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American
Syringomyelia
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ASAP Conference

ASAP members, friends, family, and physicians gathered in Arlington, VA in mid July to celebrate our 20th anniversary and for some to attend their first conference. With over 180 taking part this turned out to be one of our most attended conferences!

It became evident on Wednesday evening that we were in for a great conference as people flowed into the atrium of the Sheraton Crystal City Hotel. Volunteers greeted attendees, handed out name badges and conference materials while everyone enjoyed appetizers and mingled. Judy Hunt, President of the Board, Dick Hellner, CEO, and Fred Parker who served as local host with wife Mary, welcomed conference attendees.

Attendees experienced a whirlwind of learning, sharing and connecting over the three day event. John Heiss, MD, was instrumental in recruiting many of the top names in the syringomyelia and Chiari research including neurosurgeons Jerry Oakes, MD, Ronald Brockmeyer, MD and Ghassan Bejjani, MD. Also present were ASAP's Medical Advisory Board members Arnold Menezes, MD, John Oro, MD, and Roger Kula, MD.

Mathew McGirt, MD, one of ASAP's CNS fellowship award winners, presented results of his research which focuses on CSF flow study results in Chiari and syringomyelia patients and its ability to identify surgical candidates.

Christopher Shields, MD, presented the results of the ASAP funded research centered on post traumatic syringomyelia. His study revealed some surprising findings, He has already applied for NIH funding to continue this exciting investigation.

Bobby Jones Open Scholarship Recipient Graduates

Over the past four years, I have been honored to be one of the recipients of the Bobby Jones Open Scholarship for people with Syringomyelia or Chiari malformation. Thanks to your generous support, I successfully graduated from the University of Texas at Austin this May with a Bachelor of Science in mechanical Engineering and Minor in Business Administration.



Growing up with a condition like CM with SM definitely made acting like a regular kid more difficult. In the years before my diagnosis, my family and I were desperate for an answer for the pain and sickness that I was experiencing. When my amazing neurosurgeon discovered my rare illness and quickly operated, my family and I were scared but very relieved. ASAP has always been a very helpful and supportive resource throughout the entire ordeal and has never stopped helping. With three children in college at the same time, my parents and I will be forever grateful for the generosity you have shown us with this scholarship.

I will begin my career as a mechanical engineer in Houston, Texas soon, and I know that I could have never made it this far if it were not for the research, support, and generosity of ASAP and the Bobby Jones Open. Like Bobby Jones, I hope to never let my condition get in my way and hope that my triumph can inspire others with CM and SM to push through the pain and struggling and look forward to a brighter future. I sincerely thank you for your support and generosity, and I wish you the best of luck in your search for a cure.

Thank you and God bless,

Nicole

continued on page 5

ASAP Bulletin Board



ASAP

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1-800-ASAP-282

Save Your Canceled Postage Stamps

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

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

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

Please send stamps to:

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



Special Events

ASAP Annual Medical Conference
July 23-26, 2008
Sheraton Crystal City
Arlington, VA

Chiari People of PA Walk-a-thon
September 21, 2008 9:00 am
Fairgrounds Square Mall
Reading, PA

For more information on upcoming events visit
www.ASAP.org

Please Note: Articles in the newsletter are not intended as a substitute for medical treatment 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.

Message from the CEO Dick Hellner



Service/Assistance Dogs

At ASAP's recent annual conference, included among all the well-received presentations, the overview provided by a representative of Canine Companions for Independence has really caused a stir on the Internet.

Since the meeting, I've read a number of complementary blogs that talked about the presentation. More importantly, however, the authors also talked about committing to find out more about how dogs can help people with disabilities and whether getting a dog is right for them.

The commitment to having a canine companion is major; the work of applying for a dog and going through training is even more so. Nonetheless, when it all comes together, people are very often amazed at how they got along without the help and companionship that a well-trained dog offers.

Service Dogs assist people with disabilities other than those with vision or hearing impairments. With special training these dogs can help mitigate many types of disabilities. They can be trained to work with people who use power or manual wheelchairs, have balance issues, need to be alerted to medical issues like low blood sugar, or who have psychological and emotional disabilities.

Trained dogs can also help by retrieving objects that are out of reach, pulling wheelchairs, opening and closing doors, turning light switches off and on, barking to indicate that help is needed, finding another person or leading the person to the caregiver, assisting ambulatory persons to walk by providing balance and counterbalance and many other individual tasks as needed by a person with a disability.

Service dogs generally come from selective breeding programs and raised by knowledgeable volunteers prior to their formal training. Most service dogs are Golden or Labrador Retrievers, however, many other breeds can be trained to become adept at helping the disabled. Service dogs can be identified by either a backpack or harness that they wear while working.

If you or someone you know with a disability would like more information about what programs are available, some of which provide training and a canine companion free of charge, please call, email or write to us:

ASAP
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Longview, TX 75606
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www.ASAP.org
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My Little Sister

by Stephanie

Her name is Kimberly. At the end of May, she will celebrate her twelfth birthday. While it may be all fun and games for her, a secret lies deep beneath.

