

# ASAP CONNECTIONS

*Providing Research, Education and Support since 1988*

## **Coping as a Parent of a Child with Chiari and Syringomyelia**

by Patricia Maxwell

When your child was diagnosed with Chiari / syringomyelia you most likely experienced guilt, sadness and even anger. These are normal feelings for a parent under the circumstances. So how do you move forward?

It has been reported that a parent who takes action and focusses on the problem will experience lower levels of anxiety and depression than parents who deny or avoid the situation. When a parent feels they are in control they will experience less stress and a more positive attitude. A parent's outlook will be reflected in the child and make a difference in how they cope with their illness.

The American Psychological Association reports that parents often tend to become overprotective or overly permissive. They recommend that a parent try to maintain the same family routine as before the diagnosis as much as possible. Talk to your child about what he or she is feeling and share age-appropriate information. Without hiding the facts, try to give information in a positive way. Help them with a brief explanation they can share with their friends and classmates. You may want to enlist additional help like a psychologist and child life specialist who are trained to help parents and children accept and manage their diagnosis.

For families with additional children, it is important to take one-on-one time with them, too. They may experience resentment toward their sibling who is getting all the attention. Make them a part of the team by helping them understand the situation and how they can help.

Getting involved with a self-help group will give parents and children a source of support and information. Probably the biggest advantage of support groups is helping a parent realize that he or she is not alone – that there are other people who have the same problems. Being in a support group can also help you develop new skills to relate to others. In addition, the members of the group who have the same issues can support each other and may suggest new ways of dealing with a particular problem.

Remember it is okay to get angry or depressed; just don't stay there any longer than necessary. Taking a hands-on approach to your child's disorder will empower you.

## **Save the Date 2015 ASAP Conference**

**When: July 22-25, 2015**

**Where: Marriott Ann Arbor Ypsilanti at Eagle Crest  
1275 S Huron St, Ypsilanti, Michigan**

Start making plans now to attend ASAP's Chiari and Syringomyelia Conference. The meeting will provide information for the novice and expert alike. Include social events and support group meeting to enhance the peer to peer experience. Youth ages 5 to 15 participate in a special mini conference. This four-day meeting is a must for those wanting to learn more and a great opportunity to catch up with friends who share your unique experience.

If you have attended past conferences, you know the benefits of taking part in the annual event. If you are newly diagnosed, it is an opportunity to learn from multiple experts and share your experience with them. If you just don't feel you can afford the added expense on an already tight budget, check out the conference scholarship and the ASAP's LEARN – Points Program available to ASAP members.

The Marriott at Eagle Crest will serve as the conference meeting site this year. Individual reservations can be made by calling 1-877-757-7133 before Monday, June 27, to receive the special guest room rate of \$135 per night plus applicable taxes. You must identify yourself as part of the 'ASAP annual conference'. Reservations can be made online if preferred. You will find a link to the Marriott reservation website under conference information at [www.ASAP.org](http://www.ASAP.org). From the ASAP home page, you will click on the Great Expectations tab, then 'Annual Conference in the right side menu. Attendees are responsible for personal expenses including room and tax.

A complete list of frequently asked questions is available under conference information on our website. A registration form is included with this newsletter or you can register online at <http://asap.org/index.php/conference-register/>.

**[www.ASAP.org](http://www.ASAP.org)**

## Stamp Project

Please send postage stamps that are in good condition (attached to envelope and trimmed with a 1/4 to 1/2 inch border around undamaged stamp). Forever, special occasion and foreign stamps are accepted. Nonprofit, postage meter and presort stamps are not accepted. But Charles told me they also have an outlet for postcards. So send those too!

Charles Petkevich  
ASAP Stamp Project  
6202 SW 2nd Court  
Plantation FL 33317



## ASAP History

ASAP was founded as the American Syringomyelia Alliance Project and incorporated in May 1988 and received the IRS recognition of exemption 501(c)(3) status on January 23, 1989.

In April 1992 in his Letter from the Chairman, Don White wrote: Although ASAP was founded by Barbara and I with the help of a few others, it was never just our organization. ASAP is your organization...

In October 1992 the Bobby Jones Open provided a grant to fund the 800 line (800-ASAP-272) and continues to do so.

In April 2009 ASAP began doing business as American Syringomyelia & Chiari Alliance Project. Although the organization has since its inception provided information on both syringomyelia and Chiari the name did not accurately reflect the purpose of the group.

