ASAP Connections

Spring 2011

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

ASAP's Chiari & Syringomyelia Conference

Reclaiming Health

July 27 - 30, 2011

IN THIS ISSUE...

Take a positive step toward reclaiming your health: attend the ASAP conference this summer. Experts from across the country will present on subjects to help you accomplish the job. You will also have the opportunity to share with others. Impart coping techniques and learn what others have done to make a difference in their lives.

Host: Dr. John Oró, neurosurgeon, Medical Director of Neurosciences at The Medical Center of Aurora, founded The Chiari Care Center.

His commitment to advancing Chiari care developed during his tenure as Professor and Chief of Neurosurgery at the University of Missouri. He recalls, "In 1998, I developed a special interest in Chiari I malformation because I saw that many people were not receiving adequate evaluation and treatment." Since his initial interest, Dr. Oró's dedication to providing the best surgical procedures and patient care has increased. In 2005, he relocated to Colorado to continue his practice in neurosurgery.

Dr. Oró's expertise covers a variety of neurological disorders, including brain tumors, cerebral aneurysms and disorders of the spine. His unique dedication to aiding those afflicted with Chiari I malformation has made him one of the leading Chiari surgeons in the nation. His belief is that surgery is only a small part of getting better.

He has been listed among the Best Doctors in America since 2001, and among America's Top Surgeons since 2007. Beyond being a highly skilled surgeon, he has held numerous appointments, serving on boards and committees at the state and national levels.

Dr. Oró's involvement in research for Chiari I malformation and the tethered spinal cord remains a high priority within his practice. He continues to present his research results and perspectives at national meetings and in published articles and other materials.

Program: A full preliminary schedule of speakers is posted on **ASAP.org**. In addition to lectures by the experts, small discussion groups for parents, caregivers, spouses, teens and adults with SM and CM is included in the schedule.

The meeting will start with onsite registration and an opening reception on Wednesday, July 27 at 7:00 pm. Thursday, Friday, and Saturday will be packed with sessions and social events. Ambassadors will be available to offer support, guidance and encouragement during the four-day event. So plan a few extra days to explore Metro Denver, surrounding scenic areas, historic places, and fine museums.

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ASAP's
Chiari & Syringomyelia
Conference

Reclaiming Health

Metro Denver, CO
July 27-30, 2011

Hosted by John Oro', MD

American Syringomyelia & Chiari Alliance Project, Inc.

www.ASAP.org

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& Chiari
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American Syringomyelia & Chiari Alliance Project

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Awareness and Fundraising

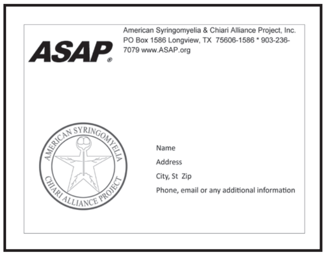
Share your ideas and experiences with others. Email a short story to Patricia_Maxwell@ASAP.org or mail a typed or clearly written article to:

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.

Spread Awareness with an ASAP Business Card

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



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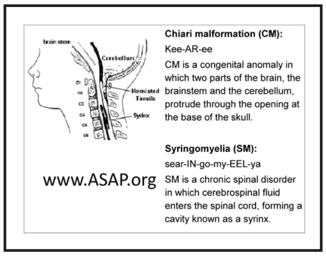
Name
Address
City, St Zip
Phone, email or any additional information

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; it may also be left blank.



www.ASAP.org

Chiari malformation (CM):
Kee-AR-ee
CM is a congenital anomaly in which two parts of the brain, the brainstem and the cerebellum, protrude through the opening at the base of the skull.

Syringomyelia (SM):
sear-IN-go-my-EEL-ya
SM is a chronic spinal disorder in which cerebrospinal fluid enters the spinal cord, forming a cavity known as a syrinx.

20 cards - $4.00
40 cards - $7.00

Mail to: ASAP
PO Box 1586
Longview TX 75606

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

Save Your Cancelled Postage Stamps

We are looking for a volunteer in the Hollywood, Florida area to take over the stamp fundraising project. If you are interested please contact the ASAP office.

Ellie McCallum

After years of service, Ellie McCallum has stepped down from the ASAP Board of Directors.

Ellie has played an important role in the organization for many years. Volunteering at numerous conferences, donating awareness merchandise, and overseeing the Telephone Outreach project are just a few of her many contributions. She will continue to vounteer where needed.

