

# ASAP Connections

*Providing Research, Education and Support since 1988*

## **Syringomyelia-Chiari 2018 International Symposium** **Organized by the Ann Conroy Trust, in association with Aesculap Academia**

An international symposium, *Syringomyelia-Chiari 2018*, an important educational event, is due to take place in Birmingham, United Kingdom, on July 17 - 20. Organized under the sponsorship of the Ann Conroy Trust, The meeting will build on the success of several similar prestigious events that were held across the world over the past ten years.

*Syringomyelia 2007*, held in Rugby, UK was followed by *Syringomyelia 2010* in Berlin, and *Syringomyelia 2013* in Sydney. More recently, in July 2017, another conference held in Long Island, New York expanded the concept. This dealt, in particular, with conditions related to Chiari malformations (CM) and Syringomyelia (SM), with presentations delivered by experts from around the world and included the patient perspective. *Syringomyelia-Chiari 2018* will maintain the impetus gained in New York but will also provide, once again, a forum for invited papers. Adding Chiari to the title of the forthcoming symposium also now better reflects the frequent overlap between these two groups of conditions. Scientists and clinicians from around the world have been invited to present their own understanding of and experiences in this fascinating field. A number of keynote speakers will share their own research and knowledge.

Topic to be covered include:

- Historical aspects/Biography
- Nomenclature/Classification
- Genetics/Epidemiology
- Anatomy/Embryology
- Physiology/Pathology
- Molecular Biology
- Experimental Work/Modelling
- Clinical Presentation/Natural History
- Hypermobility Syndromes
- Radiology/Other Investigations
- Surgical Techniques
- Audits/Outcome Assessment
- Pain Management/Non-surgical Therapy
- Physiotherapy/Occupational Therapy
- Pediatric Aspects
- Obstetric Aspects
- Veterinary Aspects
- International Collaboration
- Patient Perspectives

The conference is geared toward:

- Neurosurgeons
- Neurologists
- Neurological scientists
- Veterinary neurologists
- Pain management specialists
- Rheumatologists
- Geneticists
- Obstetricians
- Neuro-radiologists
- Neuro-pathologists
- Physiotherapists
- Occupational Therapists
- Nurses and other health professionals with an interest in neurological conditions
- Patient support group representatives



In addition to the four days of scheduled lectures there will be a poster presentations and trade exhibitions. Scientific meetings such as this help unite the medical professionals from around the world to develop a consensus concerning the diagnosis, treatment and understanding of the disorders.

*The Ann Conroy Trust (ACT)* was established in 1980 by Ann Conroy, As a Syringomyelia patient herself Ann realized others living with the conditions and their caregivers needed support. Raising funds to enable research into the condition of Syringomyelia and its associated disorders was very important to her. Today the charity is completely run by volunteers, including; consultant neurosurgeons, specialist nurses and patients living with the conditions.

The Charity is the only organization in the UK providing educational material about Syringomyelia and Chiari malformation. It funds research and provides a national help-line and support network which includes qualified support counselors. The objectives of the Ann Conroy Trust are straightforward. They wish to increase knowledge and understanding of Syringomyelia, Chiari malformation and associated conditions and to provide support for patients, their relatives and caregivers.

## Amazon Smiles

Do you shop on Amazon?

AmazonSmile is a website operated by Amazon with the same products, prices, and shopping features as Amazon.com. The difference is that when you shop on AmazonSmile, the AmazonSmile Foundation will donate 0.5% of the purchase price of eligible products to ASAP.

Every item available for purchase on www.amazon.com is also available on AmazonSmile (smile.amazon.com) at the same price.

**Since we joined AmazonSmile four years ago, ASAP has received almost \$1,300,** simply because our members shop at AmazonSmile and choose American Syringomyelia Alliance Project, Inc as their designated charity.

If you are shopping online anyway, shop at smile.amazon.com/ch/75-2245195 and Amazon donates to American Syringomyelia & Chiari Alliance Project, Inc.

**We appreciate your support!**

## Chiari Awareness

Set of 5 awareness items for just \$5 plus \$5 shipping/handling. Includes bumper sticker, collapsible flyer with pouch, adhesive phone caddy, glow in the dark bracelet and post-it note-pad.

Order online through the ASAP Store, or send a check made payable to ASAP for \$10 and let us know you want the Chiari Awareness set.



**Reduce Stress  
Increase Well-being**

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**“Be yourself;  
everyone else is  
already taken.”  
— Oscar Wilde**

## Stamp Project



ASAP members and friends have been collecting postage stamps as a fundraiser since the early 90s. It is an easy and fun way to make a difference. Stamps are sold to collectors and stamp clubs with the proceeds going to support programs for the Chiari and Syringomyelia community.