**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.

## ASAP Support Group Update

Lori Tutrow, ASAP Board member and support group leader of the Indy ASAP Chiari/Syringo support group, volunteered as Chapter Leader in September. Her duties will include working with existing groups and helping volunteers organize new groups. You can contact Lori via email at [Lori\\_Tutrow@ASAP.org](mailto:Lori_Tutrow@ASAP.org) for assistance.

### New groups recently formed:

#### ASAP's Rhode Island Chiari/Syringo Support Group

Group Leader: Michelle Dumsar  
Phone: 401-473-7457  
Email: [RI\\_Support@ASAP.org](mailto:RI_Support@ASAP.org)

#### ASAP's Maine Chiari/Syringo Support Group

Group Leader: Lisa Duton-Roy  
Glenburn, ME  
Phone: 207-570-6428  
Email: [Maine\\_Support@ASAP.org](mailto:Maine_Support@ASAP.org)



## Gear Up for Awareness

[www.ASAP.org/index.php/store/](http://www.ASAP.org/index.php/store/)

## Become An ASAP Volunteer

Submit an application at [ASAP.org/index.php/volunteer/](http://ASAP.org/index.php/volunteer/) or contact the ASAP office at 903-236-7079.

## A Word From Our President



I would like to begin by thanking everyone for all of your year end donations. Your contributions, no matter the size, go a long way to support the CM/SM community through our many programs.

As you may already know, ASAP continues to grow with new board and medical advisory board members, support groups, etc. It is with a small staff, our volunteer

board of directors, our volunteer medical advisory board and our volunteer network that we are able to serve this community through these programs since 1988. In this newsletter you will find information on our upcoming conference in Ann Arbor, Michigan hosted by Dr Cormac Maher. We welcome donations of different items to be used for our auctions throughout the year, especially the conference. If anyone has anything they would like to donate, i.e., a small item, basket filler, gift card, airline points, hotel points, timeshares, homemade crafts, etc., it would be greatly appreciated. If you know a person who owns a company and would like to be a sponsor this could help you earn points to attend. Please provide me with his/her info and I would be glad to reach out to them with our sponsor levels.

You will also find an article about our different fundraising efforts. We hope that you will find one that might spark your interest. It is always difficult to ask the many who have given so much to continue to give. Please know that your generosity is greatly appreciated.

We are posting videos from the 2014 conference in Princeton. Please visit our website at [www.ASAP.org](http://www.ASAP.org). Type in videos in the search box. I hope the information is helpful.

Please remember, I do understand what you are going through. I may be president of this organization but I also have these disorders. I understand the chronic pain, the peaks and the valleys, the frustration. We are all in this together. We need to stay positive and continue to move forward so we can find answers. Asking the question 'Why me?' will never get us there.

"The best way to cheer yourself up is to try to cheer somebody else up."  
Mark Twain

Gentle hugs always,  
Patrice

## Getting Your Exercise in the Water

by Patricia Maxwell

Exercise is not only important to our health but well-being. It improves strength, mobility and reduces stress. It has also been shown to decrease pain.

But how do we find a program that works without causing more symptoms. One of the more recommended forms of therapy for syringomyelia and Chiari patients is water aerobics.

- Aquatic centers, YMCAs and even local hotels are possible sources for finding classes.
- Water activity is lower impact due to the buoyancy of the water which provides decreased stress on joints and the spine.
- Water provides a whole body workout.
- It allows you to move in ways that you might not be able to move on land without a fear of falling.
- Exercising with a group is more fun.
- A heated pool can provide additional comfort to sore muscles.
- Did you know you can even practice Tai Chi or yoga in the water? The pool offers support, decreased worries of losing balance and movements that can be harder to attain on land.

### Starting a Water Program

As with any new form of exercise, start slow. The water can feel so good that new participants may overdo it a little because movement is so much easier.

Start your first workout with 15 -20 minutes, keep the intensity light to moderate and see how you feel over the next 24 hours. That will be your guide on how long or how intense your next pool workout can be.

Keep jumping, running and twisting actions to a minimum until your body tells you how it feels. You may not know the full effect of your intensity until after you get out of the support of the pool.

Whether doing a vigorous aerobic program, a walking program or some gentle Tai Chi, think about tall posture and full foot contact to the floor. The buoyancy can encourage people to stay up on their toes which can lead to sore calf muscles.