Jim and Ellie were introduced to ASAP in 1995. Even after Jim's death, Ellie has remained active in the organization because she feels it is important to give support to those with the disease and to fight for a cure so others will not suffer as Jim did.

Thank you, Ellie, for giving of yourself to make a difference.

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

- $160 per adult, $85 per child age 6 to 15 if preregistered by July 7.
- $185 per adult, $85 per child age 6 to 15 if registered on site.
- Family Package for 2 adults and 2 children 6 to 15 of $460 if preregistered by July 7.
- Single day registration of $60 is available (does not include banquet ticket).
- Banquet tickets are available at $65 per person for those not registered for the whole conference.
- Refunds will be given for cancellations until July 7, minus a $25 handling fee.

Hotel: We are reclaiming our health at a resort hotel nestled against the backdrop of the majestic Rocky Mountains. Golf enthusiasts will enjoy the rolling hills of the 27-hole championship course, heralded for its innovative design. Or spoil the senses and soothe the soul at the Mokara Spa. Located at the resort, the spa is 5,500 square feet and offers 9 treatment rooms in a relaxing and tranquil ambience. Nearby Flatiron Crossing has over 200 shops ranging from Nordstrom, Crate and Barrel, local boutiques and over 18 restaurants.

Omni Hotels & Resorts
Interlocken/Denver
500 Interlocken Blvd
Broomfield CO 80021
Telephone 303-438-6600
Reservations: 1-800-843-6664

Hotel Room Rate: **$129 plus 9.85% room tax**. Reservations for the event must be made by individual attendees directly with Omni reservations at 1-800-843-6664 or 303-464-3211. Let them know you are attending the ASAP conference to receive this discounted rate, which will be extended three days before and three days after the conference based on availability. To receive this special ASAP room rate, reservations must be made with the hotel by June 27, 2011.

Airport: Denver International Airport (DIA) offers 1,600 daily flights, 150 non-stop flights and utilizes 3 low cost carriers. The Omni is located 32 miles from DIA.

Ground Transportation: Although the hotel does not offer airport shuttle service, a variety of transportation options are available including: taxis, limousines, shuttles, and car rental companies. Super Shuttle runs non-stop to and from Denver International Airport on the hour. Current rate for the Super Shuttle is $25 one-way or $48 round trip (prices effective 5/2011). You can make reservations online for the shuttle at **http://supershuttle.shuttlefare.com** or call 1-877-300-4826.

A list of shuttle services is available online at **http://flydenver.com/commutershuttles.**

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 (you must be an ASAP member for at least one year). A limited number of these scholarships are available and will be awarded on a first-come first-served basis. If you are interested in applying for the scholarship, contact the ASAP office and 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.

Local Members: Your family and friends are welcome to attend the conference and 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 at a cost of $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. A few of these are chosen for the highly spirited auction. Everyone is asked to bring something, so we can have a lively auction. If you are interested in helping secure items or would like to donate to the event, contact Patricia Maxwell 903-236-7079 or Patricia_Maxwell@ASAP.org.

What to do in Denver: A visitor guide can be ordered online at **http://www.denver.org** or call 800-480-2010.

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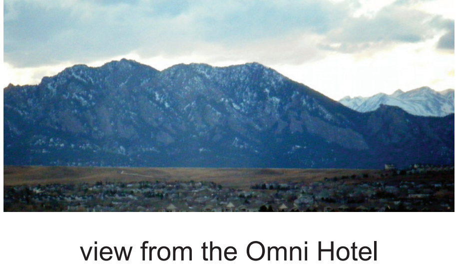


view from the Omni Hotel

Ask The Experts
Questions and Answers

Question: Have any genetic or environmental links been found in siblings with syrinx without Chiari?

Dr Koch: I think the jury is still out. We're still trying to figure out the overlap in families between Chiari as well as syringomyelia. We do find families where there is correlation like that but we also have plenty of families where there is no correlation.

Question: What are the long-term effects of the Chiari malformation? Is my child cured after decompression surgery or is she going to have problems that arise later in life?

Dr Frim: In my mind I hear this question and I think of two other diseases that we deal with in neurosurgery that are a little like this. One is hydrocephalus and one is the myelomeningocele, spina bifida. Forty or fifty years ago, certainly with the hydrocephalus, almost all those kids died because there were no shunts. In the 1950s and 60s those children who were shunted, survived. Now here we are 50 years later and we're seeing a first wave of those children who are now living to be 40 or 50 years old and it's a totally unknown area.