Please send cancelled 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 as well as postcards. Nonprofit, postage meter and presort stamps are not collectable.

Mail stamps to:  
Charles Petkevich  
ASAP Stamp Project  
6202 SW 2nd Court  
Plantation, FL 33317



**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.**

**www.ASAP.org**

**Visit us on the web and be sure to check out our YouTube and FaceBook groups.**



## A Word From Our President

**Eric J Berning**

Summer is upon us, and of course that means the ASAP annual conference is underway. This year we celebrate our 30th conference, which is amazing if you think about it. Thirty years ago I had never even heard of Chiari or Syringomyelia, let alone knew I had both.

I look back over the past 30 years and am just amazed at how much we have—and have not—learned in this time. There have been so many advances in medicine and technology that have provided information, research, and treatments for those who live within the world affected by these conditions. Yet there is so much we still do not know or understand.

The internet is a wonderful but dangerous tool that has come about in the past couple decades. It is useful because information we seek is readily available at our fingertips, yet at the same time it can be terrifying because the information we seek is readily available at our fingertips—overwhelmingly so, and more often than not, without a proper guide to direct us.

Unfortunately, along with that amount of information, the internet can also become a source of great negativity. One person's situation is not necessarily going to be the same for everyone, and even well-meaning discussions can lead to fear, anxiety, criticism, and self-doubt. The most certain truth I have discovered about our conditions is that everyone's personal experience with Chiari and Syringomyelia are completely different. I have a syrinx from C2-T12 and was decompressed in 2003. I am very fortunate that my own issues related to these conditions are manageable and, to an extent, mild in comparison to others I know. I have met many people who have much smaller syrinxes and yet are not as functional as I; the nuances and severity of related issues from Chiari and Syringomyelia are so vast it is difficult to understand how or why the complexities vary for each individual.

As a community, we need to keep this in mind when it comes to supporting and comforting each other. Too often I have seen situations on internet message boards and social media of our own community being unnecessarily harsh towards one other, and that saddens me. I understand that sometimes this “harshness” is actually born out of a deep concern for the other person, perhaps based on personal experience or frustration, but we need to realize that when someone reaches out for support and information, their experience is uniquely their own, as all of ours are. Be kind, share your experience, and allow that individual to make their own decisions based on fact, not opinion. Support is not always easy, as there are occasions when we do need to be blunt and straightforward if someone is heading towards a decision that could be harmful. But there is never a need for name calling or public “shaming.” Always, above all else, show compassion. We are here to help lift each other up, not hinder or hurt. Let's be good to each other.

ASAP's annual conference is a valuable resource for support, comfort, information, and fellowship. Patients, caregivers, and loved ones come together to hear the world's leading neurosurgeons, neurologists, researchers, and medical practitioners share their experiences in treating and working with individuals to better understand these conditions and their effects on those affected by them.

I highly encourage you to attend our conference in Orlando this July 25-28, where I look forward to seeing both new and familiar faces in our community. If you're unable to be there in person, the presentations will be available on ASAP's YouTube channel, so be sure to subscribe and click the “bell” to be notified when new videos are uploaded. (Please note, there will be a delay between the live presentations and video uploads due to formatting, editing, etc.)

As always, remember to live your life within your limits, but to live a limitless life! May you have a wonderful summer!

## Kaylee



2 months of 2nd grade  
2 life changing medical conditions  
2 brain surgeries  
Too much for me to handle?  
I don't think so  
Why should I let my health control me

This is my life  
There's no reason to be depressed  
I love my life and I'm thankful for everything God has given me  
I can't imagine any other life  
I get love and support from friends, family, and teachers  
I am stressed but I am always happy  
There is so much good in my life  
There's no point in focusing on the bad  
I am alive, I can walk, and I am healthy  
What more could I ask for  
I do homework 24/7 and I am usually exhausted  
But I am happy with what I have been given  
I live my life the way I want to  
My life is perfect if you focus on everything good  
So I have a perfect life  
Everything that has happened in my life has been good At least I think so  
This is why I love my life the way that it is  
It's too easy to focus on the bad in today's world  
Someone has to focus on the good  
That someone is me

I have two medical conditions called Chiari malformation and POTS. I have had two brain surgeries because of my Chiari. My first surgery was while I was in second grade, so I was only at school for two months that year. Chiari has also led to damage of my brain stem, the damage has caused a condition called POTS.

