

ASAP *Connections*

Issue 3, 2010
vol. 23.01



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

IN THIS ISSUE...

Contact Us
page 2

ASAP Board Members
page 3

Ask The Experts
page 4

Syrinx Shunts
page 5

Syringomyelia: Definitions
page 6

ASAP Conference
page 7

Erol Veznedaroglu, MD
page 8

I Made It!
page 8

Conference Speakers
page 9

2010 Awards
page 10

Cruisin' for Chiari
page 11

ASAP Welcomes New Board Members

The ASAP Board of Directors is pleased to announce the addition of two new members. Dr Erol Veznedaroglu has been involved with ASAP on many levels over the past year and we are very excited to have him serve on our Board. You can read more about Dr Vez on page 8 of this issue.

In addition, Dr John Oró will serve as the Research Committee Chair. This position was previously held by Dr John Heiss, who has taken over as Medical Advisory Board Chair.

Due to Dr Oró's extensive involvement with the organization we have featured him several times in *Connections*. If you would like to read more about him, please visit us on the web at www.ASAP.org.



ASAP Telephone Outreach

ASAP Telephone Support Groups are designed to offer people the chance to talk once a month with others who are sharing the experience of living with syringomyelia and/or Chiari malformation. This program provides an opportunity to meet others and share ideas.

These groups offer peer support. Participants are not medical doctors and cannot give medical advice. We ask that all callers keep the conversations confidential. What happens in the group, stays in the group!

Each call consist of fewer than 10 individuals allowing you the opportunity to share and support one another in a friendly atmosphere.

If you are interested in participating in the telephone outreach contact the ASAP office for more information.

Marcy Speer Memorial Helps Fund Duke Genetic Study

The Marcy Speer Fund was initiated to allow ASAP members the opportunity to support the genetic study underway at Duke University and to remember a great lady. One hundred percent of the donations ASAP has received earmarked for this fund was recently presented to the team continuing Marcy's work.

The following is a reprint of the acknowledgement received from Allison Ashley-Koch, PhD and Simon G. Gregory, PhD, at the Center for Human Genetics:

Thank you sincerely for your recent donation to the Chiari genetic research program at the Duke Center for Human Genetics, in memory of Dr. Marcy Speer. We are honored and privileged to receive this generous contribution from the American Syringomyelia & Chiari Alliance Project (ASAP).

As you know, before her untimely passing, Marcy was active in ASAP as a Board member and was committed to ASAP's educational and research missions. She was also very fortunate to have received funding support from ASAP early in her career that allowed her to build a Chiari genetics set. The funding she received then was crucial for laying the foundation of the work that we are currently doing today. Every research dollar counts and, like Marcy previously, we will use this gift to help us continue to dissect the genetic etiology of Chiari malformations.

Our hopes are that continued research and education will allow us to better understand the causes for Chiari which will eventually lead to more accurate genetic counseling and risk assessment, improved treatments, better prevention methods, and possibly, a cure. Not only do contributions such as yours help make these studies a reality, they are an especially rewarding affirmation of your support of our efforts. Thank you once again for your support.

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

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ASAP

Contact Us

ASAP

American Syringomyelia & Chiari Alliance Project

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Kittery Maine 03904

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Awareness and Fundraising

Share your ideas and experiences with others. Submit a short story by email to Patricia_Maxwell@ASAP.org or mail typed or clearly written article to:

ASAP
PO Box 1586,
Longview TX 75606-1586

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.

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. Over the years, ASAP has received thousands of dollars 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.

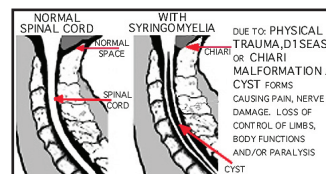


Please send stamps to:


Maynard Guss
9593 NW 26th Place
Sunrise FL 33322-2738

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
Street Address
City, State, Zip Code
Telephone No.
Email Address

ASAP American Syringomyelia & Chiari Alliance Project Inc
P.O. Box 1586 Longview, Texas 75606-1586
903-236-7079 Website: www.ASAP.org

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

Getting to Know the ASAP Board of Directors

ASAP Board members volunteer their time and skills to further the mission of the organization. They are elected for a term of three years by a majority vote of the current Board of Directors. The Directors are responsible for setting forth the policies of ASAP.



