Save the Date
July 24 - 27, 2013
ASAP Chiari & Syringomyelia Conference
Los Angeles, California
co-hosts
Ulrich Batzdorf, MD
Langston Holly, MD

Maria’s Pizza Parlor
Helping to make a difference in the lives of those affected by Chiari and syringomyelia, Maria held a fundraiser September 28 at the Acme in Doylestown, PA. She raised over $450 for research!

ASAP Telephone Support 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. The program provides an opportunity to get to know others and share ideas.

The group currently meets the second Thursday of the month at 7:30 PM Eastern. If you are interested, contact the ASAP office and request the brochure which outlines policies and provides instructions for connecting.

Write-a-thon Takes on New Look
If you’ve been involved with ASAP for many years you might remember the write-a-thon fundraiser that involved sending letters to your family and friends asking for their support. Now you have the opportunity to do it online.

Create a personal fundraising page through ASAP, add pictures, write a personal message and email your contacts asking them to support your efforts and those of ASAP. For those participating in the ASAP L.E.A.R.N. Program, every dollar you raise will get you one step closer to reaching your goal to attend the ASAP conference in Los Angeles next July. Just raise $5,000 and you will receive waived registration, hotel room and tax for four nights as well as compensation toward travel expenses.

To get started go to ASAP.org, move your curser over ‘Get Involved’ and click on ‘personal fundraising page’. Follow the easy steps to create your own personalized page. Then email the link to your friends and family.

For those of you who still love to write letters, the write-a-thon can still be conducted the former way.
Stamp Project

We sincerely appreciate everyone’s contributions to this project. Please send stamps that are in good condition (attached to envelope and trimmed with 1/2 inch border around undamaged stamp) to the ASAP office. We are looking for a volunteer to spearhead the stamp project. Interested persons should contact the ASAP office.

ASAP Stamp Project
300 N Green St Ste 412
Longview TX  75601

ASAP Welcomes New Members to Medical Advisory Board

We are excited to announce the addition of two new members to the Medical Advisory Board.

Gerald A Grant, MD, is the Associate Professor of Neurosurgery and Associate Professor of Pediatrics at Duke Medical Center in Durham, North Carolina. He obtained his MD at Stanford University School of Medicine in 1994 and continued his training at the University of Washington Medical School from 1994–2001. He also performed a fellowship in Pediatric Neurosurgery at Children’s Hospital and Regional Medical Center in Washington, 2001–2002.

Prior to joining Duke, Dr Grant served as Lieutenant Colonel in the United States Air Force. During Operation Iraqi Freedom he provided expert neurosurgical care to the US and coalition troops stationed in Balad, Iraq during 2005-2006.

Currently a member of The Center for Human Genetics team investigating the hereditary basis of Chiari type I malformation with or without syringomyelia, Dr Grant has lectured at several ASAP conferences.

Lance LaCerte, Psy D, is the first Doctor of Psychology to serve on the ASAP Medical Advisory Board and will bring a much needed perspective for the treatment of symptoms associated with the disorders.

He is the Director of Behavioral Medicine, at the Spine Center of Innovation, HealthOne Medical Center of Aurora. Dr LaCerte also has a psychologist’s office located in Aurora, Colorado, specializing in depression, anxiety, trauma/PTSD, and phobias. In addition to behavioral medicine/health psychology, he treats chronic pain, psychological issues related to medical conditions, pre-surgical and post-surgical evaluations.

Dr LaCerte has been serving the greater Metro Denver region for over 20 years.

As a guest speaker at ASAP’s Chiari / Syringomyelia Conference this past July, he presented Neuro-psychological Challenges for the Chiari Patient and Psychological Pain Management. The lecture was videotaped and will be streamed on the ASAP website.

SPREAD AWARENESS with an ASAP Business Card

Don’t Just Tell People About CM/SM... Show Them!

Order personalized ASAP business cards with a brief description of Chiari and syringomyelia on the back.

To place an order, include the information you would like on the front of the card, i.e., name, address, phone, email. It may also be left blank.

20 cards - $5.00
40 cards - $10.00

Mail to: ASAP
PO Box 1586
Longview TX  75606

If you have questions: call
903-236-7079
or email info@ASAP.org

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.
Discussion Regarding Pain Treatment

**Question:** A patient diagnosed with syringomyelia was diagnosed with a soft rating of CRPS (complex regional pain syndrome) after a fall injured the arm and wrist. Is this diagnosis another way of stating the syringomyelia is progressing?