The day she was born, everyone rejoiced and cheered with thrill that she had come out healthy, or so they thought. From the outside, she looked 100% perfect. However, within her tiny body was a disease that would later rob her of her childhood. Nobody would find this medical catastrophe until three years later. Her mother would have to fight tooth and nail to get a right diagnosis as her young child screamed in pain. It was going to be the most excruciating test of patience and waiting anyone had ever gone through. But, in this moment, baby Kimberly displayed true perfection.

Throughout the first couple years of her life, Kimberly struggled with certain milestones. She walked late, and when she finally did, it was a challenge because she would trip and fall every few steps. Although other children her age would run and play, Kimberly would not become frustrated. If she fell, she'd get back up. Because she fell walking, running seemed out of the question. When she wasn't falling, she was dealing with severe pain. Splitting headaches would ravage her little head. For the first 2 or 3 years of her life, all she did was scream out of pain. She screamed so much it became "normal" for her family. But when she saw more doctors than many see in a lifetime, nothing appeared wrong. Many of them said that her mom was making it all up. However, the mother's heart said that something was VERY wrong.

It took until Kimberly was three when she was finally diagnosed with tethered cord, syringomyelia, and Chiari Malformation 1. Her first surgery was a complete failure and made her worse off. A second pediatric neurosurgeon was discovered, and he seemed like he knew what he was talking about. So off to Chicago the family flew to meet Dr. Frim. As a result from the failed surgery, Kimberly was having more complications than before. Dr. Frim took one look at her and said that the next thing that would go was Kimberly's breathing. Two more surgeries were performed over the course of a year or two, and left her with 3 visible scars on her back and neck, and a shunt (the shunt drains excess fluid from her brain into her abdomen).

Although the surgeries could not fix the damage done by the first surgery, it lessened her pain a great deal. The scars now invite looks and questioning, but in a way they saved her life. If she had gone long enough without treatment, she could have been paralyzed, or even died. Today the pain has moved to behind her knees due to nerve damage from the first surgery. The pain is there 24/7, but gets considerably worse if she stands for a long time, or walks/runs on anything other than padded carpet. For this she uses a wheelchair in public so she doesn't have make the pain worse.

I am her older sister. It has not been easy watching her go through this. I often find myself having to explain that Kimberly CAN WALK! She can run, jump, swim, do whatever she wants, it just makes her hurt a lot. Her pain has stolen so much from her life. Many sports are difficult enough for her due to increased pain levels, despite the diagnosis of Osteoporosis she received a few years ago. Dance is really the only thing she can do without pain levels skyrocketing, because the floor is on springs. Kimberly was even not invited to a birthday party in 2nd grade because she "couldn't run." An upcoming competition at Busch Gardens is taking place for her band class at school. As much as she wants to be a normal kid these days, she will only be attending the competition, and not staying after to spend the day in the park. Medically, she is not allowed to ride the roller coasters.

Even with her differences, I have yet to hear "Why me?" come from her mouth. She has obviously gotten upset a few times, but that has NEVER taken away from her passion for life. When our 10-year old friend Megan passed away last year due to her SM/CM, it only made Kimberly more determined to fight for a cure. Kimberly has a pain scale that ranges from 1-10, with 10 being the highest. On a daily basis, she is typically a "4", even with her prescription Neurontin she takes three times a day. However, in her mind, this is no excuse for complaining. Most of the time, we don't know when her pain has increased, because she doesn't let anybody know. She keeps her pain to herself, and doesn't complain because she thinks her friends with the same conditions are worse off than her.

When asked who my biggest inspiration for life is, the answer is always "Kimberly, my younger sister." She, along with our many other SM/CM friends, provide me a reason to live each day without complaining about my own problems. They all suffer from debilitating pain and face social looks and questioning daily, but yet they always find the will to move on. They see past the pain. Even though the pain is always there, they all move towards the light at the end of the tunnel, no matter how dim.

That light is a cure, which has yet to be found. Each day a cure isn't found, hundreds of thousands suffer.

My little sister is one of them.

So when she blows out twelve candles on May 25th, she will officially have endured twelve years of pain, syringomyelia, and Chiari. But, more importantly, twelve years of inspiring others, filling the world with laughter, and beating the odds.

(In Memoriam to Megan Reynolds. We love you and miss you!)

Frank Loth, PhD, also a grant recipient, explained the mechanics of syringomyelia from an engineering viewpoint before Joan Bailey-Wilson, MD enlightened the group about the Chiari genetic study currently underway at the NIH.

Ann Berger, MD, MSN, Head of the Pain Service at the NIH Clinical Center, volunteered to continue her presentation during the Patient Support Group which was a big hit. Mr. David Melton, Public Affairs Specialist with the Social Security Administration delivered up to date, informative information for those considering disability. Ms. Terry Spearman was a success among the younger crowd as she talked about coping mechanisms.

Robert Keating, MD, presented the pediatric viewpoint on Thursday before Paolo Bolognese, MD, arrived on Friday to talk about tethered cord. If you were not able to attend the conference but are interested in learning more about the topics presented at this year's meeting, DVD's of the presentations will be available for purchase on our website later this fall.