Karen McFarland, RN

Email: Karen_McFarland@ASAP.org

Karen McFarland lives in Richmond, Virginia and is the mother of two girls, Stephanie and Kimberly. She learned about ASAP in 1999 when her youngest daughter was diagnosed with SM and CM. Karen has been an active volunteer for ASAP

for many years and both of her daughters are members of ASAP's Kids For A Cure Club.

A registered nurse in the states of Virginia and New York, Karen brings to the board fifteen years experience in home health care, medical-surgical, and peritoneal dialysis. She is currently employed as a telephone triage nurse.

Karen exemplifies the spirit of caring by offering support to newly diagnosed families and those struggling with issues relating to SM/CM. Caring for her daughter has provided on the job training in the areas of adaptive equipment, coping strategies, and alternative methods of pain relief such as acupuncture and massage therapy. She has learned to deal successfully with the school system in order to provide her daughter with necessary modifications and is always willing to share her knowledge with others.

Karen is also a volunteer and strong supporter of Canine Companions for Independence. Her family is the proud caregiver of Lace, a Labrador Retriever who provides assistance and companionship for Kimberly.

Karen is excited to be a part of the ASAP Board and is looking forward to seeing ASAP grow and expand.

Together We Can Walk & Roll

Walks are easy and fun and anyone can participate. They can be simple or elaborate. They can be held at schools, parks or through a neighborhood. You can even include various enhancements like entertainment and vendor booths.

Are you interested in coordinating a walk in your community? To find out more about *Together We Can Walk*, contact Mike Scarpone by email at Michael_Scarpone@ASAP.org or call 207-439-2538,



Patrice Schaublin

Email: Patrice_Schaublin@ASAP.org

Patrice resides in Durham, NC with her family. After a whirlwind of non-diagnoses and misdiagnoses, syringomyelia was discovered in 1993. She was later told she also has Chiari malformation. Patrice underwent decompression surgery in September of 1994.

Wanting to give back to ASAP for all she received while seeking a diagnosis, Patrice started answering support calls. Her involvement progressed to coordinating auctions at the annual conferences. She then started a support group in New Jersey. Elected to the Board of Directors in 2004, she has worked on a variety of committees, including Personnel and Revenue Generation. Patrice continues her work on the Revenue Generation Committee and is involved in grassroots fundraisers and event planning. Patrice also serves on the Conference Committee and is active in developing support groups.

Patrice knows that fundraisers raise money for research but they also spread awareness. She is always looking for the opportunity to get the word out about CM and SM. Her fundraising experience goes back 18 years. Always one to take on a challenge, Patrice brought fundraising to a new level in the different schools her children attended where she served as PTA president.

Patrice feels she must always look at the glass as half full. She has had to raise a family and show her children, you can live a normal and fulfilling life even while dealing with chronic pain. She said, "It's hard when people always say you look great, but one never knows how you feel. A doctor once said, 'It's the look-good disease'."

Patrice attended Wheeling College and was a successful sales manager. She now enjoys spending time with her family, photography, reading and her horses. Her goal is to make CM and SM a household name and help find a cure for future generations. She feels we are making bigger strides now more than ever. In 1993, very few people heard the words Chiari or Syringomyelia. Today we are breaking new ground and spreading awareness to new levels.

Ask The Experts

Questions and Answers Covering Basic Concepts

Question: Do you think it would be beneficial to have surgery on a small syrinx; do symptoms matter? I have a 6mm syrinx.

Dr Albright: I would not decompress somebody that had a 1 or maybe a 2mm syrinx in diameter but I would follow them closely. The question really is what's the minimal number at which you would operate? All of us would operate if it's a substantial syrinx. Given that the average diameter of the thoracic cord is probably about 12mm, that's half the volume of the cord.

Dr Keating: It's a great question and like every great question, there are no definitive answers. Syrinxes come in all sizes and shapes; long ones, short ones, wide ones, etc. There is no question that we will see a number of patients with a "syrinx" picked up from a car accident or something like that where the patients are perfectly fine.