I was homebound for most of seventh grade because of it. This is only part of my life but everything that has happened to me has been good. My struggles have shaped my personality, I would not be the same person without them. It is very easy to focus on everything bad in my life, especially with all my late work. I have a choice, focus on the good or focus on the bad. I chose to focus on the good. It's not as hard as it seems, because in reality it's all around us.

If I could relive my life without my pain and struggles, I would not do it. My life is perfect, I would not change a single thing. I see no point in allowing myself to be sad because of my health. No matter how many aches and pains I get every day, I will always be happy because that is who I am.

## Choosing a Medical Alert System

A medical alert system (MAS) or personal emergency response system can provide more independence. As technology advances, the range of options has grown from the basic, wearable device with a button to call a response center in case of emergency. Now systems may include fall detection or prevention, in-home health and well-being monitors, fitness trackers, movement sensors and more.

When selecting a MAS, start by evaluating your specific needs and abilities — both now and how they might change in the future. For any of these devices, you might ask if a free trial period is offered so you can see what works best.

### Things to consider:

#### What you need the system to do

- Call for help. Wearable devices with buttons to push for help may connect to a live person or directly to emergency services (fire department, police).
- Fall detection or prevention,
- Medical monitoring including medication reminders and monitoring health vitals,
- GPS location detection and tracking,
- Activity monitoring to include motion detectors and beacons that track movement in the home,
- Daily check-in services with a live person or electronic check-in,
- Fitness tracking to include built-in step counters and tools offering information, health challenges and virtual family connections,
- Home security monitoring for fire, smoke and carbon monoxide.

#### What type of equipment would work best

- Is it wearable? Is the device comfortable (beware of sharp edges or strap materials that may irritate fragile skin), and is it attractive or unobtrusive enough that you will wear it?
- Can it be worn in the shower? Can it be fully immersed in water in the sink or bathtub? Many falls happen in the bathroom and kitchen, so this is vital.
- What's its range, mobility and connectivity? Ask about the distance the device will operate from the base unit. Will it work in the yard or garage? Does it include GPS so that it works anywhere you go in the community? Does it connect to a smartphone?
- Is it high quality? Does the device have a good durability rating? Is the technology up to date?
- What are the logistics for setting it up? If there's a base unit or console, will you need more than one to cover the entire home and yard? Does it require an electrical connection, or is it battery operated or backed up (in case electricity or phone service is lost). What type of phone service is required? Will you need a land line? Can you add stationary buttons around the home?

### Details regarding response and monitoring

- Response center. Average response time should be a matter of seconds, not minutes. Does the company operate its own response center or contract externally? Is the response center certified? How are the dispatchers or operators trained, and are they able to communicate in your preferred language? Will you be able to talk with a live person via their wearable device, or do you need to be close to the base unit to be heard?
- Call routing. Can you designate how you want various types of alerts/calls (urgent, non-urgent, emergency) routed, including to a response center, family/friends or directly to emergency services (police, fire department)?
- Customer service. Quality customer relations are key. There should be a live person you can call 24/7 with questions about the service.
- Cybersecurity. How does the company protect private information and prevent hackers from accessing your system?

### Cost

- Fees. Beware of complicated pricing plans and hidden fees. Look for a company with no extra fees related to equipment, shipping, installation, activation, or service and repair. Don't fall for scams that offer free service or donated or used equipment.
- Contracts. You should not have to enter into a long-term contract. You should only have to pay ongoing monthly fees, which should range between \$25 and \$45 a month (about \$1 a day). Be careful about paying for service in advance, since you never know when you'll need to stop the service temporarily or permanently.
- Guarantee and cancellation policies. Look for a full money-back guarantee, or at least a trial period, in case you are not satisfied with the service.
- Discounts. Ask about discounts for multiple people in the same household, as well as for veterans, membership organizations, medical insurance or through a hospital, medical or care organization. Ask if the company offers any discount options or a sliding fee scale for people with lower incomes.
- Insurance. For the most part, Medicare and private insurance companies will not cover the costs of a medical alert. In some states Medicaid may cover all or part of the cost. You can check with your private insurance company to see if it offers discounts or referrals.

### Availability in your area

Many national companies offer medical alert services, but they may not all be available near you, so call and inquire about service areas. Local companies may be an option, as well. In addition to companies that have been in the medical alert business for decades, technology companies and home security companies are now offering these services.



