

Connections

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



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

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Pain Definitions and Mechanisms in Syringomyelia

by Miroslav Backonja, MD

One of the bigger issues in any neurological disorder such as syringomyelia is pain. Neuropathic pain arises as a direct consequence of diseases affecting the somatosensory system, which is part of the neural system. Because the primary pathology is central nervous system, it belongs to the category of central neuropathic pain disorders. We use these definitions to be systematic in our approach.

Frequently muscles get out of balance. This creates an increased workload on a muscle which then becomes painful.

The pain that comes from syringomyelia is one of many things that we as clinicians see. One way for us to address the issue is to assess the individual as a whole. Most of the time when a person comes to us we have to do a reverse process. We have to evaluate the symptoms together with a physical examination. We then put it together and make a diagnosis.

A patient can present with symptoms that frequently are referred to in neurology as 'a cape'. Basically both shoulders and arms are affected. Symptoms can be tingling and numbness but frequently it is also pain. It is this pattern of symptoms that prompts the physician to look into the cervical spine as a possible source of pathology.

Patients who have syringomyelia in the thoracic spine usually present with symptoms that are affecting the lower body and lower extremities. However I do have a patient with low back pain and pain radiating down to both lower extremities, all coming from a cervical syrinx.

FDA Announces Collaboration with Drugs.com

Goal is to expand online distribution of Agency's consumer health information

The U.S. Food and Drug Administration announced that it will collaborate with the website Drugs.com to expand access to the FDA's consumer health information.

Drugs.com seeks to provide patients with information to better manage their own health care and to assist in the reduction of medication errors. It attracts more than 12 million unique visitors each month.

"The FDA's partnership with Drugs.com means that reliable, useful, and timely health information will be available to an even wider audience," said Beth Martino, the FDA's associate commissioner for external affairs. "Partnerships like this are an important part of the FDA's effort to ensure the public has easy access to reliable, useful information that can help people protect and improve their health."

The FDA's partnership with Drugs.com will provide consumers with a joint resource on the Drugs.com site featuring FDA Consumer Update articles, videos, and slideshows. The partnership will also provide access to FDA health information on Drugs.com's mobile phone platform.

The complete terms and components of the partnership with Drugs.com are described in a Memorandum of Understanding published in the May 26, 2010, Federal Register and available online at <http://edocket.access.gpo.gov/2010/pdf/2010-12638.pdf>.

FDA News Release: May 26, 2010

**Visit us on the Web
www.ASAP.org**

continued on page 4

ASAP

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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: **www.ASAP.org**

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

ASAP's Chiari & Syringomyelia Conference

Roundin' up a Cure: Bridging the Gap between
Research and Reality

**July 21 - 24, 2010
Austin, Texas**

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.
Damaged stamps are not
usable.

Please send stamps to:
Maynard Guss
9593 NW 26th Place
Sunrise FL 33322-2738



Getting to Know the ASAP Board of Directors

In the last issue we met ASAP President Judy Hunt up close and personal. Now get to know the other officers. Each issue we will write about other members of the Board but you don't have to wait. You can read about each of them in the About Us section of our web site.

Theo Kotjarapoglus

Vice President

Email: Theo@ASAP.org

Theo lives in Boiling Springs, Pennsylvania. Active with ASAP for many years, he has served as chair of the Governance Committee and as a member of the Finance and Fundraising Committees.

He offers his expertise to ASAP as he extends his knowledge in the areas in which he excels. This is where his extensive experience in the non-profit community, including 35 years with the American Heart Association, benefits ASAP. He holds undergraduate and graduate degrees in Public Administration, and he is a certified fundraising executive.

Theo said, "A family history of neurological disorders brought me to ASAP. I am a firm believer that research in the area of neurology will benefit not only those directly afflicted with the disorder, but also those impacted with related conditions."