I try to go back to what I learned in medical school, treat the patient not the x-ray. As a pediatric neurosurgeon it makes me a little uncomfortable to take an asymptomatic patient with a legitimate spinal cord syrinx that is fifty percent of the canal, and tell the family and the child that they need to have an operation that has some risks to it.

You have to look at the big picture. You have to take the time as a patient or as a clinician and look at the whole story. Does the history match the exam? Does it match the diagnostic workup? I think it's easy when you come up with a very solid story, solid exam and solid testing to say it makes sense. We know that for disease X if you do it the right way you end up with a good result 96% of the time.

I always tell every one of my parents, weigh the risk versus benefit. The benefit should significantly outweigh the risk. If it's an equivocal benefit where the risks are huge and tougher to overcome, then I have a hard time justifying that to a family. You have to look at the big picture.

In time it becomes more apparent. It becomes more legitimate and it's easy to say okay. If I have an equivocal syrinx we don't necessarily operate on it. If it is small, we will watch the patient. I cannot tell you how many kids we have with scoliosis. 13 year old girls with an 18-20 degree curve. It is enough to get your attention but it's not a huge curve. They have a small, mid-thoracic syrinx. We do not operate on these patients; we watch them closely because we don't know the answers and have a tendency to be conservative.

Question: Many of us have multiple children, siblings that you get concerned about when you've had a diagnosis in your family. When should the other children get checked?

When should they get an MRI?
When should a neurologist look at them?

Dr Keating: Part of it is we don't know the whole genetic story. I'm hoping in the next five years we'll have a better understanding of what the percentage is of having another sibling with this problem. In the current scenario, we don't know that. I work in Washington DC. I see all kinds of families and patients. I have parents that will not leave your office without an MRI scan. I have other parents that say 'Well Johnny's been walking like that since he was two. He can still go to school. What's the big deal?'

One of my first questions now is if there are any other family members who have similar symptoms? If the symptoms sound suggestive or worrisome to me I think in this day and age with everybody getting scanned, it's not unreasonable to offer a scan. If you've got a mother who's got a child that has lots of issues and four other kids who are all fine, I don't try to push another whole layer of issues and problems on them. Those parents have enough things on their plate without making it more complicated.

Question: I have a question related to the diagnosis of hydrocephalus, particularly, for individuals with later adult onset of syringomyelia. When we get an abnormal headache but the tests that are done do not show hydrocephalus. Is there a connection between these extreme pressure headaches and a buildup of pressure that isn't being picked up diagnostically. The main symptom is this headache which seem to be related to pressure.

Dr Albright: Well if the headaches are relatively frequent and the ventricles in the brain are of completely normal size, pressure is probably not the cause of the headache. If the ventricles are moderately enlarged and the headaches are fairly frequent you could either do a one-time spinal tap to measure the pressure or better you can put in an intracranial pressure monitor. It's a minor procedure and then measure the pressure for 24 to 48 hours and see if you have pressure spikes.

A. Leland Albright, MD - Pediatric Neurosurgery, University of Wisconsin, Madison, WI

Robert Keating, MD - Chiari of Neurosurgery, Children's National Medical Center, Washington, DC

[The preceding is an excerpt from the 2009 Conference Notebook that is available in an affordable download through www.ASAP.org.]



Syrinx Shunts

by John Jane Jr, MD

What are the different types of syrinx shunting procedures?

In general, a “shunt” is any procedure that diverts fluid from one space to another. For a syrinx shunt, the fluid is diverted from the syrinx into another space where the fluid can be absorbed. What distinguishes one shunt from another is the location of that space. The space may be in subarachnoid space (the space surrounding the spinal cord immediately outside the syrinx), the lung lining (or pleural space), or the abdomen (or peritoneal space). Physicians name the shunts based on where they start and end. Therefore, the shunt may be a syringo-subarachnoid shunt, a syringo-pleural shunt, or a syringo-peritoneal shunt. The decision to use a shunt depends greatly on the clinical situation and the surgeon’s preferences.

When is it indicated?

In most circumstances, a syrinx is considered to be a side effect of another problem (i.e. Chiari malformation, tethered spinal cord, post-traumatic spinal cord injury). Surgeons treat the primary cause of the syrinx first before performing a direct operation on the syrinx.