Drink more water to help support what you lose during your exercise. In the water you don't feel warm and sweaty so there is less of a cue to replace fluids. As your body adjusts to the new activity, gently increase your program.

As with any new program or activity, you should consult with your doctor to make sure it is safe for you and get specific suggestions on how to proceed.

# The Patient-Doctor Relationship

by Patricia Maxwell

Building a good relation with your doctor is an important step in receiving the health care you deserve. You have a knowledge of your disorder that no doctor has. You live with the pain, the fears and the frustration. Most doctors are not experienced with treating Chiari or syringomyelia much less knowing what it is like to live with a chronic disorder or daily pain. Giving up on the medical field is not the answer you deserve.

So how do you receive the care you need?

The first step is to find a doctor who will listen and not minimize your problems. Someone who will go to battle for you to get the care you deserve. The best care happens when a doctor understands the patient. This will only happen over time. Building a long-lasting relationship will take patience and understanding on your part but the long-term benefits could make a big difference. Make sure he knows how much you appreciate his involvement and understanding.

Unfortunately there are more questions than answers associated with these disorders. Try to keep your expectations realistic. Be open to suggestions even if you don't think it will work. Your willingness to follow your doctor's suggestions will help build a strong foundation. This does not mean you should ever put up with a jerk. Not all doctors are cut out to treat chronic disorders. Keep looking until you find the right doctor for you.

The following are a few basic descriptions of doctors you might employ.

A **primary care physician** or primary care provider (PCP) is a physician who provides both the first contact for a person with an undiagnosed health concern as well as continuing care of varied medical conditions, not limited by cause, organ system, or diagnosis. This term is primarily used in the United States, although this is a recent occurrence. In years past in the US and in Britain (and many other English-speaking countries), the equivalent term was/is general practitioner.

**Physiatrists** specialize in non-surgical physical medicine and rehabilitation (PM&R) for patients who have been disabled as a result of a disease, condition, disorder, or injury. They diagnose, perform thorough patient histories, treat injuries and conditions, and direct your expanded treatment team using non-surgical methods.

Physiatrists focus on a personalized method of treatment to improve their patients' quality of life – one that involves a comprehensive approach to expand the framework of resources at a patient's disposal. As a result, a patient's recuperation involves every aspect of their lives.

A **neurologist** is a doctor that treats the brain, spinal cord and nerves. Many neurologists also have additional training

or interest in other area of neurology, such as stroke, epilepsy, neuromuscular, sleep medicine, pain management, or movement disorders.

A **neurosurgeon** is a physician who specializes in the diagnosis and surgical treatment of disorders of the central and peripheral nervous system including congenital anomalies, trauma, tumors, vascular disorders, infections of the brain or spine, stroke, or degenerative diseases of the spine.

**Naturopathic physicians** combine the wisdom of nature with the rigors of modern science. Steeped in traditional healing methods, principles and practices, naturopathic medicine focuses on holistic, proactive prevention and comprehensive diagnosis and treatment. By using protocols that minimize the risk of harm, naturopathic physicians help facilitate the body's inherent ability to restore and maintain optimal health.

**Pain specialists**, or pain medicine doctors, are experts at diagnosing the cause of pain and then treating it. Anesthesiologists, neurologists, and neurosurgeons most frequently specialize in pain management. Some physiatrists also specialize in pain management.

Orthopaedics is the medical specialty that focuses on injuries and diseases of your body's musculoskeletal system. This complex system includes your bones, joints, ligaments, tendons, muscles, and nerves and allows you to move, work, and be active.

The role of the **rheumatologist** is to diagnose (detect), treat and medically manage patients with arthritis and other rheumatic diseases. These health problems affect the joints, muscles, bones and sometimes other internal organs (e.g., kidneys, lungs, blood vessels, brain). Because these diseases are often complex, they benefit from the care of an expert. Only rheumatologists are experts in this field of medicine. He interacts with the patient and family, gives health information and partners with other health care providers.

**Neuro-ophthalmology** is an academically-oriented subspecialty that merges the fields of neurology and ophthalmology, often dealing with complex systemic diseases that have manifestations in the visual system. Since diagnostic studies can be normal in patients with significant neuro-ophthalmic disease, a detailed medical history and physical exam is essential and neuro-ophthalmologists often spend significantly more time with the patient than specialists in other disciplines.