Members who have attended the annual conference may recognize Theo as the resident Master of Ceremonies. He enjoys fishing, golf, travel, the Pittsburgh Steelers, and spending time with his wife, Cathy, his two children and three grandchildren.



Sara Patterson

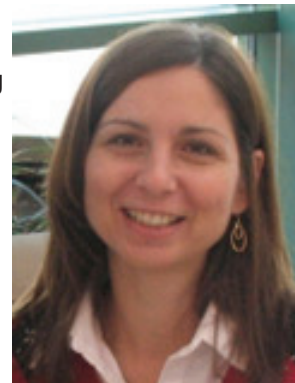
Secretary

Email: Sara_Patterson@ASAP.org

Sara Patterson resides in Palm Bay, Florida with her husband, Stuart, and three children. She learned about ASAP when her daughter, Holly, was diagnosed with syringomyelia in 1996. Since that time Holly has undergone numerous brain and spinal surgeries. Holly was the second member of the family to be diagnosed. Years earlier, Sara's mother had learned the cause of her disabling headaches, neck pain and muscle weakness were due to SM.

For the Patterson's, volunteering is a family affair. Both her husband and son have served on ASAP's IT committee. Stuart hosts an online saltwater fly store which donates all proceeds to ASAP. Daughters Hope and Holly are well-seasoned fundraisers and ASAP ambassadors. Both are members of the ASAP Kids For A Cure Club and have organized many fundraisers to benefit ASAP.

Sara holds a B.A. in Public Administration. She currently works part-time at a nonprofit inclusive preschool for children with and without special needs. This is Sara's second time serving on the ASAP Board of Directors. She completed a three-year term in 2000, and is now serving as ASAP's secretary. She currently serves on the Program, Conference, Information Technology, and Governance Committees.



Barbara White Annual Memorial Fund

The Barbara White Annual Fund is the backbone of ASAP programs. Your contributions have a direct impact on the lives of families across the United States and are applied in a variety of ways.

We've had a good response to the drive but we still need your help. ASAP offers thousands of individuals helpful and informative resources and, with your assistance, we can continue to do so.

Thank you to all who have donated so generously. If you have not contributed yet but would like to, please go to www.ASAP.org to make your gift today or use the form on page 11.

Together We Can Make A Difference!

Together We Can... Walk and Roll

The ASAP walk-a-thons are off to a great start. With the recent events held in Richmond, Virginia, Pleasantville, New Jersey and Greenfield, Indiana over \$10,000 was collected. Additional walks are planned for later this fall.

If you are interested in coordinating a walk in your community, contact Michael Scarpone. He will work with you and supply the needed materials to ensure that your event is successful. Mike can be reached at 207-439-2538 or Michael_Scarpone@ASAP.org.

The whole idea is to understand that symptoms go beyond the primary level of the injury to the nervous system. Many times we need to start talking about the mechanisms. In addition to neuropathic pain other types of mechanisms occur. It might be decreased mobility of the spine. In that case we are talking about problems that are known as mechanical related pain—a form of muscular-skeletal pain.

Frequently muscles get out of balance. This creates an increased work load on a muscle which then becomes painful. Sometimes when examining a person with that kind of problem we diagnose myofascial pain syndrome.

Individuals with spinal cord diseases, including syringomyelia, usually have more than one type of pain. The predominant problem is most frequently neuropathic pain, which is the pain that comes from injury of the nerves. A person can present with many different symptoms. Sometimes they are well defined and sometimes not.

For physicians who are not trained in pain management, positive sensory phenomenon which is pain, tingling, paresthesia is frequently overlooked. For clinicians who do not understand this, they frequently say it is all in your head. My comment is: I'm a neurologist; everything is in your head.

As I mentioned before, it is more than likely that patients with neuropathic pain have more than one type of pain. In my clinical experiences, (keep in mind that my professional experience is biased because I see patients who have more complicated problems), the number of different pain diagnoses is three. Pain specialists should be able to treat as many types of pain as patients might have. Sometimes the treatment is the same but many times they are different. That is what trained pain medicine providers do, they make a differential diagnosis and then try to address the different pain disorders.