**DR. MAILIS-GAGNON:** CRPS was termed previously as reflex sympathetic dystrophy. This is another one of these disorders that has baffled the scientists for many years. It is considered to be a combination of nervous system and probably the muscular skeletal system with both central and peripheral factors.

In my own experience I have seen patients with syringomyelia (SM) who carried the diagnosis of RSD in the beginning just to be shown later on that what they had was SM. On the other hand when you have any disorder that affects the nervous system you have a malfunctioning nervous system that responds to stimulation in an abnormal manner. I have published recently on CRPS, in my experience 2 out of 3 cases diagnosed as CRPS are not. Unless I see, touch and examine the person and put all the pieces of the puzzle together I can’t make the diagnosis.

**DR. BACKONJA:** I absolutely agree with that. As many times as patients come to me referred the diagnosis of CRPS, probably half of the time I find another reason, another diagnosis. The same thing applies to fibromyalgia. So many times doctors don’t know what it is; they just put the label to pacify the patient. On the other hand if you apply specific criteria and these are not very difficult criteria, just careful history and physical examination, there’s a good chance that some other things could be found. It could be anything from infections to all kinds of medical possibilities, so in my experience clinicians should always re-evaluate the diagnosis.

Certainly there is no mystery to complex regional pain syndrome. It’s a chronic painful disorder which responds reasonably well to basic principles of pain management; relieve the pain and rehabilitate. Even if you find something else, the basic principle could apply for general pain management but on the other hand, if you have something else that’s fueling that pain problem, either a broken bone or infection, so certainly the evaluating is really important.

**DR. MAILIS-GAGNON:** So in summary the answer is yes, no and maybe. What it means, you take it back to your doctor and have them sit you down and make sense to you. Because so many times in pain management we see labels thrown right and left, because once we throw you a label it seems that it satisfies presumably the patient and the doctor. That is not true! One of my worst syringomyelia patients was diagnosed with fibromyalgia for years. He kept complaining of this increasing pain. Somebody smart thought to look at his shoulders and he had literally pushed up his shoulders.

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**Discussion Regarding Pain Treatment**

the shoulders were eaten up. That’s not normal because the shoulder is not a weight-bearing joint so you don’t see that in a 35-year-old man. Only then they investigated to find Chiari and a syrinx from the top of the foramen magnum down to the conus medullar. This man went for years untreated, they never investigated his shoulders properly. Having the label of fibromyalgia for years cost him investigations. So every time you get something like that in an extra diagnosis say ‘Sit down and make sense to me’.

**DR. BACKONJA:** It really comes down to examining the patient. A patient with fibromyalgia should have a totally normal neurologic exam except for hypersensitivity. But patients with SM frequently have a sensory, motor and reflex abnormality. Unfortunately a lot of times hearing a diagnosis is a path to lesser resistance to doctors, nurses, whoever else is involved. They say ‘Well, you have a diagnosis, we’ll just move on’.

**Moderator:** Dr. Mailis-Gagnon mentioned in her talk that many of the patients require chronic opioid use that means long-standing narcotic administration. This is a problem for many patients for a number of reasons. Logistically we have trouble in trying to manage patients that are at a distance with primary care physicians dispensing narcotic medications; many refuse to do it. I’d like her opinion; maybe we can talk a little bit about this. What about the issue of chronic narcotic medication? How high do you go? How do you maintain that without escalating narcotic dependence?

**DR. MAILIS-GAGNON:** We have this huge issue. I actually belong to a very powerful narcotic panel as an advisor to the ministry of health and we are going to redefine the prescribing patterns and dispensing of medications, particularly opioids in my province. I’m also a guideline developer and I’m one of the primary authors of national opioid use guidelines. We have the same problems with physicians who are scared stiff to prescribe because they are not educated.

Our own guideline now is going to tell the physicians this is the standards of practice. These are the caveats and you have to keep the records and be very aware of abuse and behaviors. What happens is this. Neuropathic pain doesn’t respond very well to opioids.

As I said, opioids are necessary for many of the people in modest doses but in some others, mega doses don’t work and patients abandon them because they have side effects. So it’s a mixed bag.

**DR. BACKONJA:** At pain meetings, if you really want to bring out a subject where everyone jumps up and gets excited, it’s opioids. I don’t want to be a stickler for being a language police but I think it reflects on us how we communicate and what we really mean.

Opioids are medications that are prescribed for treatment of pain. Narcotics are illegal substances of abuse. So as a physician I do not prescribe narcotics, I prescribe opioid analgesics. The unfortunate part is actually that some of these medications are sold as illicit drugs and those same drugs become narcotics. So that’s what has really become a problem and is at a level of FDA and DEA now to impose much stricter regulations in prescribing opioid analgesics because they do become narcotics.

