ASAP Connections

Issue 1, 2010
vol. 22.03

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

IN THIS ISSUE...

American
Syringomyelia
& Chiari
Alliance
Project, Inc.

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

Outreach Program Workshop for Caregivers

This workshop is designed to help caregivers see themselves as not only an essential part of the care team for a loved one but also important in and of themselves. Caregivers often put all their energy into caring for someone else and forget to take care of themselves. This leads to compromised health, depression and burnout. Learning ways to nurture yourself as well as nurture others is a gift you give to everyone.

Wednesday, April 21, 2010
12:30 PM ET

Title: Caregiver Workshop
Keynote speaker: Donna Schempp, LCSW, Program Director, Family Caregiver Alliance

Register online at ASAP.org or contact the Longview office for call-in information.

Donna Schempp, LCSW, is the program director at Family Caregiver Alliance. FCA is a non profit organization that helps caregivers get respite and support for their caregiving roles. FCA serves people with chronic illnesses, such as Alzheimer's, MS, Parkinson's, stroke, etc., as well as caregivers of frail elders.

Previous to coming to FCA, Donna worked with Kaiser insurance plan to increase use of community organizations. She was senior case manager at Jewish Family and Children's Services of the East Bay. She has experience as a medical social worker in hospice and home care and is involved in San Francisco End of Life Network. She is past president of the Board of Directors of Planning for Elders in the Center City in San Francisco and past chair of the ethics committee at Center for Elder Independence in Oakland. Since her first career was working with children and families, she has experience working with clients across the life span.

ASAP's Chiari & Syringomyelia Conference

Looking for answers to your questions about CM/SM?

Want to hear what the experts say about current trends in treatment?

Want to meet others who are diagnosed with or affected by CM/SM?

If you're tired of the run-around, check out ASAP's Chiari & Syringomyelia Conference July 21-24, 2010 in Austin, Texas. You will find top experts in the field sharing the latest research and current standards for managing patient care. Attend lectures covering surgical treatments, medical management as well as information on associated disorders.

In addition, there will be practical workshops that will give you techniques for coping and information on how you can improve your quality of life. Best of all, you'll experience this with others who know what it is like to live with similar issues and challenges. Adults, children, parents, caregivers and spouses all attend the conference to learn and share with one another.

This year's theme is ***Roundin' Up the Cure: Bridging the Gap between Research and Reality***. Conference organizer and host, Dr. Timothy George, will bring together a wide variety of speakers to help attendees gain a sense of where we are today in the progress towards the cure and where things stand with our current understanding of the disorders and their complex presentations.

For More Information:

- Logistics - page 5
- Conference Host - page 6
- Scholarships - page 6
- Austin - page 9

ASAP
Contact Us

ASAP
American Syringomyelia & Chiari Alliance Project

Address: 300 North Green Street, Suite 412
Longview, Texas 75601

Phone: 903-236-7079

Fax: 903-757-7456

Toll-free: 800-ASAP-282 (800-272-7282)

Staff: Patricia Maxwell & Jamie Mayhan

Email: info@ASAP.org
Patricia_Maxwell@ASAP.org
Jamie_Mayhan@ASAP.org

Chief Executive Officer: Michael F Scarpone, MS

Address: 4 Deer Ridge Lane
Kittery Maine 03904

Phone: 207-439-2538

Email: Michael_Scarpone@ASAP.org

Get Important Updates Faster!

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

If you are not receiving these announcements, contact info@ASAP.org. Let us know you would like to receive eBlasts. If we have your email address, please be sure to add the domain name ASAP.org to your safe sender list.

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.

E-Connections

Sign-up for E-Connections today and get your digital copy of the next issue of *ASAP Connections* when it goes to the printer. You will be able to read your newsletter online or download at your convenience from your own personal computer. E-Connections will be available for viewing online for an extended period of time.

Sign-up now: **http://www.asap.org/go_green.html**

You can also read back issues of *ASAP Connections* at ASAP.org. Just type *ASAP Connections* into the search engine on the home page.

ASAP Trivia

ASAP has conducted 21 conferences since 1989 in 16 different states. For a complete list of conference cities and the year turn to page 6.

Between June 1997 and May 1998
ASAP distributed approximately 12,000 newsletters and 600 information packages.