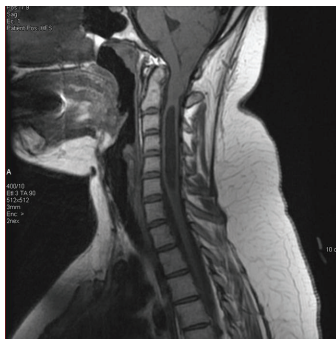
In the setting of a Chiari I malformation, a syrinx shunt is not the first procedure that is performed. Most often, the Chiari decompression will effectively treat the syrinx. If the Chiari decompression fails to decrease the syrinx size, the surgeon may consider whether the decompression was inadequate, whether there is evidence of a tethered cord, or whether there is hydrocephalus. If these situations are either not present or have already been addressed surgically, then the surgeon may consider performing a syrinx shunt as a last resort.

Similarly, in the setting of a tethered cord that is associated with a syrinx, the surgeon will most often perform a tethered cord release first. If this fails to decrease the syrinx and there are no other potential causes of the syrinx, the surgeon may consider performing a syrinx shunt.

Post-traumatic syringes can be difficult to treat surgically. Surgeons often will attempt to treat the scarring that is present around the spinal cord first. Should this fail to treat a progressively enlarging and symptomatic syrinx, the surgeon may consider performing a syrinx shunt.

What are some possible complications?

In order to place the shunt into the syrinx, an incision must be made in the spinal cord. Whenever an incision is made in the spinal cord there is a risk of injury and therefore paralysis but more often there is minor sensory



disturbances resulting from shunt placement. When possible the surgeon will make an incision at a level that is below the nerves that go to the arms. This is generally below the first thoracic vertebra. One of the more common complications of a shunt is that it can fail after a period of time working. Shunt failure can occur because of scarring, or the catheter may become clogged and is no longer able to divert fluid from one space to another.

Shunt failure may not cause symptoms (asymptomatic) and may only be apparent when an MRI is performed and shows that the syrinx has refilled or enlarged. When symptomatic, it typically presents with a return of the symptoms that were occurring before the shunt was inserted.

There is some debate about whether any restrictions are needed in patients who have shunts. Some surgeons prefer patients to not perform contact sports or activities that may cause twisting that could put tension on the shunt. However, other surgeons place no specific restrictions on patients with shunts.

One Woman’s Battle for Awareness

by Patricia Maxwell

Julie Jarvis is a self-imposed gladiator for awareness. The thought of genetics, future generations and the lack of knowledge pertaining to physicians in southwest Michigan has spurred her to no longer settle for as is. For Julie, creating awareness and understanding about Chiari malformation and syringomyelia is a priority.

Julie said, “As my symptoms progress and my energy level decreases, I will fight harder to make awareness a reality. Syringomyelia brought me to this point in time. I accepted its challenge and lean on my deep faith in God and prayer to stay strong and pursue.”

Julie purchased numerous conference notebooks and DVDs to send to hospitals and doctors in her area. Each package also includes a personal letter and the ASAP brochure. Doctors are encouraged to pass the information to others after they have read it.

She has received mixed responses from the doctors, some favorable others not. But that does not discourage Julie. She is determined to continue her fight, hoping one day to know that the children will not have to endure the uncertainty.

Syringomyelia: Definitions, Concepts and Treatments

By Bermans Iskandar, MD

This is a basic overview of what syringomyelia is. It is a cyst in the spinal cord. It can be caused by many things and has different names. There is controversy as to what you should call it – hydromyelia, syringomyelia, syringohydromyelia, spinal cord cyst, et cetera. If it goes into the brain stem, it is called syringobulbia.

The diagnostic study of choice is spinal MRI. You need to get the brain MRI as well to rule out things like Chiari, brain tumors, hydrocephalus, et cetera. You need a complete spinal image to look for tethered cord, spinal cord tumors, et cetera.

Treatment is in two categories. If you have a very thin syrinx that is not symptomatic, it is best managed conservatively. Don't do anything, watch it over time and most people do fine. If you can identify a cause, if the syrinx is bigger and causing significant symptoms, treatment should be considered. Treatment is best performed on the cause of the syrinx. It's very disappointing to treat the syrinx itself by putting a stent in or draining it; they often come back because you haven't treated the original cause.

