same treatment and research afforded the more well known diseases out there.

ASAP has a strong and growing research program for CM and SM. Please join me—help fight for awareness and research monies. Stand up and be heard—for your own sake and for our children's. Thank you!

## Getting the Word Out

*by Patrice Schaublin*

Our fight against CM and SM is long, hard and never-ending. However, over the last few years we have had more success in spreading the word. As a member of the Board of Directors, I attended the last few annual conferences. When I started, I introduced myself and indicated that one of my main goals was to make CM and SM household words like MS and fibromyalgia. Since then I've worked very hard at staying the course to spread awareness. I speak at various fundraising events, at dinners, schools and basically anywhere I am given the opportunity. Like many within our community, I am a volunteer with SM and CM and the parent of children with CM.

ASAP publishes a bi-monthly newsletter with medical research news, member stories and support information. We also offer many outreach programs including webinars and teleconferences. We provide crucial information to newly diagnosed members and assistance for support groups. We have a yearly conference for patients and caregivers, a kids club, a media library, a college scholarship program and support promising medical research. We also offer a chat room, message board, listserv and peer support.

We have been able to do many things with the funds that our members send us. We've become experts over the years at stretching our resources to accomplish much more than our modest budget would ordinarily allow. It is important to note that the world may be facing critical economic times but we will continue to provide needed programs. ASAP is a publicly supported organization; we need your help to continue raising funds. We are in this together.

I have been working closely with our Chief Development Officer, Arnie Hulteen. We would love to hear from you to talk about how you can help our cause. Fundraisers can be as simple as doing a write-a-thon or selling pencils or more time-consuming like putting on a dinner or golf tournament. We have lots of ideas and whether you are interested in spreading awareness or fundraising we are here to help. ASAP can provide educational materials for your event.

Please feel free to contact:
Arnie at Arnie_Hulteen@ASAP.org / 678-615-7690 or
Patrice at Patrice_Schaublin@ASAP.org / 919-382-5658

Thank you!

## Arizona Support Group News

*by Debbie Juengel*

Arizona State Senate

Senate Proclamation

FOR SEPTEMBER CHIARI AND SYRINGOMYELIA AWARENESS MONTH

WHEREAS, Chiari malformations (CM) are defects in the cerebellum, the part of the brain that controls balance, that create pressure on the cerebellum and brainstem which may block the flow of cerebrospinal fluid to and from the brain. Syringomyelia (SM) is a neurological disorder characterized by the formation of a fluid-filled cyst (syrinx) within the spinal cord. This cyst may, for unknown reasons, expand during adolescence or the young adult years, destroying the center of the spinal cord as it does.

WHEREAS, the condition Chiari was first identified by German pathologist Professor Hans Chiari in the 1890's. He categorized the CMs in order of severity: types I, II, III and IV. In 1898 W. Wagner and P. Stolper are credited with the discovery of post- traumatic syringomyelia, while in 1950 Gardner and Angel linked syringo with Chiari I.

WHEREAS, the cause of Chiari I malformations is unknown but scientists believe it is either a congenital condition caused by exposure to harmful substances during fetal development or that it could be a genetic condition, as it may appear in more than one family member. There are two major types of SM. In most cases it is related to Chiari I. SM can also occur as a complication of trauma, meningitis, tumor, arachnoiditis, or a tethered spinal cord.

WHEREAS, CM symptoms usually appear during adolescence or early adulthood and can include severe head and neck pain, vertigo, muscle weakness, balance problems, blurred or double vision, difficulty swallowing and sleep apnea. SM symptoms include but are not limited to: loss of sensitivity, especially to hot and cold, muscle weakness and spasticity, motor impairment, loss of bowel and bladder control, as well as osteoporosis and scoliosis. The majority of patients suffer from headaches and chronic pain.

WHEREAS, the National Institute of Neurological Disorders and Stroke of the National Institutes of Health is conducting research to find alternative surgical options and identify the cause of CM and SM to create improved treatment and prevention plans.