Between June 2008 and May 2009
ASAP distributed approximately 39,000 newsletters and 3,000 information packages. The newsletters were also available online for thousands more.

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

ASAP's President Judy Hunt

Judy lives in Blaine, Minnesota. She was diagnosed with syringomyelia in April 1997. Her sense of community is strong, and she is deeply committed to ASAP's mission to improve the lives of persons affected by syringomyelia, Chiari malformation and related disorders while we find the cure.

In addition to two Bachelor of Science degrees in Education, Judy brings practical experience to ASAP. She served for seven years as a board member of her local paratransit agency, which works toward achieving better transportation for people with disabilities in the Twin Cities metropolitan area. Other volunteer ventures include serving on the board of directors of her townhouse association and coordinating an online writing community.

Judy began serving on the ASAP Board of Directors in 1998; her term as president began in 2004. Although the position of president is an ex officio member of all committees, Judy holds a special interest in the programs, governance and conference committees.

"I have firsthand experience with the many problems associated with this disorder, ranging from difficulties dealing with doctors to the grieving of our lives as they used to be. Members need to feel connected with ASAP. Only then will they become involved. Then we, as a group, can better confront the challenges that face us."

Our ASAP Website Has a New Look

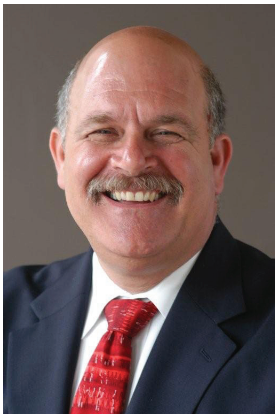
ASAP launches new and improved website!

We've been working hard behind the scenes to bring you an updated, easy to navigate website. Stop by and take a look at the new layout and browse the updated content.

Our new website is specially designed to meet the Web Accessibility Guidelines to ensure content is accessible for those with disabilities. Enjoy! Let us know what you think. Email comments to info@ASAP.org.

Together We Can... Walk and Roll

by Michael Scarpone, MS



On Saturday, May 22, 2010, a national walk will be held to support ASAP's research and educational programs. The Together We Can Walk and Roll will unify communities across the country in the fight against syringomyelia and Chiari malformation. Participation in the walk has the potential to bring unlimited awareness to your community.

Thousands of children and adults are fighting this battle alone, unaware of support, information and sometimes even a proper diagnosis. Hold a walk in your community to spread the word that these disorders exist and together we can make a difference.

ASAP will launch a national media campaign and plans to solicit national sponsorship. We will show the world that our united front is ready to fight the battle to find a cure and stop the hidden suffering of thousands.

May 22 was selected in honor of our founder Barbara White, who was born May 20. The first fundraising event she held on behalf of ASAP was a walk in her hometown of Corrigan, Texas. Barbara and her husband Don participated in the fundraiser, Don pushing Barbara in her wheelchair.

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.

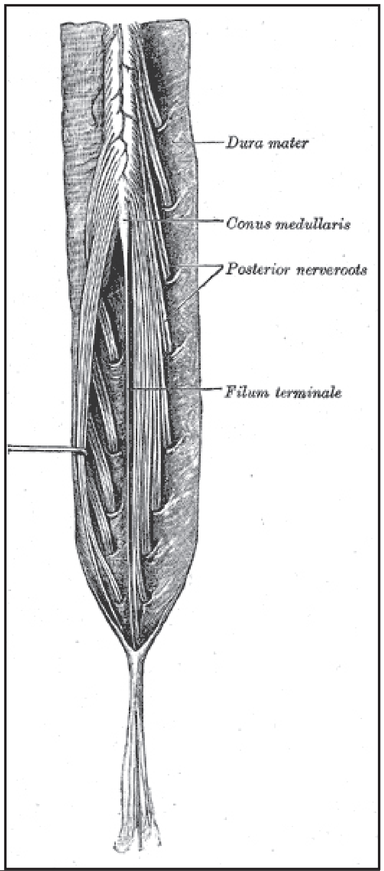
Are you interested in coordinating a walk in your community? I would like to work with you and supply the needed materials to ensure that your event is successful. To find out more about Together We Can Walk and Roll, contact me at Michael_Scarpone@ASAP.org or call 207-439-2538.