If you have a Chiari I malformation you can have a syrinx related to it. Treatment is posterior fossa decompression. Almost always the syrinx goes away.

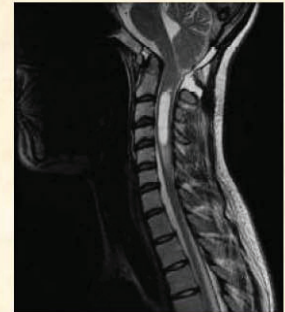
Another cause for syringomyelia is Spina Bifida, a myelomeningocele, which is an abnormality in the spinal cord that kids are born with. They end up with a Chiari II malformation, where all the posterior fossa contents herniate, not just the tonsils. The syrinx can be caused by different things, hydrocephalus, Chiari II malformation, or tethered cord. So this is a very complex patient population and treating the syringomyelia in this population is very difficult.

Arachnoiditis, scar tissue around the spine, whether from spinal taps or infections, is difficult to treat and can cause syringomyelia. The key to treatment is to treat the arachnoiditis. Trauma is the most difficult one to treat. Often times there are severe arachnoiditis or the syrinx is caused by atrophy. All of a sudden you form a cavity but this cavity is not under pressure therefore it doesn't need to be treated. The symptoms you see are from damage to the spinal cord, not from the syrinx being there.

Finally the term idiopathic, which means no identifiable cause, is probably the majority of the patients we see. A lot of patients come in and we have no idea why they have the syrinx. It is causing some symptoms that are questionable and we don't know how to treat them. If it's huge we will often either put a stent in the syrinx or in some cases it's been shown that a posterior fossa decompression might

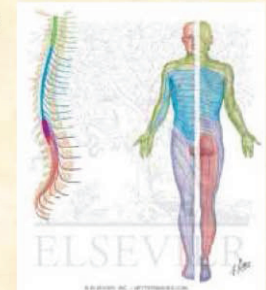
SYRINGOMYELIA

- ✗ Fluid-filled cavity within the spinal cord
- ✗ Other nomenclature
 - + Hydromyelia
 - + Syringohydromyelia
 - + Spinal cord cyst



SIGNS AND SYMPTOMS

- ✗ Dissociated sensory loss
- ✗ Central cord syndrome
- ✗ Brainstem symptoms and signs
- ✗ Scoliosis
- ✗ Chronic pain



help. That is what was termed Chiari Zero, but that is very controversial. It's rare. This is a very difficult area to treat.

In conclusion, prognosis with Chiari decompression the syrinx goes away, almost always. The symptoms improve usually. It's better in children than in adults by the way because as you get into your 40s, 50s and 60s the syrinx has probably caused a lot of damage to the spinal cord and a lot of times the symptoms are coming from that damage, not from the presence of the syrinx.

Spina Bifida can have excellent outcomes when we know the whole picture. Often time it's the VP shunt or the hydrocephalus that is the problem. Arachnoiditis, if it's a focal arachnoiditis, a very small area that we can cut down, then that usually does well. But if it's diffuse where the whole spine is scarred, it's very difficult to treat. Trauma is also difficult to treat, poor outcomes both in pain and in syringomyelia. Tumors are excellent outcome for syringomyelia but outcome depends on the nature of the tumor.

Medical Articles Available

www.ASAP.org/disorders/articles

ASAP Chiari & Syringomyelia Conference

Bridgin' the Gap between Research and Reality

New Hope

by Gail Donahue

For the first time since I was diagnosed, I had the opportunity to meet others trying to cope with difficult medical issues resulting from a Chiari malformation or syringomyelia or both. I enjoyed being able to talk with knowledgeable physicians who have patients with Chiari and syringomyelia.

I was diagnosed in March 1987 by MRI in a clinic in London; I was then sent to Landstuhl, Germany for evaluation by a neurosurgeon. Within a few days, I was in intensive care recovering from spinal decompression and restructuring of the cerebral tonsils. My spinal cord was filled with fluid from the C1 to T10 level. Recovery was a slow process. I was blessed to have a doctor with the courage to tackle this complicated problem.

Although my experience with Chiari I and syringomyelia has been an uphill battle, I now feel hopeful that the attention brought to this complex medical problem through ASAP will help us all.