The neural system is very complex, consisting of a peripheral nervous system component, a central nervous system component, the spinal cord and brain. Multiple mechanisms are at play. One aspect of the way the nervous system works is that it has to transmit a message that is perceived in the extremities to the brain for the person to be aware of where they are or what is going on around them. That is what we call 'feed forward' type of information. You need the information to propagate up the nervous system. Then built into the system itself is

what is called 'modulation' where the signal is modulated continuously. So the fact that you're sitting and maybe your bottom is a bit sore, you can ignore that because your descending modulation inhibition is working so you can sit through a talk. But for those people whose descending modulation is not working, sitting for five minutes might be very painful.

When we look at the mechanisms for neuropathic pain and chronic pain in general, there are a number of commonalities. On one hand there is neuronal hyper-excitability which is mediated through a number of factors. And on the other hand

there is altered modulation where you have a loss of inhibition, either it is at a local level or it is in the descending inhibition. Recently we've also recognized what's called descending facilitation. So you have a system that when it is working properly it is very fine tuned and doing a wonderful job, allowing us to be comfortable most of the time. When we have some trauma we can respond to it appropriately. But in patients who have chronic pain, especially those with neuropathic pain, this system is very disturbed and the problem could be either an increased hyper-excitability on one hand or with the other hand loss of inhibition.

The implications of all of these understandings for us is to know that indeed we have to apply what is now, in most of the advanced pain management centers, a multimodal and multidisciplinary pain management.

[Dr. Backonja is a professor of neurology, anesthesiology and rehabilitation medicine at the University of Wisconsin School of Medicine and Public Health.]

ASAP Chiari & Syringomyelia Conference 2010 Pain Topics

Pain Definitions and Mechanisms presented by Robert Buchannan, MD

Alternative Treatments of Pain presented by Nathan Rudin, MD, MA

Surgical and Novel Treatments of Pain presented by Robert Buchannan, MD

Spasticity presented by Karen Richards, MD

Straight Talk About Pain and Fatigue presented by Nathan Rudin, MD, MA

Common Central Neuropathic Pain Disorders

- Multiple Sclerosis
- Spinal Cord Injury Pain
- Central Post-stroke Pain Syndrome (CPSP)
- Syringomyelia

New Formulation for OxyContin Approved

The U.S. Food and Drug Administration approved a new formulation of the controlled-release drug OxyContin that has been designed to help discourage misuse and abuse of the medication.

OxyContin is made to slowly release the potent opioid oxycodone to treat patients who require a continuous, around-the-clock opioid analgesic for management of their moderate to severe pain for an extended period of time. Because of its controlled-release properties, each tablet contains a large quantity of oxycodone, which allows patients to take their drug less often. However, people intent on abusing the previous formulation have been able to release high levels of oxycodone all at once, which can result in a fatal overdose and contributes to high rates of OxyContin abuse.

The reformulated OxyContin is intended to prevent the opioid medication from being cut, broken, chewed, crushed or dissolved to release more medication. The new formulation may be an improvement that may result in less risk of overdose due to tampering, and will likely result in less abuse by snorting or injection; but it still can be abused or misused by simply ingesting larger doses than are recommended.

“Although this new formulation of OxyContin may provide only an incremental advantage over the current version of the drug, it is still a step in the right direction,” said Bob Rappaport, M.D., director of the Division of Anesthesia and Analgesia Products in the FDA’s Center for Drug Evaluation and Research.

The manufacturer of OxyContin, Purdue Pharma L.P., will be required to conduct a postmarket study to collect data on the extent to which the new formulation reduces abuse and misuse of this opioid. The FDA is also requiring a REMS (Risk Evaluation and Mitigation Strategy) that will include the issuance of a Medication Guide to patients and a requirement for prescriber education regarding the appropriate use of opioid analgesics in the treatment of pain. Purdue Pharma is based in Stamford, Conn.