Visit us on the Web
www.ASAP.org

Ask The Experts
Questions and Answers Covering Basic Ccncepts

Question: How do you make a distinction between the typical tethered cord that we see and when you section the filum terminale, and occult tethered cord? How do you determine this? What kind of diagnostic criteria do you use?

Dr. Kula: We put together four or five streams of clinical information. One is the clinical symptomatology as we just talked about and Dr. George described. We also look at urodynamics studies and we sometimes do this in patients that are nearly normal and find evidence of neurogenic bladder features. You have to be a little clear on how you quiz the patients. Because you say 'Do you urinate all right?' And they say 'It's fine. I go 20 times a day. I don't have any trouble.' That's not normal. That's urgency and that's frequency. So you have to do a very careful urologic clinical assessment to see what's normal and what's not. Is there nocturia? Getting up at night to urinate? Then [we look at] delicate issues of sexual function and sensation. As we got into this a bit more we became much better at eliciting the clinical information and really talking about some of these things.



Cauda equina and filum terminale seen from behind. The dura mater has been opened and spread out, and the arachnoid has been removed.

Another evidence is the presence of a terminal syrinx or a syrinx below the level of T5 in the absence of a cervical syrinx. Syrinxes below T5 do occur and they're often in association with a cervical syringomyelia or an extension of that. When you have isolated terminal syrinx changes our experience is tending to suggest that that may be related to a cord tethering process.

The other is the presence of scoliosis. In fact one of our orthopedic individuals is very interested in the idea that there may be an occult tethering process, maybe in some ways this can explain idiopathic scoliosis. But we've seen scoliatic curves in young people improve by significant magnitudes following detethering which is very gratifying. Sometimes if you don't examine patients carefully you don't pick up scoliosis. My most telling question is, "Did some chiropractor in grade school tell you that you had scoliosis at some point?" Usually they're picked up early on in the teens and they don't get examined that well thereafter and it's easy to miss.

We've gotten to the point of doing more specific scoliosis screening films measuring cobb angles and looking at things like that because sometimes we miss it if we don't really look at the spine. Subtle occurrence of scoliosis may be a telling association.

We're talking about morphometric measurements of very small tolerances. We are splitting hairs when sorting 1 mm here and there on MRI studies. Look at the changes that take place with consistent measurements, i.e., evaluative tools. There is an elevation of the brainstem and a reduction in the elongated length of the brainstem when looking at certain criteria.

Patients ask how do you know if your detethering worked? We really look at the measurements again because adults tend not to retether while I understand the incidence in children is higher. We usually look for changes in the brain stem, downward displacement and elongation which improve following detethering. If they don't we have in an isolated two or three patients found on re-exploration that they had retethering with an inflammatory process or they had an arachnoid cyst or some other process that wasn't recognized at the initial surgery and prevented them from being effectively detethered.

We have a lot to learn about that. You also don't need to rush into things [surgery]. I tell my patients that if you're tethered you've probably been tethered since you were a teenager. So if you're symptomatic from that it may be contributing to a certain extent but we are learning more about this. You can always have a procedure. You cannot 'unhave' it.

Is it a particular detail of the surgery that is causing the improvement? Are you improving it because you're cutting the filum? Are you improving it because you're opening the dura? So these would be important issues to discuss over time and I'm sure with the number of patients that you have these questions will be answered over time.

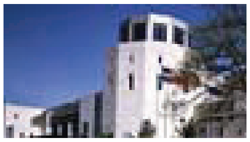
In the tethered cord paper that was just published there are normative data for our patient population. Our hope is that we can entreat neuroradiologists far and wide to begin to look at some of these morphometric things, because it's a labor of love. It's not an easy thing to do, it takes about a half an hour and it's quite labor intensive and not something that radiologists are likely to do.

[Roger W. Kula, MD, is a neurologist and Medical Director of the Chiari Institute in Great Neck, New York.]