Learning

by Debbie DeBartolo

I enjoyed the conference so much and learned an unbelievable amount of information! I didn't realize how much Joe and I did NOT know about my conditions. I was never told any of it, but have suffered for so long(years) with the syringomyelia and the autonomic dysreflexia symptoms thinking I was crazy and turning into a hypochondriac. Now that I'm on a few medications for the problems, things are a little better.

I'll never forget my trip there, it was a long one but so worth it. I'm hoping the new testing will help find out why my condition worsened since the surgery.

Hope Renewed

by Sara Patterson

It happens every year. Attending an ASAP conference renews the spirit and breathes new hope into what seems like hopeless situations. This year was no exception.

My daughter just celebrated her sweet sixteenth birthday. All she wanted was to attend the conference- her one chance to see and talk with other kids who face the same challenges she does.

She wasn't able to participate in most of the activities- her pain levels kept her in the hotel room most of the time. But still she said it was great, and can't wait to go again. And myself? Well, I left with great information that is going to help me get my daughter functioning again. For the first time in months, I feel hopeful and confident that help is out there. Now I know what to look for and where to go.

Maybe you are feeling as downhearted as I was when I stepped off the plane in Austin. If I can share one thought with you- it's this: don't give up. Stay connected to ASAP and keep reading and searching and asking questions. Together we can do this!

Understanding

by Debbie Culver

Going to the ASAP Conference helped me to realize so many things that Kaya (my granddaughter) had been and is still going through. I talked with people that could actually explain what they were feeling. I wish I would have gone a long time ago. Meeting and making so many new friends made me want to go out and raise more money and get awareness along with the research out there. I hope to return next year to see what we have learned. Really interested in finding out if it is hereditary or not. Thank you so much for all you had to offer.



Poster created by youth at conference, raised \$500 for research.

Meet Erol Veznedaroglu, MD, FACS

Dr Erol Veznedaroglu is director of Neurosciences and Endovascular & Cerebrovascular Neurosurgery at Capital Health. He was formerly director of the Division of Neurovascular Surgery and Endovascular Neurosurgery and director of the Cerebrovascular Fellowship Program at Thomas Jefferson University Hospitals.

Following his fellowship training in cerebrovascular/neurointerventional neurosurgery and neuro-critical care at Thomas Jefferson University Hospital for Neuroscience, he became a nationally recognized endovascular and cerebrovascular neurosurgeon in the treatment of aneurysms, arteriovenous malformations, stroke and other potentially fatal conditions of the brain. Dr Veznedaroglu's expertise includes skull base vascular neurosurgery and he is one of the most experienced physicians on the East Coast in providing patients with expert diagnosis and treatment for structural defects such as chiari malformations.

Dr Veznedaroglu has designed and invented coils for the treatment of wide-necked aneurysms. He was the first doctor in the mid-Atlantic region to use the wingspan stent system, the first FDA-approved stent used to open clogged arteries in the brain. He is also one of only a few physicians in the nation chosen by trial investigators to treat aneurysms with a "glue-like" substance called Onyx HD500. This substance is injected into an aneurysm where it quickly solidifies and cuts off the area's blood supply to prevent a potentially fatal burst.

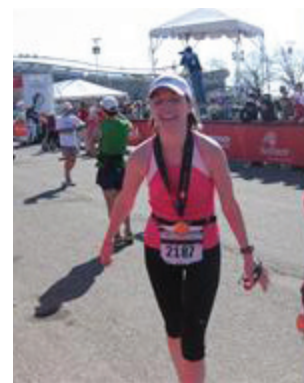
Erol Veznedaroglu was also the first in the region to use the Merci Retriever and Penumbra devices as well as the Cordis Enterprise Stent. A corkscrew-like device that removes blood clots in the brain caused by stroke, the Merci Retriever increases blood flow to the brain and limits the amount of brain damage caused by stroke, allowing patients to recover faster with less permanent stroke impairments. While the Merci Retriever pulls the clot out, Penumbra is a tiny vacuum device that sucks up the blood clot and restores blood flow to the brain. The Cordis Enterprise Stent treats patients with wide neck aneurysms through a specially designed microstent that allows aneurysms to be treated through a minimally invasive surgery without opening the skull. In addition to leading these and many other innovative best practices in stroke and cerebrovascular care, he is the only physician in the region who can proctor and train other physicians across the country on these same devices.