## **FDA Approves Extended-release, Single-entity Hydrocodone Product with Abuse-deterrent Properties**

The U.S. Food and Drug Administration today approved Hysingla ER (hydrocodone bitartrate), an extended-release (ER) opioid analgesic to treat pain severe enough to require daily, around-the-clock, long-term opioid treatment and for which alternative treatment options are inadequate. Hysingla ER has approved labeling describing the product's abuse-deterrent properties consistent with the FDA's 2013 draft guidance for industry, Abuse-Deterrent Opioids – Evaluation and Labeling. <http://www.fda.gov/downloads/Drugs/GuidanceComplianceRegulatoryInformation/Guidances/UCM334743.pdf>

Hysingla ER has properties that are expected to reduce, but not totally prevent, abuse of the drug when chewed and then taken orally, or crushed and snorted or injected. The tablet is difficult to crush, break or dissolve. It also forms a viscous hydrogel (thick gel) and cannot be easily prepared for injection. The FDA has determined that the physical and chemical properties of Hysingla ER are expected to make abuse by these routes difficult. However, abuse of Hysingla ER by these routes is still possible. It is important to note that taking too much Hysingla ER, whether by intentional abuse or by accident, can cause an overdose that may result in death.

"While the science of abuse deterrence is still evolving, the development of opioids that are harder to abuse is helpful in addressing the public health crisis of prescription drug abuse in the U.S.," said Janet Woodcock, M.D., director of the FDA's Center for Drug Evaluation and Research. "Preventing prescription opioid abuse is a top public health priority for the FDA, and encouraging the development of opioids with abuse-deterrent properties is just one component of a broader approach to reducing abuse and misuse, and will better enable the agency to balance addressing this problem with ensuring that patients have access to appropriate treatments for pain."

Hysingla ER is not approved for, and should not be used for, as-needed pain relief. Given Hysingla ER's risks for abuse, misuse and addiction, it should only be prescribed to people for whom alternative treatment options are ineffective, not tolerated or would be otherwise inadequate to provide sufficient pain management. As a single-entity opioid, Hysingla ER does not carry the serious liver toxicity risks associated with hydrocodone combination products containing acetaminophen. The FDA encourages health care professionals to review and consider all available information as part of their decision-making when prescribing opioid analgesics.

Strengths of Hysingla ER contain 20, 30, 40, 60, 80, 100 and 120 milligrams (mg) of hydrocodone to be taken every 24 hours. Doses of 80 mg per day and higher should not be prescribed to people who have not previously taken an opioid medication (opioid non-tolerant). While Hysingla ER contains larger amounts of hydrocodone compared to immediate-release hydrocodone combination products, the range of tablet strengths of Hysingla ER is comparable to existing approved ER opioids.

The safety and effectiveness of Hysingla ER were evaluated in a clinical trial of 905 people with chronic low back pain. Additional data from studies conducted in laboratories and in people demonstrated the abuse-deterrent features of

Hysingla ER for certain types of abuse (oral, snorting and injection). The most common side effects of Hysingla ER are constipation, nausea, fatigue, upper respiratory tract infection, dizziness, headache and drowsiness (somnolence).

The FDA is requiring postmarketing studies of Hysingla ER to assess the effects of the abuse-deterrent features on the risk for abuse of Hysingla ER and the consequences of that abuse in the community. In addition, Hysingla ER is part of the ER/LA Opioid Analgesics Risk Evaluation and Mitigation Strategy (REMS),

which requires companies to make available to health care professionals educational programs on how to safely prescribe ER/LA opioid analgesics and to provide Medication Guides and patient counseling documents containing information on the safe use, storage, and disposal of ER/LA opioids.

Hysingla ER is manufactured by Stamford-based Purdue Pharma L.P.

FDA News Release November 2014

[The FDA, an agency within the U.S. Department of Health and Human Services, protects the public health by assuring the safety, effectiveness, and security of human and veterinary drugs, vaccines and other biological products for human use, and medical devices. The agency also is responsible for the safety and security of our nation's food supply, cosmetics, dietary supplements, products that give off electronic radiation, and for regulating tobacco products.]



## Fundraising Ideas for 2015



A new year has begun and the annual spring fundraising season is upon us. As we venture into 2015 we are excited to have many ways in which you can be a part of our mission...to improve the lives of persons affected by syringomyelia, Chiari malformation and related disorders while we find the cure.