For more information:

OxyContin - Questions and Answers

<http://www.fda.gov/Drugs/DrugSafety/PostmarketDrugSafetyInformationforPatientsandProviders/ucm207196.htm>¹

A Guide to Safe Use of Pain Medicine

<http://www.fda.gov/ForConsumers/ConsumerUpdates/ucm095673.htm>²

FDA News Release - Apr. 5, 2010

Consumer Inquiries: 888-INFO-FDA

2010 Conference Topic Overview

Thursday

- Health Care Reform-What’s Important to Know Now
- Evidence-Based Medicine: Understanding Research, Expert Opinions and Guidelines
- Chiari Malformations and Syringomyelia: Basic Definitions & Concepts
- A Diagnostic Methodology for the Evaluation of Chiari I Malformation
- How to Make Sense of a Radiology Report
- Visual System Dysfunction
- Neuropsychological Issues
- Vestibular & Otological Dysfunction
- Outcome Study Update
- Genetics
- Hydrocephalus and Shunts
- Tonsillar Herniation Associated with Craniofacial Malformations
- Incidental Chiari I in Children
- Scoliosis: Diagnosis and Treatment
- Idiopathic Intracranial Hypertension: Diagnosis, Management and Treatment
- Support Group Meetings

Friday

- Post Traumatic Syringomyelia
- Syringobulbia
- Rehabilitation and Independence
- Surgery for Chiari I: Overview
- Orthopedic Complications of Chiari Surgery
- Complex and Controversial Problems
- Occult Spinal Dysraphism and Tethered Cord Syndrome
- Complex Chiari: To Fuse or Not to Fuse
- Chiari Surgery
- How to Talk to your Neurosurgeon
- Sexual Dysfunction with Spinal Disorders
- Disability Insurance
- Physical and Occupational Therapy
- Coping and Depression
- Writing an IEP

Saturday

- Pain Definitions and Mechanisms
- Alternative Therapies for Pain Management
- Medical Management of Pain
- Surgical & Novel Treatments of Pain
- Spasticity
- Straight Talk About Pain and Fatigue
- The Origin of Syrinx Fluid
- Debate: How to Manage Asymptomatic Chiari?
- Cranial Compliance
- Revision Surgery in Failed CM Decompression
- Mechanisms of Cerebellar Tonsil Herniation
- Surgical Results Comparing Duraplasty vs Dural Splitting Techniques

Perfectly Imperfect

by Fred R. Jacobeit

As I near retirement age after 32 years in the teaching profession, I take time to ponder how fortunate I am to be at the mercy of a relentless, insatiable neurological disorder called syringomyelia. This disease inflicts a brutal dose of discomfort upon its recipients, both in the physical realm and psychologically.

I have met SM patients who experience pain only in their hands, those whose sensitivity in nerve endings makes wearing clothes intolerable, and folks who deal with searing, burning sensations in various areas of the body. Personally, my symptoms fall somewhere in the middle, where I contend with stabbing pain in my hips and groin, the stiffness in my lower joints of a petrified forest, and the sensation that my lower extremities have been asleep for as long as Rip Van Winkle.

The eloquent Martha Washington once was quoted as saying "Our misery or happiness is not dictated by our circumstances but by our attitudes." Although I barely missed the opportunity to meet Martha by about two centuries, I am a strong proponent of her philosophy. Nobody on earth has the power to control my emotions but me.

I derive great satisfaction in self effacing remarks that put people at ease with my physical limitations. When my legs go into spastic convulsions I simply say, "I guess I'm going to do my Elvis impression again." When I am refereeing a basketball game in my physical education class I sometimes get flattened by someone on the dead run. I struggle to my feet as the class becomes deadly silent and emphatically call a charging foul on the perpetrator. If laughter is truly the best medicine I plan to live to 150.