NOW, THEREFORE, I Jack Harper, Arizona State Senator, do hereby designate each September as Chiari and Syringomyelia Awareness Month.

Jack Harper
Arizona State Senator

Presented to
AZ Syringo & Chiari
Support Group
September [illegible]

We have exciting news to share with our ASAP SM/CM family!

The AZ Syringo Chiari Support Group has been presented with an Arizona Senate Proclamation declaring the month of September as Chiari and Syringomyelia Awareness Month.

"Now, therefore, I, Jack Harper, Arizona State Senator, do hereby designate each September as Chiari and Syringomyelia Awareness Month."

We are honored and blessed to have received this wonderful recognition!

### Newly Forming Support Groups

Shane & Melissa Gray
Support Group for parents of children with CM
in the Raleigh-Durham-Chapel Hill, NC area
mow_er_racer@hotmail.com or 336-376-0067

***************

Alana Ficco
Western Pennsylvania Support Group
trendzthesalonspa@comcast.net or 724-433-0449

***************

Brian Murphy
Central New Jersey Support Group
Shrewsbury, NJ
bmurphywalk@comcast.net or 732-383-8133

***************

For information on established support groups check out the ASAP site for location and meeting times.
http://www.asap.org/resources/support-list.html

Peer support groups are a beneficial way for those affected by syringomyelia and/or Chiari to share with others who understand their unique situations. If you would like to join a local support group, contact a group leader listed on our web site. If you do not find a local group and would like to start one contact Jamie at Jamie_Mayhan@ASAP.org or 903-236-7079.

ASAP support groups are not monitored or regulated by ASAP. We will provide information and resources based on availability.

## Don White Memorial Fund Underwrites Virtual Support Groups and Teleseminars

*by Sara Patterson*

The ASAP Board of Directors is pleased to announce that donations to the Don White Memorial Fund will be used to underwrite the ASAP Outreach Program. Our founders, Don and Barbara White, started this organization to connect people and combate isolation. Their grassroots efforts centered on disseminating information through an international newsletter prepared and sent from their dining room table. In its second year ASAP held the first syringomyelia (SM) and Chiari malformation (CM) conference to bring people—patients, caregivers, doctors, researchers—interested in SM/CM together. What a moving experience for those attendees! For the first time in their lives they realized they were not alone. They found comfort just to sit with someone who understood their frustration and suffering. They felt reassured that physicians were taking notice and had an interest in finding answers.

Yet twenty years later, that isolation continues to persist. We still get daily calls from individuals who have received inaccurate medical information or no information at all. People still face the disorders in seclusion. Each year at the annual conference people come face-to-face with others who share the same experience. A special magic happens when kindred souls meet and share something that can't be explained in words. It touches the heart and renews the spirit. Support is essential and will always be a part of ASAP's mission.

While the number of new local support groups is growing, there are still many states and many areas where one-on-one support is lacking. This year, ASAP has launched a new program to tackle this problem. ASAP Outreach telephone support groups are the next best thing to bringing together people in person. These unique monthly meetings allow individuals to talk via the telephone from all over the country. Groups consist of 8 to10 members and meet monthly. The calls are free to support group members; ASAP covers the cost of these hour-long meetings.

In addition to the telephone support meetings, ASAP combats the isolation associated with the lack of medical information by hosting periodic teleseminars that feature keynote speakers of various interests to the SM/CM community. Members are invited to call a toll-free number and hear an interactive presentation with leading researchers in the field.

To make a donation to the Don White Memorial Fund, please visit www.ASAP.org or call 903-236-7079.

## FDA Increases Clinical Trials Information Available to the Public

The Food and Drug Administration (FDA) is increasing its public reporting requirements for information about clinical trials progress and results. This requirement was mandated under the Food and Drug Amendments Act of 2007 and expands the number of clinical trials that must submit data to its web site: www.clinicaltrials.gov.

Initial registration information on a new trial must be posted within 21 days of enrolling the first subject and changes must be posted within 30 days. Results of a trial must be posted within 12 months of completion.