Thursday night attendees enjoyed a special evening dinner on the Potomac River with Spirit Cruises aboard the *Spirit of Washington*. The evening including dining, professional entertainment and dancing and – yes – the limbo and conga line! ASAP members hit the dance floor and several participated in the evenings show, including ASAP's own, Roger Kula, MD! Who knew ASAP had so many talented dancers, singers, and performers?

The crowning event ending the four day experience was the Saturday night banquet. Theo Kotjarapoglus as Master of Ceremonies announced the 2008 Awards and

the organization presented Patricia Maxwell with a dozen red roses in honor of her dedication to those affected by syringomyelia and Chiari malformation. The ASAP 20th anniversary cake was wheeled around for all to see, while Lee Miller and Harriet Davis gave a moving tribute to our co-founder, Don White. Later Lee and Harriet had the honor of making the ceremonial cut of the cake. Jamie Mayhan created a slide show of photos collected over the years. It brought back warm memories of people and events and showcased just how far we've come since Barbara and Don founded ASAP in the back room of their house.



As usual Patrice Schaublin created a fantastic raffle and silent auction. Finally, the last call on bids was made and attendees scrambled to make sure they were taking home their favorites! Arnie Hulteen and Patrice held a live auction which included the ASAP afghan, a 7 day cruise, 50 pounds of fresh crab and jewelry.

If you'd like to experience this event for yourself, start making plans to attend the 2009 SM/CM conference in Madison, Wisconsin July 15-18. See you there!

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Thirty Ideas In Thirty Minutes

Members at this year's conference took a few minutes to share tips and treasures they have found through the years to help them cope with everyday life. Here are some of the ideas that were shared and places to find them. Thanks to Kimberly for keeping track of the list!

1. Tie a large round dowel to the blind strings for easier pulling
2. Getting fridge doors that open towards the wall
3. Memory foam cushion for the back of your seat
4. Panoramic mirrors for your car
5. Ulu knives (rocking knives) recommended for people with hand problems. www.uluknives.com
6. Try lever door handles for easier grasping
7. Don't go alone to doctor appointments!
8. Photo copy medicine bottles so you have all the information
9. Put medicine list in a plastic protector for your purse or wallet to keep it safe
10. Voice-activated recorders for doctor appointments
11. Mirrors for buttoning collars (or a spouse 😊)
12. Full length mirror for ironing, keeps you from turning your head.
13. Pillow to sleep face down – one resource is skymall.com Relax n Nap pillow
14. Indoor/outdoor carpet for wheelchairs, new styles look like carpet and wear well.
15. Grippers for pens/pencils make them easier to use.
16. Great resource for assistive technology for students of all ages www.onionmountaintech.com
17. Use bicycling gloves for canes, wheelchairs, etc. helps with grip and protects the hands.
18. Book holders for holding the pages open when reading. Save your arms!
19. Bubble baths to help with pain
20. Rings to put on your fingers when you are writing, typing, etc.
21. Pool therapy
22. "Komfort Kollar" for planes to help with neck pain, www.magellans.com
23. Mountain dew with Excedrin for headaches.
24. Motion-activated lights and lower peep holes to make your home safer
25. Two cups of sea salt in a bathtub
26. Acupuncture
27. Bolt the sneakers to bike pedals, great for athletes
28. Book rack – "relax the back"
29. Rice bags – like a heating pad but won't burn you if you fall asleep with it
30. Coloring books, gives you something to do during hospital stays and distracts you from pain

Read for ASAP

Do you like magazines? Do your family and friends like them? Do you like to give them as gifts? Now you can renew or subscribe to many of your favorite magazines and ASAP will receive 40% of your purchase! It's easy. Just visit www.magfundraising.com/asap.

While you're there, you can also use the site to invite friends and family to participate. Check it out at www.ASAP.org or the address provided above.

CNS/ASAP 2009 Fellowship

Congratulations to Dr. Spiros Blackburn, a fifth year resident at the Washington University in Saint Louis. Before attending medical school at UT Southwestern in Dallas, Dr Blackburn earned a mechanical engineering degree from Old Dominion University.



He will be working under the direction of Dr. Michael Chicoine to evaluate anatomical changes in the posterior fossa during surgical decompression using intra-operative MRI. They hope to shed light on why certain patients improve with a bone-only decompression and determine if it is possible to identify these patients prior to surgery.

In addition to skull base neurosurgery, Dr. Blackburn's subspecialty interests include cerebrovascular and endovascular surgery.

Did You Know?

ASAP has earned \$1,708.59 thanks to our members shopping and surfing the web through iGive.com. If you would like to learn more about how you can donate while you shop visit www.iGive.com.

For questions or comments pertaining to this column or for information about the disorders, visit us on the web at www.ASAP.org, Email the ASAP office: info@ASAP.org, call 903-236-7079 or write ASAP, PO Box 1586, Longview, Texas 75606. To help with *Teen Connections* or to get more involved with teen projects, contact teen_connections@ASAP.org.

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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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ASAP Connections is published bimonthly for ASAP members. 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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