I walk like the old time children's toys Weebles who wobble from side to side. Unlike the Weebles jingle I do, however, sometimes fall down. I scrape my knees, bump my head,

sprain my ankles, crack my bones and bruise my ego. I sometimes am forced to revert to a walker or wheelchair when a cane alone fails to provide adequate support. I am no longer self conscious about my means of transportation partly because at age 50 one ceases to care what others think (what a liberating concept!)

I try to exercise daily because I know that what is lost is lost forever. Like a used car, I try to maintain my level of function, knowing that getting better is probably a pipe dream. Like a steel framed car rarely driven but left to the elements, my inside tells me that I am still young and virile but I am in serious need of new wiring, touch up paint, and a good body man to smooth out my creases. My mind insists that I am 30 while an attempt to walk to the refrigerator suggests that I am 97.

I can no longer play one-on-one in the driveway, go for a long moonlight stroll, or dance the mambo or salsa. I require a sturdy partner to hold me up in the event that a slow dance opportunity presents itself (sturdy partners are not something I'm customarily used to seeking out.)

I am blessed with a unique perspective of the world and almost impervious to normal causes of stress (who needs money anyway?). I hold no fear whatsoever of dying and am consumed only with the challenges of daily living.

I am perfectly imperfect. I believe people are physically attracted to the uniqueness of an individual whether it be a birthmark, skin pigmentation or tattoo. Some people go to great lengths to create individuality. I have a 14-inch scar that spans the length of my spine, a nose like a toucan and I drag my legs like 200 lb. logs when I walk.

I can honestly say that I rejoice in my plight every day. I'm sorry Mr. Shakespeare, but woe is definitely not me.



Richmond Walk-a-thon

by Karen Spiroff

We completed the Richmond walk and it was a successful first-time event. We had about 50 people in attendance, the weather held out for us and we brought in over \$6,000. A remote walk associated with this one was going on at the same time on a cruise. We have not heard how much that yielded but our donation will certainly increase. We also had interest from a walker who would like to do her own event so that was a big positive as well.

I had many people tell me that they can't wait for next year's walk before they had even left this one. Awareness was defi-

nately spread about ASAP and SM/CM so I know that the benefits will be further reaching than just the one event.

I personally would like to extend appreciation to Matt for helping out with organizing this; Jamie and Patricia for always being so quick to respond to whatever was needed and to Mike for problem-solving, quick answers, much needed help and support. Taking this on for the first time can seem somewhat overwhelming but it was certainly made much less stressful having that support and guidance available. Thank you!

Awareness and Fundraising: Kids Making A Difference

A Jeans Day Fundraiser

My name is Amanda. I am 12 years old, and a member of ASAP Kids For A Cure Club. I was diagnosed with Chiari and syringomyelia last October and underwent cranial decompression surgery in December. I still deal with pain in my neck and back almost every day, just not as severe as before my surgery.

When I was diagnosed, I started searching the internet for web sites that would better help me understand what exactly I had and that could answer questions I had about Chiari and syringomyelia. ASAP was that web site. The information on their site helped me and my family have a better understanding of what I was going through. We especially found the message board to be a great place to ask questions and get them answered by someone who had gone through or was going through the same thing. I also like the fact that ASAP has various ongoing research projects listed on their web site so that I could see what is being done to find a cure.

Because I thought the work ASAP is doing to find a cure for Chiari and syringomyelia is so impressive, I wanted to do what I could to help. I wrote a letter to Mayor Jack Kirksey at the City of Livonia requesting to hold a "Jeans Day Fundraiser," wherein each employee would pay a minimum of \$3.00 for the opportunity to wear jeans to work on a specific day. He was kind enough to approve this request and on Friday, March 5, 2010 the fundraiser was held. This gave my mom the opportunity to tell others about Chiari and syringomyelia, so I think being able to educate others about these disorders alone made having the "Jeans Day Fundraiser" worthwhile.