Every state in the United States has a medical board and there are standard guidelines for physicians on how to prescribe opioid analgesics for pain control. Unfortunately, there are doctors who don’t want to touch it which is really unfortunate because opioid analgesics are really useful medications especially in acute pain and other circumstances. But they do have limitations. They do not cure the pain. They relieve the pain but at the cost of many side effects and one of the side effects is abuse and addiction. There is no mystery. Like in any other good care it’s paying attention to what the issues are.

Regarding the dosages, for a period of time on the basis of what we’ve learned from cancer pain there was a comment that there’s no ceiling effect to opioid analgesics. Unfortunately there’s a level where you hit and receive no further benefits. We are also learning as of lately that if you’re getting mega doses of opioid analgesics that same drug can actually make the pain worse and produce general hyperalgesia or opioid induced hyperalgesia. It does require care and the same care that we would need to prescribe any medication because there are good benefits and side effects of all drugs. Certainly they are a very important class of drugs. There are a number of logistics issues to go back to the prescribing, because this is the only class of drug that you can only prescribe for a month at a time. You have to go to a clinician to get your prescription once a month, it becomes a logistics issue and access to care and a number of problems can arise quite quickly. But it is a real important tool.

Transcript taken from 2009 ASAP Chiari & Syringomyelia Conference, Madison, Wisconsin.

About the doctors:

**Angela Mailis-Gagnon, MD** - Division of Rehabilitation Medicine, University of Health Network, Toronto, Canada - Founder and Director of the Comprehensive Pain Program at the Toronto Western Hospital.

**Miroslav Backonja, MD** - Department of Neurology, Anesthesiology and Rehabilitation Medicine, University of Wisconsin, Madison, Wisconsin - Professor of Neurology, Anesthesiology and Rehabilitation Medicine. Clinical trials investigator focusing mainly on neuropathic pain disorders.
Fundraising for ASAP

Shop from your seat, not on your feet.

ASAP is pleased to announce a new Holiday Season Event.

Give comfort to someone’s life with a set of high quality microfiber sheets equivalent to 1500 thread count. We have partnered with Amadora to offer you fine quality bedding at fantastic prices that will also raise money for research, education, awareness and continuing support of our community.

Orders must be received by November 30th for holiday delivery. Take advantage of this opportunity to shop early for your friends and loved ones, giving a gift that will be appreciated every night.

With two ways to participate and bonuses galore you have every reason to start shopping NOW!

HOW IT WORKS

Watch a video online to learn more:
http://asap.amadoragiftoflove.com/

Option 1 - Individual Orders

Go to http://asap.amadoragiftoflove.com/our-products/ click on ‘shop’. From the drop-down menu click on ‘ASAP.org orders’. Start shopping by choosing from many different sizes and colors.

IT’S THAT SIMPLE!

Option 2 - Team Leader

After you collect orders of 12+ sets of sheets, go to http://asap.amadoragiftoflove.com/submit-a-team-leader/ From the left margin of the home page click ‘contact us’. Fill in your information. In the ‘subject’ field, type ‘ASAP Fundraiser’. You will be contacted to discuss participation as a team leader.

Your participation in this exciting new program will give you quality bedding at great prices in addition to helping ASAP to continue its mission.

Bonus selling rewards:

Level 1
Sell (purchase) 12-35 sets to receive a free ASAP T-shirt.

Level 2
Sell (purchase) 36-72 sets to receive a free Apple iPod.

Level 3
Sell 72-144 sets to receive a free Kindle Fire.

Level 4
Sell 144+ sets to receive a free Apple iPad.

Additional bonus - for every dollar donated to ASAP on your behalf you will receive 1 point towards attendance at the National Conference as a participant in the ASAP’s L.E.A.R.N! (Leadership, Education, Awareness, Research, Now!) Points Program. Information about the program is available at www.ASAP .org or by contacting the ASAP office.

With so many reasons to participate why not start today. To qualify for the higher bonus levels become a team leader and offer these fine linens to friends, family and coworkers. Host a home party, post on the bulletin board at your office and use your social network. Anything you can think of will quickly qualify you to receive one of the many bonuses offered.

Don’t wait, start TODAY!

Editor’s Note: For interested parties without internet access please contact Lori Jurans at 855-262-3672 extension 101 to request an information package.