It's the same thing with the myelomeningoceles: 90% needed to be shunted. They had open spinal cords touching the air and there was very high mortality. Then the techniques to close that became available to us. Now here we are 40 or 50 years later with the same things: what happens to those children as they age?

We have a lot of data about what happens in the first week after Chiari decompression and the first three months and the first year and maybe the first five years and then it starts to peter out. It's clear that there are many people with Chiari who we see in the office who have no symptoms. There certainly is a population of patients, more in the children's population than the adult, who have Chiari surgery, recover and then seem to be just fine a year later. Every so often I get the Christmas pictures and they're going to college and getting married. I got invited to my first Chiari patient wedding just a few weeks ago, someone that I operated on a long time ago. So there clearly is a population of the patients who seem to do fine.

And then there's another population of the patients who continue to have problems. It is the reason that we talk about failed surgery. Is it something about the surgery? Is it something about the patient? Is it something about the way we do the surgery? We don't really know.

In our group we've paid a lot of attention to the CSF pressure and about four to five percent end up with high CSF pressure. They end up being shunted either from the ventricle or the lumbar space and that carries its own problems. Is that Chiari pseudotumor a whole separate disease? So far we have not been able to predict who will have it.

We're so mired now just in the first few months and years after surgery that to answer the question 'What is my child going to be like when he turns 60?' is very difficult to even imagine. Will all those kids who were operated on who are doing fine start having spinal cord issues and brain fatigue as they get into their 40s and 50s?

I have accumulated a fair number of hydrocephalus, spina bifida and tethered cord patients in Chicago. What we've noticed in those who are operated on 40 and 50 years ago is that their spinal cord function seems to deteriorate in their 50s and 60s. Most non-affected person's spinal cord function might deteriorate in their 70s and 80s. Is that because there's something wrong with the spinal cord that it can't take the daily wear and tear because they were born with this problem? Similarly the people who were shunted 50 years ago seem to develop cognitive problems 20 years earlier than a non-affected person.

Are Chiari patients going to have the same problem? I don't know.

About the Experts:

Allison Ashley-Koch, PhD, Associate Professor Medical Genetics, Duke University, Durham

David Frim, MD, Professor of Surgery and Pediatrics, Chief of Neurosurgery, University of Chicago

Ask the Experts

Attend ASAP's Chiari & Syringomyelia Conference July 27-30 to ask a panel of experts your questions.

New This Year! Attendees will have the opportunity after each session to query the specialist.

Make plans now to attend!

FDA Approves Horizant to Treat Restless Legs Syndrome

On April 6, the U.S. Food and Drug Administration approved Horizant Extended Release Tablets (gabapentin enacarbil), a once-daily treatment for moderate-to-severe restless legs syndrome (RLS).

RLS is a disorder that causes a strong urge to move the legs. This urge often occurs with unpleasant feelings in the legs. People who have RLS describe feeling pulling, itching, tingling, burning, or aching in their legs, and moving the legs temporarily relieves these feelings. The urge to move often happens when a person is inactive, and the symptoms typically are worse in the evening and early morning.

“People with restless legs syndrome can experience considerable distress from their symptoms,” said Russell Katz, M.D., director of the Division of Neurology Products in the FDA’s Center for Drug Evaluation and Research. “Horizant provides significant help in treating these symptoms.”

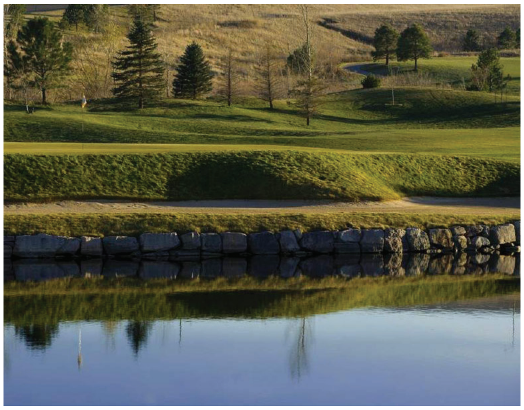
The effectiveness of Horizant was studied in two 12-week clinical trials in adults. The trials showed that people taking the medication had an improvement in their RLS symptoms, compared with people taking an inactive pill (placebo).

Horizant will be dispensed with an FDA-approved Medication Guide that explains the drug’s uses and risks. Horizant may cause drowsiness and dizziness and can impair a person’s ability to drive or operate complex machinery.