I raised a total of \$340. It was very nice of Mayor Kirksey to let me have this fundraiser and it was very cool to get to meet him and sit in his office chair.

I would also like to thank Jamie at ASAP without her help this would not have come together so smoothly. She was a big help in making the posters and answering e-mail questions. She is definitely an asset to ASAP.

Looking forward to doing more for ASAP in the future.



Awareness Magnets

At the age of 5 1/2, Preston started complaining of headaches. He would find every ice pack he could in the freezer, fill a pillowcase, and lie down. We thought maybe he was starting to get migraines, because of a family history. His headaches gradually became worse and more frequent.

Preston had his first MRI in April, 2008. Shockingly, the MRI revealed that Preston had something we had never heard of Chiari. He was referred to a neurosurgeon, who ordered a MRI of his spine which showed he also had syringomyelia. His cerebellar tonsils were herniated 20mm. So at the age of 6, Preston underwent decompression.

Shortly after surgery, he began getting very intense headaches and after a couple trips back to the hospital, he was diagnosed with pseudotumor cerebri. A LP shunt was placed. On Christmas Eve, 2008, a routine follow-up MRI showed his Chiari returned, with a 9mm tonsillar descent, and his syrinx was larger. His shunt was turned to a high setting (essentially off). Thankfully, a repeat MRI in March, 2009 showed improvement of his Chiari, with only a 4mm tonsillar descent.

We are very blessed that Preston is doing wonderful right now. He only occasionally complains of "tiny" headaches, and his legs tire easily. He is scheduled for a MRI in June, 2010, and will hopefully have his shunt tied off and removed a few months later.

Preston is a member of the Kids For A Cure Club with ASAP (American Syringomyelia & Chiari Alliance Project). He is helping raise money for research to help find a cure for Chiari. Beth, Preston's mother, searched online for a Chiari and syringomyelia awareness magnet ribbon for her car but could not find one. So they decided to have one created for Preston's fundraiser.

Please help spread the word about Chiari by purchasing an awareness ribbon magnet for your car. Magnets are \$3 each or 2 for \$5 (plus shipping). All proceeds from the magnets are donated in honor of Preston to ASAP. Magnets are 3 1/2" x 8".

To order magnets, please contact Preston at ChiariKid@cox.net or contact the ASAP office.



Meet the Medical Advisory Board Bermans Iskandar, MD

Bermans J. Iskandar, MD, is Director of Pediatric Neurosurgery and Associate Professor of Neurosurgery and Pediatrics at the University of Wisconsin Hospital and Clinics and University of Wisconsin Children's Hospital.



Dr. Iskandar started his college studies at the American University of Beirut, where he majored in Biology. Dr. Iskandar received his college degree in Biology in 1985 from the California State University in Northridge and his medical degree in 1989 from the University of Pennsylvania School of Medicine. He completed his neurosurgery residency at the Duke University Medical Center in 1996. He followed his residency with a fellowship in pediatric neurosurgery at Children's Hospital Birmingham, Alabama. Then in 1997, he became an assistant professor of neurosurgery and pediatrics at the University of Wisconsin. In 2003 Dr. Iskandar became an associate professor.

Dr. Iskandar is the author of over 23 publications and numerous presentations/papers. The subject matter of many of these has been Chiari malformation, syringomyelia, and tethered cord in both adult and pediatric patients.

Dr. Iskandar has been an ASAP Research Committee member since 2004. A speaker at multiple ASAP conferences, Dr. Iskandar hosted the ASAP Chiari & Syringomyelia Conference, Quest for Understanding, in July 2009

Awareness and Fundraising Across the US

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

ASAP
PO Box 1586,
Longview TX 75606-1586

What is Occupational Therapy and How Can It Help Patients with Chronic Pain?

by Susan Sparkevicus OTR/L

Occupational Therapy (OT) promotes health by enabling patients to increase function. An OT works with individuals, families, groups and communities to facilitate health and well being through engagement or re-engagement in specific activities. The primary goal of the therapy is to enable people to participate in actions of everyday life. This outcome is achieved by enabling the person to do things that will enhance their ability or by modifying the environment to better support participation.