Primary investigator of numerous clinical and basic science studies related to cerebrovascular disease, Dr Veznedaroglu is a nationally recognized academic leader in this area of care. He has written chapters and articles in various publications that are used as data for his colleagues across the country and he is invited to lecture and chair at international conferences for physicians around the world.

I Made It!

by Kerry Chu

I got into the NYC marathon and I am running to raise awareness and funds for Chiari & syringomyelia!



The premier event of New York road runners, the ING New York City Marathon is one of the world's great road races, drawing more than 100,000 applicants annually. The race attracts many world-class professional athletes, not only for the more than \$600,000 in prize money, but also for the chance to excel in the media capital of the world before two million cheering spectators and 315 million worldwide television viewers. As any one of the more than 700,000 past participants will attest, crossing the finish line in Central Park is one of the great thrills of a lifetime.

I had surgery in November 2004 for Chiari malformation. Since then I have become active in the American Syringomyelia & Chiari Alliance Project. Last summer I started a local support group on Long Island. We meet every fourth Wednesday of each month from 6:30 PM till 8:00 PM in Garden City, New York. For more information you can contact me at nyasapsg@yahoo.com.

This will be my fifth marathon and I am doing it in honor of my fellow support group members and all those that suffer the devastating effects of Chiari and syringomyelia. Please help fund research, education and support by making a donation at www.firstgiving.com/kerrychu1. Your prayers and support are greatly appreciated!

Many thanks for your support -- and don't forget to forward this to anyone who you think might want to donate too!

Editor's Note: [If you would like to make a donation in honor of Kerry but you do not have internet access, just send your check to the ASAP office with a note that it is in honor of Kerry.]

Upcoming Events

www.ASAP.org/get-involved

Submit information about your upcoming ASAP events to info@ASAP.org

2010 ASAP Chiari & Syringomyelia Conference Speakers

The 2010 ASAP Chiari & Syringomyelia Conference provided a wide variety of topics. We take this opportunity to recognize the following men and women. They took time out of their busy schedules to share their experience and knowledge for which we are extremely grateful. Our appreciation to Child Life Specialist of Dell Children's Medical Center for their assistance with the the children's conference.

Robert Buchanan, MD – Chief, Functional Neurosurgery, Seton Brain and Spine Institute, Austin, TX

Norman Chenven, MD – CEO/Founder of Austin Regional Clinic, Austin, TX

Jennifer Farley, RN, MSN – Clinic Program Coordinator at Neurosurgery Center at Dell Children's Medical Center of Central Texas, Austin, TX

Christopher Garrison, MD – Physical Medicine and Rehabilitation doctor at University Medical Center Brackenridge, Austin, TX

Matthew Geck, MD – Spine and Scoliosis Surgeon; Co-Chief of Seton Spine and Scoliosis Center, Austin, TX

Timothy George, MD – Conference Host, Medical Director of the Pediatric Neurosurgery Center of Central Texas at Children's Hospital, Austin, TX

Gerald Grant, MD – Associate Professor, Pediatric Neurosurgeon. Duke University Medical Center, Durham, NC

Raymond Harsbarger, MD – Craniofacial Surgeon, Dell Children's Medical Center of Central Texas, Austin, TX

John D Heiss, MD – ASAP Medical Advisory Board, Head Clinical Unit, Surgical Neurology Branch, NINDS/ NIH, Bethesda, MD

Mary Hughes – Advocacy Incorporated, Austin, TX

LaDonna Immken, MD – Genetics, Specially for Children, Austin, TX

Bermans Iskandar, MD – ASAP Medical Advisory Board, Director of the Pediatric Neurosurgery Program, University of WI, Madison, WI

John Jane, Jr, MD – ASAP Medical Advisory Board, Associate Professor of Neurosurgery & Pediatrics, University of Virginia School of Medicine, Charlottesville, VA

Robert Keating, MD – ASAP Medical Advisory Board, Chief of Neurosurgery, Children's National Medical Center, Washington, DC