## What is Autonomic Neuropathy (AN)?

Damage to the nerves that help your organs and organ systems to function can cause a condition called autonomic neuropathy (AN). This nerve damage disturbs signal processing between the autonomic nervous system and the brain. Injured autonomic nerves can affect your:

- blood pressure
- heart rate
- perspiration patterns
- bowel movements
- bladder emptying
- digestion

AN is often associated with other medical conditions and diseases and certain medications. Your symptoms may vary based on the cause of your neuropathy and the location of your nerve damage.

**Your organs can be affected by AN and cause an array of symptoms.**

**Bladder** - The symptoms affecting your bladder may include frequent urinary tract infections, urinary incontinence or an inability to empty your bladder.

**Digestive system** - Symptoms can include frequent indigestion or heartburn, vomiting undigested food, diarrhea, swollen abdomen, constipation, feeling full after eating a small quantity of food and poor appetite.

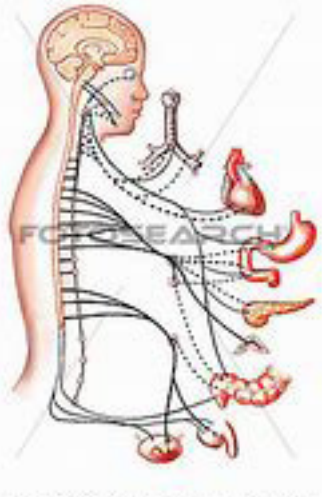
**Reproductive organs** - Symptoms can include erectile dysfunction, premature ejaculation, difficulty achieving an orgasm and vaginal dryness.

**Heart and blood vessels** - Symptoms can include dizziness when rising or standing, fainting, difficulty breathing during exercise, rapid heart rate at rest or heart attack without any warning signs.

**Eyes** - The symptoms that affect your eyes can include slow pupil adjustment from dark to light and difficulty driving at night.

**Sweat glands** - The symptoms that affect your sweat glands can include dry skin on your feet and excessive sweating or lack of sweating.

**Other symptoms** - Other symptoms of AN can include unexplained weight loss and low blood glucose without warning signals, such as shakiness.



## What is Peripheral Neuropathy?

Peripheral neuropathy is damage of the peripheral nerves. Your peripheral nerves—the nerves in your toes and fingertips—are the ones on the periphery of your body. When the nerves are damaged, they don't function properly. People with peripheral neuropathy have decreased or abnormal sensation in their toes and fingers. Sometimes, they develop problems moving these parts of the body as well.

### Causes

Although the most common cause of peripheral neuropathy is diabetes, Other causes include:

- Certain medications, including some chemotherapy drugs.
- Heredity; some people have a family history of peripheral neuropathy.
- Advanced age; Peripheral neuropathy is more common as people age.
- Arthritis; certain type of arthritis can cause peripheral neuropathy.
- Alcoholism; according to the US National Library of Medicine, up to half of all long-term heavy alcohol users develop peripheral neuropathy.
- Neurological disorders; certain neurological disorders, including spina bifida and fibromyalgia, are associated with peripheral neuropathy.
- Injury; acute injury to the peripheral nerves may also cause peripheral neuropathy.

### Symptoms

The most common symptoms of peripheral neuropathy include burning, numbness, tingling, or shooting or stabbing pain in the toes and/or fingertips. Any change in sensation in the fingers or toes may be a symptom of peripheral neuropathy. Be sure to report any abnormal sensations to your doctor. Those sensations may be the first sign of another problem, such as diabetes.

### Diagnosis and Treatment

A podiatrist, family physician, internist, neurologist or physician who specializes in diabetes can diagnose peripheral neuropathy. The diagnosis is made on the basis of a physical exam, health history, and your reporting of symptoms. The doctor may order additional tests including blood work, advanced imaging or nerve conduction studies.

Treatment depends on the cause of the neuropathy. Any systemic cause or nerve impingement needs to be addressed. Often peripheral neuropathy is permanent and goals of treatment are to slow the progression of the disease, to maintain foot health, and to decrease pain (if present) and improve the quality of life.

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 and loved ones.

We will send an acknowledgement card to individuals or families when you make a \$5 (or more) donation to the organization. Please indicate whether the gift is 'in honor of' or 'in memory of' and provide name and mailing address of the recipient.

#### In Honor of Person

Donor

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## Healthy Foods for Chronic Pain

Chronic pain can be so pervasive that drugs and even mind-body approaches may not be enough to give you a break. As many as four out of five people with chronic pain have tried alternative remedies, including eating certain foods or ingredients that are thought to bring some pain relief. Some have research – not just anecdotal evidence – behind them.