ASAP's Walk and Roll creates awareness and funds research for syringomyelia, Chiari malformation and related disorders. This has been an annual, national event for many years.

Syringo-my-what!? Steps across the States began last May and brings us back to our roots. This walk highlights syringomyelia and is growing in popularity. In designating May as Syringomyelia Awareness Month, we hope this will spotlight SM.

Kicks and Licks! Dogs provide new insight into Chiari malformation and syringomyelia in humans. We are funding cross species research that will benefit both humans and canines alike. Animals are unharmed as we learn from these studies. This event is an open format and will include support from the canine community, their owners, veterinary professionals and is open to all others.

Heads Up for SM & CM! This is a fun and funky walk/run for those who like to show their true colors. Hair is colored purple, blue, or purple and blue. Feel free to add color anywhere you like and have some fun spreading awareness.

Please consider joining us in our mission. It is a small investment of time with a huge outcome that benefits many. Through these efforts, ASAP provides research funding, support groups, the annual conference, extensive online resources and videos, and much more. Above are just a few ways to get involved. There are many others. In addition to knowing that your efforts help thousands in our community, all net monies raised by May 31st will qualify for ASAP's L.E.A.R.N. program and may entitle you to a trip to this years' annual conference (see website for full details <http://asap.org/index.php/get-involved/asaps-le-a-r-n-points-program/> ). Please contact our office at (903) 236-7079 or Patrice\_Schaublin@asap.org for more information.

**Be Sure to Check out the New Videos Online Now!**

<http://asap.org/index.php/disorders/online-video-library/2014-conference-presentations/>

### **10 Reasons to Attend the ASAP Annual Conference**

1. Top specialists in these disorders bring you the most up-to-date information
2. The opportunity to ask questions from a panel of experts
3. Peer to Peer support group meeting
4. Subjects dealing with a variety of topics related specifically to syringomyelia and Chiari
5. Special activities for children
6. Learn new relaxation techniques
7. Meet friends from Facebook
8. First time held in Michigan
9. Get inspired by cutting edge research
10. Enjoy the tranquil park setting and resort-style amenities of the Marriott Ypsilanti at Eagle Crest

## **Thank You!**

Your donations:

- provide thousands with free information each year;
- fund research;
- provide brochures, bookmarks and awareness cards to members at no charge;
- make conference presentation available through video streaming at [www.ASAP.org](http://www.ASAP.org);
- offset the cost of our annual conference;
- and more...

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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Elbert Hodges, Jr.

### In Memory of Barbara Forrestall 1957 - 2014



Hero can be attributed to many and should be. Barbara Forrestall was one. She did not wear a cape but instead wore a big smile. Her badge was Courage and Inspiration.

A daughter, sister, aunt and friend, Barbara was born in 1957 in Valleyfield, Quebec. She grew up in Scarborough, Ontario and attended St. Kevin School, Notre Dame and Paris District High Schools. She started her career at CCH and then went on to work as a Real Estate agent.

When she was 30 years old Barbara was diagnosed with syringomyelia and Chiari malformation and underwent three brain and spinal cord operations in one year. But our hero didn't give up. She started up a charity that would provide support to people like herself who wanted to learn more about these conditions. With the encouragement of Dr. Charles Tator, Barbara started The Canadian Syringomyelia Network (CSN). Working alongside Dr. Michael Fehlings, CSN raised over \$400K for brain and spinal research.

Barbara loved life and all those in her life. She was an inspiration to her family and those around her. She was in pain for many years but would always say "it could be worse" and she really meant it. She once told her Mother that she had syringomyelia, syringomyelia didn't have her.

She was grateful for every day. You always felt better after a conversation with Barbara or "The Babs" as she often referred to herself. She was a great listener and had a wicked sense of humour that always left people in awe that she could be so positive given her situation. Everyone that met Barbara walked away a little more compassionate, a little more empathetic and certainly more willing to take their challenges in life head on because "it could be worse".

#### Contact Information

Mailing Address: PO Box 1586  
Longview TX 75606-1586

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)

Email: [info@ASAP.org](mailto:info@ASAP.org)

**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 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.

Email: [Patricia\\_Maxwell@ASAP.org](mailto:Patricia_Maxwell@ASAP.org)

Mail: *ASAP Connections*  
PO Box 1586  
Longview TX 75606

*ASAP Connections* Editor: Patricia Maxwell