Roger W Kula, MD – ASAP Medical Advisory Board, Medical Director of the Chiari Institute, Great Neck, NY

Mark Lee, MD, PhD – Pediatric Neurosurgeon; CEO of Seton Brain and Spine Institute, Austin, TX

Frank Loth, PhD – Associate Professor of Mechanical Engineering, University of Akron, Akron, OH

Valery S. Maercklein – Public Affairs Specialist, Dallas Region of the Social Security Administration, Austin, TX

Christina Markunas – Genetics, Duke University, Durham, NC

Arnold Menezes, MD – ASAP Medical Advisory Board Chair, Professor and Vice Chairman, Dept of Neurosurgery, University of IA, Iowa City, IA

Nancy Nussbaum, PhD – Psychologist, Austin Neuropsychology, Austin, TX

Hillary Onan, MD – Ophthalmologist, Eye Associates of Central Texas, Austin, TX

John Oró, MD – ASAP Medical Advisory Board, Neurosurgery Center of Colorado, Aurora, and founder Chiari Care Center, Aurora, CO

Christopher Richards, MD – Neuro-radiologist, Austin Radiological Association, Austin, TX

Karen Richards, MD – Pediatric Neurologist, Specially for Children, Austin, TX

Nathan Rudin, MD, MA – UW Health, Rehabilitation Medicine, Medical Director, Pain Treatment and Research Center, Madison, WI

Charlotte Smith, MD – Medical Director, Seton Rehabilitation Center, Austin, TX

Theodore Spinks, MD – Director of Pediatric Neurosurgery at Scott & White Hospital, Texas A&M Medical School, Austin, TX

Kevin Stark, PhD – Clinical Director of Psychological Services, Texas Child Study Center, Dell Children's Medical Center, Austin, TX

John Stokes, MD – Neurosurgeon at Seton Spine and Scoliosis Center, Austin, TX

Mary E Trentham – Occupational Therapist, Austin, TX

Syboney Zapata, MD – Pediatric Otolaryngologist, Austin Ear, Nose & Throat, Austin, TX

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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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2010 ASAP Awards

Each year ASAP acknowledges the people who have given their time, energy, and efforts throughout the year to help ASAP fulfill its mission. We were pleased to present our annual Volunteer awards at the 2010 Chiari & Syringomyelia Conference to the following individuals and families that embody the "Together We Can" Spirit!

Helping Hands Volunteers

Sheryl Andre
Melanie Gaffney
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Shining Star Volunteers

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Kerry Chu
Ashleigh Schaublin
Sara Eaton

Key Volunteer Award

Richard Schaublin

Barbara White Award

Arnold Menezes, MD

Honor a loved one or a friend through a gift to ASAP. Send a check or money order to the ASAP office in Longview, Texas with the name and address of the person or family member you would like to honor.

An acknowledgement card will be sent in your name to the person honored or the family of a dearly departed friend or loved one for a donation of \$5 or more. Please include the name of the individual you wish to honor or remember.



A very special 'Thank You' to all our members who have organized, assisted and participated in awareness events and fundraiser on behalf of the American Syringomyelia and Chiari Alliance Project. You make it possible for ASAP to fund research, provide information and develop programs. Unfortunately it is not possible to list all the names but please know your efforts are greatly appreciated.

"Yes, I want to make a difference!"

Enclosed please find my tax-deductible gift
to support research and expand membership programs.

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Donations should be mailed to: ASAP, Inc. PO Box 1586, Longview TX 75606-1586

9-2010

Awareness and Fundraising

The 2nd Annual Cruisin' for Chiari sailed on Saturday, August 21. The sunset cruise was attended by individuals who enjoyed the calm waters of the Manasquan River, Point Pleasant Canal and Barnegat Bay in New Jersey. The four hour dinner and dancing fundraiser featured music provided by DJ Mindless Entertainment and a silent auction.

April Barillari who hosted the event would like thank the following for their help: Chris Neff, DJ; Stacy Howland, photographer; Corey Sperling; John Caemmerer; Amber Navara; Michelle Klecan; Allison Seavers; Nicole Livingston; and Patrice Schaublin.



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 or ASAP, PO Box 1586, Longview TX 75606

Patricia Maxwell Editor, *ASAP Connections*



ASAP's Mission

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

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