ASAP's Chiari & Syringomyelia Conference

Roundin' Up the Cure: Bridging the Gap between Research and Reality

July 21 - 24, 2010



Hotel Room Rate: $129 plus tax per night. Reservations for the event will be made by individual attendees directly with Hyatt reservations at 1-800-233-1234 or 512-477-1234. Let them know you are attending the ASAP conference to receive this rate. **To receive the discounted ASAP rate, room reservations must be made before June 30, 2010.** You can also make reservation online at https://resweb.passkey.com/go/amsyring

Hotel: Hyatt Regency Austin Texas
208 Barton Springs Road
Austin, TX 78704
Phone: 512-477-1234

Program: The program is designed to foster a better understanding about syringomyelia and Chiari malformation and what is happening in the field. Experts will present the latest treatment options, alternatives in symptom management, and advancements in research. With multiple opportunities to speak with the presenters, ask questions and learn from specialists, the conference provides an opportunity to the newly diagnosed and veteran alike that is not available elsewhere. As the understanding of these disorders is constantly evolving, there is always something new to be learned. If you have been to previous conferences, you can learn something new and mentor those who are at their first conference. If you have not been to a conference, come make friends and learn from a wide variety of experts on various aspects of these disorders.

A full preliminary schedule of speakers will be posted on the website and appear in an upcoming issue of *Connections*. In addition to lectures by the experts, also included in the schedule will be small discussion groups for parents, caregivers, spouses, teens and adults with SM and CM will be included in the schedule.

The meeting starts Wednesday evening with onsite registration and an opening reception. Seminars and social events fill the rest of the days. Ambassadors will be available to offer support, guidance and encouragement during the four-day event. Plan a few extra days to explore the Texas capital, surrounding scenic areas, historic places, and fine museums.

Cost: Full registration includes all morning and afternoon sessions, welcoming reception, three continental breakfasts, and the Saturday evening banquet.

$160.00* per adult, $85.00 per child 6 to 15**
$185.00 per adult, $85.00 per child 6 to 15 on site.
$460.00* Family Package (2 adults and 2 children**)
$60.00 Single day registration (does not include banquet)
* preregister by July 7.

Banquet tickets are available for those not registered for the conference at $65.00 per person. **Refunds minus a $25.00 handling fee cannot be given after July 7.**

Airport: Austin is served by the Austin-Bergstrom International Airport [AUS]. The airport is located minutes from downtown Austin and the Hyatt Regency Austin and is serviced by many major airlines and offers nonstop flights to 36 destinations.

Ground Transportation: Travel to and from the airport can be by taxis (approximately $25 for the 10 mile trip) or Super Shuttle ($12).

- Austin Cab (512-478-2222)
- Yellow Cab (512-452-9999)
- Lone Star Cab (512-836-4900)
- Airport Super Shuttle (512-258-382, 800-258-3826)

Capital Metro is the local transit system; they do not offer direct service from the airport to the hotel. Bus service through the city is extensive; 24 hour pass can be obtained on the bus for $2.00. Tell the driver before you put your money in that you want the 24 hour pass, one way fares are $1.00 in cash. Buses are handicap accessible.

Bring your family and friends to the conference so they can see for themselves why ASAP is so important to you. If they can't make the conference, please invite them to join us for the closing banquet. Tickets can be purchased for $65 per person.

Fundraising Raffle: Remember the raffle and auction at the closing banquet! Members donate some items while others are donated by local companies. Many are handmade by friends and relatives. If you are interested in helping secure items or would like to donate to the event, contact Patrice at Patrice_Schaublin@ASAP.org or call 585-747-9651.

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

2010 Conference Host

by Fred Parker

You are cordially invited to attend *ASAP's Chiari & Syringomyelia Conference,* July 21-24. Please register early to assist with plans for meeting room space and other activities.

Timothy M. George, MD, FACS, FAAP, is Medical Director, Pediatric Neurosurgery at Dell Children's Medical Center of Central Texas; Chairman & CEO Pediatric Surgical Subspecialists, NPHO, Austin; Director Pediatric Educational Translational Research Institute, University of Texas at Austin; Adjunct Professor Section of Molecular Cell & Developmental Biology, College of Natural Sciences, the University of Texas at Austin and Clinical Assistant Professor Division of Neurosurgery, University of Texas Medical Branch, Galveston, Texas.

A native of Brooklyn, New York, Dr. George moved to Austin, Texas in 2006 from Durham, North Carolina where he was the Associate Professor of Neurosurgery, Pediatrics and Neurobiology at Duke University. While at Duke, Dr. George worked with Marcy Speer, PhD, on the genetic research of Chiari I and syringomyelia, a multi-year study sponsored by the Bobby Jones Open and American Syringomyelia & Chiari Alliance Project.