All of the following foods have a place in a healthy diet, so eating and cooking with them can be good for you in general. Even so, it is always a good idea to let your doctor know what kinds of remedies you're trying to be sure that none will interfere with another.

- Ginger
- Coffee
- Olive oil
- Salmon
- Turmeric
- Red grapes
- Thyme



[EveryDayHealth.com]

## ASAP History

As we enter our 30th year here are a few facts you might not know.

ASAP was incorporated in the state of Texas on May 31, 1988.

The organization received its 501(c)(3) status, making donation tax deductible, on January 23, 1989.

Angela, a six year old diagnosed with Syringomyelia was the first ASAP 'poster child' in 1988.

In March 1989, Mr Bernard Williams, a consultant neurosurgeon from Birmingham, England stopped off in Longview, Texas to make a presentation to a handful of people about his work with Syringomyelia patients in the UK.

During the first year of ASAP's existence, membership grew from twelve to 140 people. Word of the organization's existence had spread internationally. By the fall of 1991 the number of members affected by Syringomyelia had doubled.

In 1992, ASAP added an 800 number that was funded by the Bobby Jones Open. The BJO also funds several college scholarships each year and provide grants to ASAP members for assistance in purchasing needed equipment or items to help improve a person's quality of life.

In 1993 ASAP produced it first Public Service Announcement. The PSA starring Fabian (an American singer/actor who rose to fame in the 1950's as a teen idol) was aired on various radio stations around the country..

In 1995 ASAP recorded its one-thousandth member. This was obviously before the wide spread use of the internet and social media. Creating awareness in the early days of the organization involved mailing letters, making phone calls (no cell phones), publishing articles in local papers and public service announcements. We've come a long way!

In 1996 under the leadership of Dr Marcy Speer with the Center for the Study of Inherited and Neurological Disorders, a study to determine the hereditary possibility of Syringomyelia and Chiari was initiated.

In 1996 ASAP's first research fellowship went to a young resident with an interest in developing experimental models of non-communicating syringomyelia. That person was Dr Ian Heger, who is co-hosting the ASAP conference with Dr Eric Trumble in July.

**What I cannot do alone, with the coming together of my family and friends we can make miracles happen.**

**Barbara White**

# **“Thank You for Supporting ASAP!”**

Let us hear from you, update your contact information.

Name \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

Email \_\_\_\_\_ Phone # \_\_\_\_\_

Yes, I would like to continue receiving the newsletter.

No, please remove me from your mailing list.

\*\*\*\*\*

Your support makes a difference in the lives of thousands. Please help us to continue our programs and research funding with a donation today. Every dollar counts!

Check enclosed payable to ASAP, Inc. – You can also make your donation online at [ASAP.org](http://ASAP.org)

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

## **ASAP Live on FaceBook**

In June doctors Ian Heger and Eric Trumble donated their time and knowledge to answer questions live on FaceBook. Dr Heger took the first session June 5. Even with a few technical issues the first time the sessions were a success. The audience posted questions which were answered by the doctors. Unfortunately they were not able to answer all the question in limited time but they were able to cover a wide range of topics involving the disorders..

The idea of hosting a live question and answer session was designed to promote the ASAP Chiari and Syringomyelia Conference. A preview of what is available during the four day meeting held every July in a different geographical location.

Dr Trumble went live on June 12. We had over 200 viewers during the two sessions and over 10,000 views and counting during the following days.

The interest shown and questions asked by the Chiari & Syringomyelia community indicates that many patients are not receiving the information that is pertinent to their well being. It is a commitment of those involved with ASAP to find creative and fruitful ways to educate those who need the information most. We will continue to promote education and spread awareness until a cure is found.

## **Music Therapy**

Have you ever heard the phrase music can sooth the soul? Research has found that when used as a clinical intervention, music can help patients by: reducing the amount of pain they perceive.

Therapist are using music with chronic pain management to promote relaxation and alleviate anxiety and stress. It can give a positive mood boost. This type of therapy is used to teach the patient to relax and release pain. They partner soothing music with relaxation techniques and eventually the patient learns to relax automatically when listening to the music.

Patients undergoing music therapy for chronic pain management have been found to require less pain medication, have significant improvements in their respiration, blood pressure, heart rate, and muscle relaxation. They enjoy more peace of mind and better quality of life.

Music therapists are accredited health care professionals. Many cancer and pain clinic offer the service. You can check with your doctor for a referral or visit [www.musictherapy.org/](http://www.musictherapy.org/) for more information. As with every therapy it may not work for everyone.



**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 quarterly 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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