People with chronic pain face more than one obstacle. Pain is extremely complex and occupational therapists understand it in many dimensions. They understand the subjectivity and respect a patient's self report. By evaluating the physical, cognitive, and psychological elements together in someone with chronic pain the therapist can help patients cope with and manage their pain so they can accomplish the activities that are most important to them. Occupational Therapy helps clients to live and function more productively. OT's evaluate the pain's impact on a patient's desired activities and quality of life. Then they equip them with the skills and strategies to manage the pain.

Therapist can show patient's how to redirect their pain so that it interferes less in their daily lives. Relaxation and visualization activities cognitively redirect pain. The therapist will work on gentle exercises to increase strength and stamina. They may also use activities such as self hypnosis, meditation and yoga, all of which can be effective ways of coping with pain. The effectiveness of these activities depends largely on the patient's attitude and beliefs on pain.



Trained as an occupational therapist, I specialized in neurological rehabilitation. I am unable to work in my selected field but I have so much information to share and I want to help others. If you have any questions or a topic related to rehab you would like me to discuss, please email me at suzie.sparks@gmail.com.

Visit ASAP's New Improved Web Site

www.ASAP.org

ASAP Resource Book Now Available

Eight modules, twenty-seven lectures with PowerPoint slides, and seven question and answer sessions have been transcribed from ASAP's Chiari & Syringomyelia Conference, Quest for Understanding. This incredible resource covers a wide range of topics pertaining to Chiari malformation, syringomyelia and related disorders from leading experts.

This year ASAP is offering our annual resource book in an affordable download. No waiting for shipping or processing, you can begin reading your Conference Notebook immediately, save it to your computer and print a copy on your home printer. A PDF reader such as Adobe is required. Cost for downloading is \$35.00. Visit the ASAP Store at www.ASAP.org to purchase your copy today.

If you don't have Internet access or would just like to receive a printed copy, contact the ASAP office, The cost is \$45.00 plus \$10 for shipping and handling.

Overview of the 2009 meeting:

MODULE 1: BASIC REVIEW

The Chiari Malformations: Definitions, Concepts and Treatments - Timothy George, MD
Syringomyelia: Definitions, Concepts and Treatment - Bermans Iskandar, MD
Questions and Answers Covering Basic Concepts - Panel of Experts
A Diagnostic Methodology for the Evaluation of Chiari I Malformation - Roger W. Kula, MD

MODULE 2: ASSOCIATED CLINICAL PROBLEMS

Audio-Vestibular Dysfunction Associated with Chiari I: A review - Burke Richmond, MD
Sexual Dysfunction and Urological Problems - John V. Kryger, MD
Neuropsychological Issues - Bruce P. Hermann, PhD
Rehabilitation and Independence - Michael Ward, MD

MODULE 3: COMPLEX AND CONTROVERSIAL PROBLEMS

Goals and Objectives for Complex and Controversial Problems - Bermans Iskandar, MD
Occult Spinal Dysraphism and the Tethered Cord Syndrome - W. Jerry Oakes, MD
Complex Chiari: to Fuse or not to Fuse - Arnold H. Menezes, MD
Scoliosis: Diagnosis and Treatment - James McCarthy, MD
Questions and Answers with the Experts - Panel of Experts

MODULE 4: PAIN

Pain Definitions and Mechanisms - Miroslav Backonja, MD
Pain and Syringomyelia - Angela Mailis-Gagnon, MD
Questions and Answers Concerning Pain - Panel of Experts