Dr. George completed his medical training at New York University; his residency in neurosurgery at Yale University School of Medicine; and his Pediatric Fellowship at Children's Memorial Hospital in Chicago. He is board certified by the American Board of Neurological Surgery and the American Board of Pediatric Neurological Surgery. He is also a member of the American Society of Pediatric Neurosurgeons, Congress of Neurological Surgeons, American Academy of Pediatrics and other scientific societies and organizations.

Current areas of research include genomics and surgical outcomes of Chiari malformation, cranial nerve stimulation for pediatric epilepsy, genomics of neural tube defects, and molecular and cellular mechanisms and abnormal development of the spinal cord. Dr. George has received numerous honors the most recent being the Castle Connolly Top Doctors awards. He has published 65 articles, 14 book chapters and 59 abstracts and a frequent lecturer at hospitals and medical conferences.

Dr. George is an ASAP research grant recipient and a speaker at several ASAP conferences. He is working on an agenda that will focus on *Roundin Up a Cure: Bridging the Gap between Research and Reality*, the theme for this year's meeting,

Conference Scholarship

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

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

ASAP Conference Cities

Colorado Springs, Colorado 1989
Nashville, Tennessee 1990
San Francisco, California 1991
Crystal City, Virginia (Washington, DC) 1992
Kansas City, Missouri 1993
San Antonio, Texas 1994
Chicago, Illinois 1995
Wakefield (Boston), Massachusetts 1996
Beaverton (Portland), Oregon 1997
Durham, North Carolina 1998
Key Biscayne (Miami), Florida 1999
Cleveland, Ohio 2000
Los Angeles, California 2001
Saint Louis, Missouri 2002
New York, New York 2003
Miami, Florida 2004
Iowa City, Iowa 2005
Denver, Colorado 2006
Seattle, Washington 2007
Arlington, Virginia (Washington, DC) 2008
Madison, Wisconsin 2009
Austin, Texas 2010

Save the Date!

ASAP's Chiari & Syringomyelia Conference
July 21 - 24, 2010

check-in Wednesday, July 21
check-out Sunday, July 25

Awareness and Fundraising: Working Together

Make a Difference

Whether you're already raising funds for the American Syringomyelia & Chiari Alliance Project or this is your first fundraising campaign, Jeans Day is a terrific way to show others that your company supports ASAP© and also promote awareness about the disorders.

What is Jeans Day?

The Jeans Day concept is simple. Individuals or groups can participate in Jeans Day and support ASAP©. Talk with your employer about designating a day where employees can dress casual for a minimum donation of your choosing. All funds raised go directly to supporting programs and research funded by ASAP©. Go casual for syringomyelia and Chiari by wearing jeans!

If you would like more information or need promotional items for Jeans Day, contact Jamie Mayhan by email at info@ASAP.org or call 903-236-7079.

Support Groups Make a Difference

Our son was not diagnosed with CM/SM until he was 12 ½. He was always sickly until surgery in 2005 at 13 years old. He is now 17 and much better than we had ever hoped. Since his diagnosis, your website has provided a wealth of information to us and our son Devon.

We were glad to meet other Chiari patients at the Spaghetti Dinner and would like to be more involved with ASAP. My son is still uncomfortable talking about his pre-surgery life but knowing that there are so many others living with CM/SM is a great help to him to always look forward.

Sincerely
Rose P. & family
Ship Bottom, NJ

Awareness and Fundraising Across the US

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

ASAP
PO Box 1586,
Longview TX 75606-1586

Chiari....my lifelong companion

by Cindy Nicholson

Like a thief in the night you stole my life from me
You're always hiding in the dark, come out, where I can see

After years of suffering, I finally know your name,...
Now that I know, my life will never be the same.
That fateful day I'll never forget which wasn't too long ago.

You caused my head to explode and my heart was pleading "no!"

Symptoms can be there for years 'til you raise your ugly head,

You even steal my sleep away; I no longer sleep in my bed.
The pains in my head sometimes stay all day.
Please learn to love me and take the pain away.
Sometimes you are patient, just waiting to attack,

Where will the pain be this time? In my head, my neck, or back?

The pain in my back is like a twisting knife,
Take what you want but give me back my life.
You try so hard to visit each day,
Causing me pain, keeping my smile away

Right now, I feel alone, even though I know you're there
Lurking in my head, causing more pain for me to bear.
Life is not about suffering, but you give us pain each day
We, Chiarians together, will fight you all the way.