Horizant contains gabapentin enacarbil that becomes gabapentin, a drug used to treat seizures in people with epilepsy, when absorbed into the body. All drugs used to treat epilepsy carry warnings that they may cause suicidal thoughts and actions in a small number of people. Horizant will have the same warning.

Horizant was developed by GlaxoSmithKline of Research Triangle Park, N.C., and Xenoport of Santa Clara, Calif.

[FDA News Release: April 7, 2011]



Enjoy the beauty of the Omni Resort July 27-30

An Introduction to Restless Legs Syndrome

What is Restless Legs Syndrome?

Restless legs syndrome (RLS) is a neurological disorder characterized by unpleasant sensations in the legs and an uncontrollable, and sometimes overwhelming, urge to move them for relief. Individuals affected with the disorder often describe the sensations as throbbing, polling, or creeping. The sensations range in severity from uncomfortable to irritating to painful.

Is there any treatment?

For those with mild to moderate symptoms, many physicians suggest certain lifestyle changes and activities to reduce or eliminate symptoms. Decreased use of caffeine, alcohol, and tobacco may provide some relief. Physicians may suggest that certain individuals take supplements to correct deficiencies in iron, folate, and magnesium. Taking a hot bath, massaging the legs, or using a heating pad or ice pack can help relieve symptoms in some patients.

Physicians also may suggest a variety of medications to treat RLS, including dopaminergics, benzodiazepines (central nervous system depressants), opioids, and anticonvulsants. The drugs ropinirole and pramipexole have been approved by the U.S. Food and Drug Administration for treating moderate to severe RLS.

What is the prognosis?

RLS is generally a life-long condition for which there is no cure. Symptoms may gradually worsen with age. Nevertheless, current therapies can control the disorder, minimizing symptoms and increasing periods of restful sleep. In addition, some individuals have remissions, periods in which symptoms decrease or disappear for days, weeks, or months, although symptoms usually eventually reappear.

What research is being done?

The National Institute of Neurological Disorders and Stroke (NINDS) and other institutes of the National Institutes of Health (NIH) conduct and support RLS research in laboratories at the NIH and at major medical institutions across the country. The goal of this research is to increase scientific understanding of RLS, find improved methods of diagnosing and treating the syndrome, and discover ways to prevent it.

[Information provided online by the Nationals Institutes of Neurological Disorders and Stroke http://www.ninds.nih.gov/disorders/restless_legs/restless_legs.htm#What_is]

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.

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Conference Agenda Sneak Peek

- Chiari I Malformation with John Oró, MD
- Syringomyelia with John Heiss, MD
- Chiari I Malformation & Enlarged Central Canal with Robert Keating, MD
- Treatment Options for Syringomyelia with Bermans Iskandar, MD
- Chiari I Malformation In Pediatrics with Arnold Menezes, MD
- CM & Pseudotumor Cerebri with Harold Rekate, MD
- Complications of Treatment of SM & CM with Paolo Bolognese, MD
- A Doctor's Guide for Reclaiming Your Health with Gerard Guillory, MD
- Hydrocephalus:Definition, Causes, and Treatment with John Jane, Jr, MD
- Genetic and Other Causes of Chiari with Simon Gregory, PhD
- Non-Surgical Management of Persistent Symptoms Following Surgery for CM & SM with John Oró, MD and Roger Kula, MD
- Spinal Cord Regeneration Research with Scott Falci, MD
- New Research on Nutrition in Neurological Function with John Oró, MD

“Yes, I want to make a difference!”

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

____ $ 5,000	____$1,000	____ $ 500	____ $ 300	____ $ 200
____ $ 100	____$ 50	____ $ 25	____ $ ________Other	

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

5-2011

Awareness and Fundraising

2011 Member Drive

Thank you to all our members who were able to participate in our recent Member Drive. Your donations will support ASAP programs like the free information package, our website, outreach programs and more.

We are excited about the success of some of these prograns. ASAP has already held two webinars this year. Hosted by Dr. John Oró, the Chiari 101 webinar was attended by over forty individuals. More than eighty people logged on to the Pain Management webinar led by Dr. Ann Berger.

Another benefit you have made possible is the teleconference support call coordinated by Ellie McCallum. This program offers the opportunity for those without internet access or local support groups to share and encourage with others.

If you would like to make a donation to support ASAP programs, please use the above form or go to www.ASAP.org and click on the Donate button.

Special thank you to all those involved in making the Spring Gala a success!

American Syringomyelia & Chiari Alliance Project Inc.
P.O. Box 1586 Longview, Texas 75606-1586
ASAP®

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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