MODULE 5: CLINICAL RESEARCH I

Measuring Outcomes after Chiari Decompression for Syringomyelia Nicholas Wetjen, MD
Neuropsych Issues in Patients with Chiari and Syringomyelia - David Frim, MD
Trends in the Surgical Treatment of CM/SM in North America: Results - Brandon Rocque, MD
Genetics Research and Techniques: Review - Allison Ashley-Koch, PhD
Questions and Answers - Panel of Experts

MODULE 6: PEDIATRIC ISSUES

Hydrocephalus and Shunts - A. Leland Albright, MD
Incidental Chiari I in Children - Robert Keating, MD
The Patient and Family Experience to Hospitalization and Illness - Julie Auen-son BS CCLS
Questions and Answers - Panel of Experts
Ocular Manifestations of Chiari in Children and Adults - Michael Struck, MD

MODULE 7: CLINICAL RESEARCH II

MRI Research and Techniques: Review - Victor Haughton, MD
Mechanical/Computer Models Research and Techniques: Review - Frank Loth, PhD
The Origin of Syring Fluid - John D. Heiss, MD
Questions and Answers - Panel of Experts

MODULE 8: CENTRAL NERVOUS SYSTEM HEALING

Epigenetics - Bermans Iskandar, MD
Nervous System Regeneration and Repair - Raghu Vemuganti, PhD
Stem Cells - Paul Clark, PhD
Questions and Answers - Panel of Experts

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When It's Time to Remember Loved Ones

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The Conference Experience

Still trying to decide if you should attend ASAP's Chiari & Syringomyelia Conference in Austin, Texas? Maybe the experience of others can make that decision a little easier.

Sheila R after attending her first conference said, "I had a hard time sleeping due to excitement the first night before the conference started. To go downstairs and meet the people I had been corresponding with was amazing. My husband was fascinated with the lectures and with the doctors who were willing to discuss syringomyelia with us and give us hope for the future. This 'loner' found friends she never dreamed she would have."

Diane W wrote, "We came with three needs: information, validation and hope. We left with so much more."

In 2002 Barbara K said, "This was my third ASAP

conference, they get better and better every year."

Laura K attending her first conference in 2002 found it informative and helpful to meet others in person. She explained, "When talking on the phone, we get a one-sided opinion, this conference allowed us to meet with a group."

In 2003 for Selena speaking with other members and the doctors made it an invaluable experience. It was during the conference that she learned many of her symptoms were Chiari related.

In 2003 Constance's 10-year-old son, John said, "It was really great to talk to other kids who have Chiari."

Don't delay make your reservations today!

"Yes, I want to make a difference!"

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NL 6-2010

A Mother's Perspective

by Ilesha Goldsberg

I remember being up at 3 AM watching *Mystery Diagnosis* and there was a young girl who was diagnosed with Chiari. She had this contraption hanging from her doorway into which she strapped her head. She used it to relieve some of the pressure she was having from those horrible headaches and then I watched her have the surgery.

I thought to myself, "Oh my, that poor baby." Little did I know a day and a half later that I would get a call saying my baby had the same disorder. Naturally, I thought this was all my fault, and I must have done something wrong while I was pregnant. I worked out too much, I didn't take enough vitamins or eat the right foods. This is all my fault.

But lucky for us we have a great pediatrician. It may have taken her a while to convince me that it wasn't my fault and I am not to blame. This is something that unfortunately just happens and I should stop beating myself up. Thankfully she found us great doctors to treat Josh. They answer any questions we have.

Thanks to Christine Marchesano I know Josh is not alone. She answers any questions he or we may have. We are so blessed that Joshua is such a happy-go-lucky kid that when we told him what was wrong with him, he said, "Ok, can I go play football now!"

[On May 24, children at the Leeds Ave Elementary School walked in honor of Christine and Josh raising almost \$1,000.]



ASAP'S MISSION

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

See You in Austin!

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

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

For more information visit www.ASAP.org

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

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