How can Doctors help us, if they don't know what you do?
We are not hypochondriacs, our problems are you!!

When will all the pain and suffering end,
Please let me know, so I can be your friend.

Why do you hurt me so bad, can't you learn to love me,
Just take the pain away and set me free.
Chiari, if you could grant me one wish, all I ask of you,
Is that you haven't passed this curse, onto my babies too!

About the Author

I have suffered 16 years of head pain and 12 years of back pain. In October 2009 a cat scan revealed Chiari... my MRI showed 11mm herniation. I have 5 great kids, my oldest daughter is 24 and suffers from William's syndrome and cerebral palsy. My poem helped me release all the emotions that being diagnosed with Chiari brings. And it has helped me come to terms with it. I think all Chiarians can relate to every word of it. For others who don't have Chiari, it will give them a little insight of what life is like living with Chiari.

Meet the Medical Advisory Board
Ann Berger, MD

Dr. Ann Berger earned her undergraduate degree, a BS in nursing, from New York University, followed by a MSN in oncology nursing from the University of Pennsylvania. After working as an oncology clinical nurse specialist for several years, she completed her medical training at Medical College of Ohio in Toledo. Dr. Berger next did an internship and residency at Hartford Hospital in Connecticut and a fellowship in medical oncology and pain/palliative care at Yale University in Connecticut. Then, as an assistant professor in medicine and anesthesiology at Yale, Dr. Berger started a palliative care service.

Dr. Berger founded her second successful palliative care service while serving as an assistant professor in medicine and anesthesiology at Cooper Hospital/University Medicine and Dentistry in New Jersey. During her four-year tenure there, her service was actively involved in the care of patients and in education and research. She initiated a palliative care course for medical students, residents and fellows and also used her expertise while chairing the ethics committee.

In addition, Dr. Berger served as medical director of Lighthouse Hospice and as director of supportive care services at Cooper Hospital/University Medicine and Dentistry in New Jersey. During this time she received two grants as project director of a pain and palliative care scholars program and as project director for a project designed to develop pain/palliative care teams in New Jersey long-term care facilities.

Since August 2000, Dr. Berger has been chief of the Pain and Palliative Care Service at the NIH Clinical Center, where she has clinical, teaching, research and administrative responsibilities.

Nationally, Dr. Berger has been chair of the NIH CC Pain and Palliative Care Collaborative Working Group and member of the steering committee for the National Palliative Care Consensus Project.

Dr. Berger joined the ASAP Medical Advisory Board in 2009.

T-shirt Design Contest

Share your creativity ~ design a T-shirt that will spread awareness about syringomyelia and Chiari malformation.

Design should include www.ASAP.org. You can submit your design electronically (.jpg image not larger than 72 dpi) to info@ASAP.org or send your 8x10 original drawing on white paper to the ASAP office.

Top five designs will be featured on ASAP's Café Press site. The top two will receive a free T-shirt!

Submit by mail:
ASAP
PO Box 1586
Longview TX 75606-1586

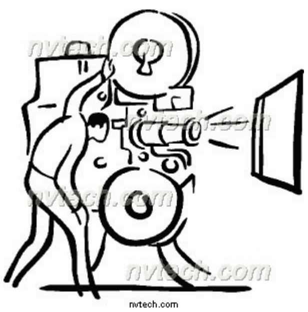
Contest ends May 31, 2010.

Share the Care

ASAP Personal Story Video Contest: We Want to Hear Your Story

Do you have a personal story to tell about your experience with syringomyelia/Chiari? Does someone you know have a personal story to tell about their experience with syringomyelia/Chiari?

Share the Care ASAP's personal story video contest is the perfect way to let your story be heard. Everyone has a unique story to tell about how SM or CM has changed their lives. Sharing these experiences with the ASAP community will not only strengthen our society as a whole, but also help raise important awareness.



For additional information and full contest rules visit www.ASAP.org or contact the ASAP office.