This information will be required for approximately 3,000 trials of drugs and biologics, and 450 trials of medical devices each year. The agency also estimated that nearly 12,000 other voluntary data submissions will be collected.

ClinicalTrials.gov is a registry of federally and privately supported clinical trials conducted in the United States and around the world. For people interested in finding out more about participating in a trial, the site gives you information about a trial's purpose, who may participate, locations, and phone numbers for more details. Enrollment should only be considered in conjunction with advice from your doctor.

## Central New Jersey Support Group Meets

*by Brian Murphy*

The Shrewsbury Firehouse was the location for the first Central New Jersey Chiari and Syringomyelia Support Group.

- There were 10 people present dealing with a disorder with 10 different stories.
- Out of the 10 people the ages ranged form 6 to 80, so there is support needed for all ages.

Coming together and seeing each other and knowing that you are not the only one in the room fighting this battle made it easier for everyone to relax and enjoy the time spent with each other. We plan on a meeting every third Thursday of each month. The next meeting will be held on November 20.

Brian Murphy
Central New Jersey Support Group
Shrewsbury, NJ
bmurphywalk@comcast.net or 732-383-8133

## Meet the Medical Advisory Board

### Barth A. Green, MD

Barth A. Green was born in Shoemaker, California and grew up in Chicago, Illinois. He is the son and grandson of family physicians, each of whom made significant commitments to serve disadvantaged patients in Chicago. His mother Sonia was a strong advocate of civil rights and social justice, both as an educator and a community activist.

During his medical school years, Dr. Green was exposed to the extraordinary courage and integrity of paraplegics who volunteered in the spinal cord injury research laboratory where he worked as a research assistant. His early admiration for these paralysed individuals developed into a life-long commitment toward creating effective treatments and a cure for paralysis. This quest for the cure to paralysis continued throughout his residency training at Northwestern University. His research accomplishments resulted in his recruitment by the University of Miami School of Medicine.

He arrived at the University of Miami Medical Center in 1975. He was charged with creating within the largest and busiest public hospitals in America—Jackson Memorial Hospital—a spinal cord injury center, as well as with enhancing the spinal cord injury program at the Miami Veterans Administration. By 1985, Dr. Green's research and clinical activities led to his co-founding with the Buonicontis, The Miami Project to Cure Paralysis, now the largest and most productive spinal cord injury and paralysis research center in the world. Their research projects range from very basic molecular biology and genetic engineering to the most clinically applied programs including computer-assisted walking and allowing paraplegic men to father their own children. Many of the innovations created by The Miami Project scientists and clinical researchers are already being utilized in hospitals all over the United States and around the world.

Another major effort of Dr. Green is his work with Project Medishare for Haiti which he co-founded with Dr. Art Fournier approximately 10 years ago. Project Medishare is committed to the welfare and health of tens of thousands of Haitians living in the most isolated and underserved part of that country—the central plateau.

Dr. Green also serves on the board of the Center for Haitians Studies and Health Services in Little Haiti and is active in many of their community outreach programs. In his spare time, Dr. Green is Professor and Chairman of the Department of Neurosurgery at the University of Miami and Chief of Neurosurgery at Jackson Memorial Hospital and the Miami VA Medical Center where he performs several hundred surgical cases a year and sees and treats thousands of patients.

All of the aforementioned has been made possible by the support Dr. Green receives from his wife Kathy, sons Jeremy and Jared, and daughter Jenna. He is supported by his colleagues at the medical center as well as in the community.

Dr. Green's research interest comprise translational research for spinal cord injury including cellular transplantation and neural tissue protection, especially as it applies to mild hypothermia. Also the surgical management of spinal cord injury and diseases, including spinal cord tumors, myelopathy, tethered spinal cords, Chiari I malformation and syringomyelia. He has published over 60 book chapters and monographs, 211 abstracts and 156 journal articles.

Having served on ASAP's Medical Advisory Board since 1996, Dr. Green has been an integral part of our growth. He hosted the ASAP Annual Conference in 1998 and again in 2004.