Workplace Giving

Workplace giving is an easy way to help support ASAP. Many employers allow you to contribute to your favorite charity through payroll deductions. Ask your employer if they have an employee gift program or if they participate in United Way campaigns. If so, look for the Donor Designation Program and write in American Syringomyelia & Chiari Alliance Project as your charity of choice.

Walk For A Cure

Help raise awareness about Chiari and syringomyelia by holding a walk next spring. Patrice Schaublin is booking events for spring 2013 and will help you to make your event fun while spreading the word and raising funds to support ASAP programs and research.

For more information contact Patrice at 585-747-9651 or email Patrice_Schaublin@ASAP.org
Remember ASAP...

When It’s Time to Remember Loved Ones
Our appreciation to everyone who made a recent donation to ASAP on behalf of their friends / loved ones.

In Honor of
Donor
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James Austrausky
   Sandol Austrausky

Honor a loved one with a gift to ASAP on special occasions or just to let them know you care. For donation of $5 or more, ASAP will send an acknowledgement card to the individual.

Remember family and friends with a memorial gift to ASAP. Acknowledgement cards will be sent to family when an address is provided.

ASAP’s Parents Page
Are you the parent of a child with Chiari or syringomyelia? Find support through Facebook on ASAP’s Parents Page. Meet other parents, share your story, or just drop by to help others. The next time you are on Facebook, just search ASAP’s Parents Page.

ASAP History
ASAP’s first headquarters was the spare bedroom of Barbara and Don White’s home in Longview, Texas. An old typewriter, a copier, filing cabinet and telephone were the office fixtures but Barbara was the heart and soul of ASAP. She found the strength to get beyond her own physical problems to reach out to others. Every day was a new opportunity to make a contact with a new member, find an article about SM/CM or get a check in the mail to pay for more postage.

The original newsletters were like personal letters from Barbara. Her willingness to share her feelings openly helped so many others come to terms with their disorder. The Message from Barbara column was always inspirational, sometimes funny and sometimes heartbreaking. Her emotional experiences mirrored so many others.

From these humble beginnings, ASAP has evolved into an internationally recognized nonprofit with a membership in excess of 10,000 and a strong financial record.

Contact Information
American Syringomyelia & Chiari Alliance Project

Physical 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
"Yes, I want to make a difference!"

Name  ________________________________________________________________________
Address  ______________________________________________________________________
City  _____________________________ State  _______________________ Zip  _____________
Email  ___________________________________________  Phone #  ____________________

I am making a tax-deductible donation to support the Barbara White Annual Fund

__ Check enclosed payable to ASAP, Inc. -- You can also make your donation online at ASAP.org

__ Credit Card   __  MasterCard     __   Visa    __  Discover  __  American Express
Card #  ________________________________________________________________________

Name of Cardholder  _____________________________________________________________
Signature ________________________________________________________________________
Expiration Date  ________ Security Code________  Amount  $  ___________________________

Return form to: ASAP, Inc., PO Box 1586, Longview TX  75606-1586

2012 Barbara White Annual Fund

The Barbara White Annual Fund is the backbone for programs and services at American Syringomyelia & Chiari Alliance Project (ASAP). Contributions have a direct impact on the everyday lives of families and are applied in a variety of ways. The fund helps to cover the costs of our support office infrastructure, production and printing of education materials, design and maintenance of our website as well as our developing support group/chapter initiative.

Our patrons have made it possible for ASAP to provide support, information and fund research for 25 years!

• Every day people receive information through the mail or internet that provides answers.
• Thousands have found a caring voice on the other end of the phone line when they were scared or felt alone.
• ASAP’s social media outlets provide friendship and connections around the world.

You can ensure no one faces this battle alone.

Make a donation to the 2012 Barbara White Annual Fund.

Incorporated in 1988 by Barbara and Don White, ASAP has been providing free information to thousands challenged by Chiari (CM) and syringomyelia (SM). Making a difference in the lives of families around the world who are affected by these disorders - chronic pain, changing physical abilities, loss of independence, financial difficulties, an uncertain future. They wait with hope for that ray of sunshine.

Together, we’re making progress. ASAP continues to fund vital research that is slowly but surely uncovering new knowledge about both Chiari and syringomyelia. And this knowledge is the most important step in discovering better treatment.

The American Syringomyelia & Chiari Alliance Project (ASAP) continues to make a difference in the lives of those affected by syringomyelia and Chiari, thanks to the continued support of our members and friends.

Barbara 1988
What I cannot do alone, with the coming together of my family and friends we can make miracles happen for people with no hope.
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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ASAP Connections
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 contributions of articles, letters, and photos are encouraged. The editor reserves the right to edit any article in order to accommodate space.

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