What to Do and See in Austin

by Fred Parker

Austin is the proclaimed “Live Music Capital of the World”. The Hyatt Regency is located at the start of the SOCO (South Congress) area known for it’s shops, dining and nightlife. The older historic portion of the city is approximately one mile away. The Hyatt Regency’s Web site has an extensive listing of shopping, dining, nightlife, and attractions that include hours, fees, bus routes where applicable as well as a description from Frommer’s travel guide with favorites marked. This information can be found at http://austin.hyatt.com. The austintexas.org web site provide a wide variety of information of sites, tours, discounts, etc.

Top 10 things to do in Austin

- Barton Springs- Three acres in size, the pool is fed from underground springs and water temperatures remain a constant, cool 68 degrees year-round. 2201 Barton Springs Road (located in Zilker Park) Austin, TX 78704. The Springs are 1.5 miles from the hotel, the 30 bus can be taken. http://www.ci.austin.tx.us/parks/bartonsprings.htm 512-476-9044

- Bob Bullock Texas State History Museum- From rare artifacts to interactive displays, the Bob Bullock Museum creatively tells the story of Texas. 1800 N. Congress Ave., Austin, TX 78701. The Museum is 2 miles from the hotel, various buses can be used to include the 1M, 5, 29 and 101 buses. http://www.thestoryoftexas.com/ 1-866-369-7108

- Texas State Capitol- With more than 1 million visitors per year, the Texas State Capitol ranks as one of Austin’s most popular attractions. Completed in 1886, the Texas State Capitol is the largest in square footage of all state capitols and surpasses the national Capitol in height by 14 feet. 1100 Congress Ave. Austin, TX 78701. The Capitol is 1.3 miles from the hotel, various buses can be used to include the 7, 30 and 101 buses. 512-463-0063, http://www.tspb.state.tx.us/spb/plan/tours.htm

- Warehouse and Sixth Street Entertainment Districts- Four blocks of Fourth and Fifth Streets comprise the Warehouse District. The buildings have been renovated from warehouses to trendy, distinctive hot spots. Austin’s Sixth Street is widely known for its unique blend of dance clubs, live music venues, restaurants and bars. This area is around a half mile from the hotel, various buses can be used to include the 7, 29, 30 and 101 buses

- Congress Avenue Bats- Only in Austin will you find millions of bats and thousands of humans all hanging out under the same bridge every night. Austin boasts the largest urban colony of Mexican free-tail bats in North America with a population of 1.5 million. The sunset exodus of the bats creates a nightly spectacle from March through October with onlookers watching as the nocturnal creatures emerge from beneath the Congress Avenue Bridge. First Street & Congress Avenue; Bat Conservation International, The Congress Avenue Bride is two tenths of a mile from the hotel. 512-327-9721, http://www.batcon.org/

- Highland Lakes- Austin stands as the gateway to seven Highland Lakes that stairstep 100 miles through the Central Texas Hill Country. Area lakes offer a variety of aquatic adventures, from sailing on Lake Travis (19 miles away)to water-skiing on Lake Austin (6 miles away) and canoeing along Town Lake (1 mile away)

- Town Lake Hike & Bike Trail- Ten miles of trails border Town Lake in downtown Austin and serve as a social hub for runners, walkers and cyclists. Access to trail is only a tenth of a mile from the hotel.

- SoCo- One of the hippest Austin hangouts is SoCo, a colorful stretch of Congress Avenue lined with funky shops, trendy dining spots, unique accommodations, art galleries and music venues. On the first Thursday of each month, merchants keep their doors open until 10 p.m., playing host to an array of events and activities. This neighborhood starts at the hotel and goes south along Congress Avenue for about 1.5 miles. South of the Congress Avenue Bridge http://www.firstthursday.info/

- Harry Ransom Center- 21st and Guadalupe Streets. Home to the Gutenberg Bible and the world’s first photograph, the HRC also archives 30 million literary manuscripts, 1 million rare books, 5 million photographs and more than 100,000 works of art. The Center is 2.1 miles from the hotel and can be reached using various buses to include the 1L, 5, and 101 buses 512-471-8944 http://www.hrc.utexas.edu/

- The Lyndon Baines Johnson Presidential Library- The life and legacy of LBJ are on exhibit at the nation’s most visited presidential library. University of Texas, 2313 Red River Street. The Library is 3.8 miles from the hotel and can be reached by various buses to include the 7, 10 and 20 buses. 512-916-5137, http://www.lbjlib.utexas.edu/

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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.