## Thank You!

*by Patrice Schaublin*

Thank you for your generosity in donating many wonderful items to the auctions at our conference and special events. We could not have done it without you. We received donations of handmade necklaces, earrings, bracelets, birdhouses, quilts, afghans, pine needle baskets, handmade cards, airline tickets, perfumes, coffee pots, handmade wood items and Alaskan crabs. We received such a variety of items that it is impossible to list them all.

I am looking forward to next year's conference in Wisconsin. If you would like to get involved in the auction or have any questions, please contact me by email: Patrice_Schaublin@ASAP.org. Remember we are all in this together.

**Save the Date**
**2009 Annual Conference**
**July 15 - 18**
**Sheraton Madison Hotel**
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**Thank you** for contributing to ASAP's recent membership drive. We have received over $30,000 and the donations are still coming. Thank you for helping us to continue providing the programs and services that are so desperately needed by those fighting the battle against syringomyelia and Chiari malformation. If you have not returned your 2008 membership drive materials there is still time to participate.

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Chiari and Syringomyelia: Introduction and History of Treatment Methods

- W. Jerry Oakes, MD

Pain Management in Patients with Chiari I and Syringomyelia

- Ann Berger, MD

The Ins and Outs of Social Security Disability

- Mr. David Melton

**DVD 08-02**

Tethered Cord Syndrome

- John Oro, MD

Treatment of Chiari and Syringomyelia in Children

- Robert Keating, MD

Moderated Questions from Attendees

- Jerry Oakes, MD
- Ann Berger, MD
- David Melton, PhD
- John Oro, MD
- Robert Keating, MD

**DVD 08-03**

Association of Chiari and Tethered Cord Syndrome: Preliminary Results of Sectioning the Filum Terminale

- Paolo Bolognese, MD

Scoliosis and Other Deformities in Chiari I and Syringomyelia

- Douglas Brockmeyer, MD

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- John Heiss, MD

**DVD 08-04**

Techniques and Problems of Craniovertebral Fusion for Craniocervical Instability and Hindbrain Herniation

- Arnold Menezes, MD

How a Service Dog Can Enhance Your Life

- Canine Companions for Independence

Moderated Questions from Attendees

- Paolo Bolognese, MD
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**DVD 08-05**

Investigation on the Pathogenesis of Post-Traumatic Syringomyelia

- Chris Shields, MD

Urological Issues in Patients with Spinal Cord Dysfunction

- Toby Chai, MD

Moderated Questions from Attendees

- Chris Shields, MD
- Toby Chai, MD
- John Heiss, MD
- Roger Kula, MD

**DVD 08-06**

Engineering Analysis of Syringomyelia

- Frank Loth, PhD

Selective Cognitive Abnormalities Underlie Patient Complaints of “Brain Fog” in Chiari I Malformation

- Roger Kula, MD

Headache in Patients with Chiari I Malformation and Its Response to Surgery

- Charles Sansur, MD

**DVD 08-07**

Intracranial Hypertension (Pseudotumor Cerebri) and Hydrocephalus in Chiari I Patients

- Ghassan Bejjani, MD

Genetic Studies of Chiari I

- Joan Bailey-Wilson, PhD

Moderated Questions from Attendees

- Frank Loth, PhD
- Charles Sansur, MD
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- Roger Kula, MD
- John Heiss, MD

**DVD 08-08**

CSF Flow Studies in CM/SM Patients

- Matthew McGirt, MD

Primary Spinal Syringomyelia

- John Heiss, MD

Moderated Questions from Attendees

- Matthew McGirt, MD
- John Oro, MD
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*Celebrating* 20 Years of Excellence

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 or ASAP, PO Box 1586, Longview TX  75606

Patricia Maxwell   Editor, *ASAP Connections*

ASAP's MISSION
*"Help Us"*

To improve the lives of persons affected by syringomyelia, Chiari malformation and related disorders while we find the cure

## ASAP Board of Directors

## ASAP Medical Advisory Board