FDA Approves Morphine Sulfate Oral Solution for Relief of Acute and Chronic Pain

Approval is part of Agency's unapproved drugs initiative

The U.S. Food and Drug Administration approved Morphine Sulfate Oral Solution for the relief of moderate to severe, acute and chronic pain in opioid-tolerant patients. This medicine will be available in 100 milligrams per 5 mL or 20 milligrams per 1 mL.

This is the only FDA approved morphine sulfate oral solution available at this concentration. Although the use of this medicine to manage pain has been common practice for many years, this form and concentration of morphine was not FDA approved until now.

Today's action is part of the FDA's unapproved drugs initiative. As part of this program, the FDA has worked with the manufacturer of the now-approved product, Roxane Laboratories, to ensure that there is enough drug available for patients. The FDA will also be working with patient organizations and prescribers so that they are aware that an approved product is available, and can notify the FDA if there are any problems with availability.

"An important goal of the unapproved drugs initiative is to make sure that marketed drugs meet current FDA standards," said Douglas Throckmorton, M.D., deputy director for the FDA's Center for Drug Evaluation and Research. "Our action today reflects a careful balance between ensuring patient access to necessary medicines, while making sure companies comply with the law."

One benefit of the FDA approval process is a requirement for manufacturers to provide sufficient information on how to safely prescribe and use a drug. Manufacturers may also have to establish additional safety measures to manage unique risks of a medicine. For this formulation of morphine, the manufacturer had to develop a safety program prior to approval to address the known risks of morphine misuse, abuse and overdose.

FDA News Release Jan. 26, 2010

FDA Warns about Serious Side Effects from Maalox Product Mix-Ups

Maalox product maker agrees to name change to avoid

The U.S. Food and Drug Administration warned consumers about the potential for serious side effects from mistakenly using *Maalox Total Relief* instead of other *Maalox* products. The two products are intended for the relief of different symptoms and contain different ingredients.

Maalox Total Relief is an upset stomach reliever and anti-diarrheal medication, while traditional *Maalox* liquid products *Maalox Advanced Regular Strength* and *Maalox Advanced Maximum Strength* are antacids. Both *Maalox Total Relief* and *Maalox* are made by Novartis Consumer Health Inc. (NCH) and are available without a prescription as over-the-counter liquid medications. The maker of *Maalox* brand products has agreed to change the name of *Maalox Total Relief* to one that does not include the word "Maalox" and will change the drug's packaging to avoid further confusion.

Maalox Total Relief's active ingredient (bismuth subsalicylate) is chemically related to aspirin and may cause similar harmful side effects such as bleeding. As such, *Maalox Total Relief* is not appropriate for individuals with a history of gastrointestinal ulcer disease or a bleeding disorder. *Maalox Total Relief* also should not be taken by children and teens if they are recovering from a viral infection, nor by individuals who are taking certain medications including: oral antidiabetic drugs (OADs), anticoagulation (thinning the blood) drugs such as warfarin (Coumadin) and clopidogrel (Plavix), non-steroidal anti-inflammatory drugs (NSAIDS), and other anti-inflammatory drugs.

Packaging and labeling of *Maalox Total Relief* and traditional *Maalox Advanced Regular Strength* and *Maalox Advanced Maximum Strength* are very similar and easily confused. Due to this confusion, NCH has agreed to:

- Change the name of *Maalox Total Relief* to one that does not include the root name *Maalox* as well as change the product label design;
- Conduct an educational campaign with outreach to healthcare professionals and consumers regarding different *Maalox* products and ways to select the appropriate *Maalox* brand product; and,
- Actively monitor and report adverse events associated with the use of *Maalox* brand products.

"The FDA is concerned about the public health impact of medication mix-ups for products that have the same names or portions of the same name, but contain different active ingredients," said Ms. Holquist. "We want companies to consider the potential for name confusion when choosing names for their drugs."

The renamed product is expected to begin selling in September 2010. Until that time, FDA is advising consumers and healthcare professionals to carefully check the labels of all *Maalox* products to ensure the appropriate product is being selected for the patient's symptoms.

Any *Maalox* side effects or other product problems should be reported to FDA's MedWatch Adverse Event Reporting program at www.fda.gov/MedWatch or by calling 1-800-332-1088.

FDA News Release February 17, 2010

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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*

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

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