

ASAP CONNECTIONS

Providing Research, Education and Support since 1988

Dr Gerald Grant to Host 2016 Conference



We are honored to have Gerald Grant, MD, FACS as the host for the **ASAP Chiari & Syringomyelia Conference 2016**. A native of Rockaway, New Jersey, Dr Grant is a graduate of Duke University. He has served on the ASAP Medical Advisory Board since 2012 and serves as Chair of the ASAP Research Committee.

His professional education includes:

- Board Certification: Pediatric Neurological Surgery, American Board of Pediatric Neurological Surgery (2008)
- Fellowship: University of Washington (2002) WA
- Residency: University of Washington (2001) WA
- Internship: University of Washington (1995) WA
- Board Certification: Neurological Surgery, American Board of Neurological Surgery (2005)
- Medical Education: Stanford University School of Medicine (1994) CA
- Bachelor of Sciences, Duke University, Neurosciences (1989)

After completing his fellowship in pediatric neurosurgery, Dr Grant entered active duty with the United States Air Force as part of a Health Professions Scholarship Program and was Chief of Neurosurgery at Wilford Hall Medical Center, Lackland Air Force Base in Texas. He deployed to Landstuhl Regional Medical Center, Germany and Balad Air Base, Iraq, as Chief of Neurosurgery, in support of Operation Iraqi Freedom. He is a member of multiple boards, advisory committees and organizations. His international endeavors include Stanford Neurosurgery in Uganda, Mulago Hospital.

In 2013, Dr Grant was recruited back to Stanford to be the Division Chief of Pediatric Neurosurgery, Vice Chair of the Department of Neurosurgery at the university.

Dr Grant's natural leadership abilities and attention to detail guarantee a conference that continues to improve and impress. We hope you will join us July 21-24 in San Francisco.

Obstructive Sleep Apnea Damages the Brain

A study involving nine people with obstructive sleep apnea compared to nine healthy control subjects reported the first evidence that obstructive sleep apnea contributes to the breakdown of the blood-brain barrier.

The finding was made possible by a MRI procedure that is used by only a handful of research teams. The noninvasive procedure uses the brain's own blood and fluids to measure the breakdown of the blood-brain barrier.

The blood-brain barrier plays an important role in protecting brain tissue. It limits harmful bacteria, infections and chemicals from reaching the brain. UCLA researchers reported that the blood-brain barrier becomes more permeable in obstructive sleep apnea, a breakdown that could contribute to brain injury. It is believed that this type of brain injury can affect memory, mood and cardiovascular risk.

Research conducted at UCLA over the last 12 years shows that gasping during the night damages the brain in ways that lead to high blood pressure, depression, memory loss and anxiety. The reduction of oxygen to the body is the likely reason for damage to the brain. However more research is needed to confirm and understand the causes and progression of the brain injury.

[For more information see the September 1 (2015) issue of the Journal of Neuroimaging for the complete article.]

2015 Conference Videos Available Online

Presentations from the **ASAP Chiari & Syringomyelia Conference** held July 2015 are now available on the ASAP website and YouTube channel.

To view videos using a flash player go to www.ASAP.org click on the **Conditions** tab in the top section of the home page. Then click on the **Online Video Library** link in the box on the right side.

To view videos in mp4 format (works well with Apple products) go to www.ASAP.org and click on the YouTube icon in the upper right section of the page.



Stamp Project



ASAP members and friends have been collecting postage stamps as a fundraiser since the early 90's. 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



Save The Date

ASAP

Chiari & Syringomyelia

Conference

San Francisco, CA

July 21-24, 2016

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.

Syringomyelia Awareness Month

Don't forget May is **Syringomyelia Awareness Month**.

Consciousness raising (also called awareness raising) is a form of activism, popularized by United States feminists in the late 1960's. It often takes the form of a group of people attempting to focus the attention of a wider group of people on some cause or condition.

Do something special during the month of May to promote awareness of syringomyelia! Take photos of your event or project and email to the ASAP office (info@ASAP.org).

Suggestions for promoting awareness:

- Have your governor or mayor declare May as Syringomyelia Awareness Month with a proclamation. This is a newsworthy event. Get media coverage of you receiving the document.
- Get your local paper to publish a story about syringomyelia. Local papers are always looking for personal stories for their Lifestyle or Health section.
- Plan a walk or awareness event in your town.
- Start a social media campaign to spread awareness.
- Give a presentation about syringomyelia at your local schools or social clubs (Lions, Women's Clubs, etc.).
- Have your scout troop learn about syringomyelia.
- Share information with classmates, co-workers, neighbors, church family and friends.
- Make a YouTube video and tag ASAP.
- Tweet #maysyringomyeliaawarenessmonth
- Learn more about syringomyelia. Knowledge is power!
- Honor someone with syringomyelia through a donation to ASAP.
- Get your employer involved in a workday giving program.





A Word From Our President

You have all warmed my heart! Thank you for thinking of ASAP. Your year-end donations have crossed my desk. Please know that your money is put to very good use. We will be funding new research projects and programs for the Chiari and syringomyelia community.

As the new year begins, we're all busy making plans. I honestly can't believe we are already planning another conference. It seems one just ends and its time to get ready for the next. I hope we will get to see many of you in San Francisco, CA July 21-24. For those who would like to attend but are concerned over cost please ask us about our scholarships and also the LEARN Program. We will do our best to help you attend. We can tell you what you can do to earn points to attend the conference at little cost to you. Many people reading this have attended the conference through these programs. ASAP does its best to give back to you. We want you to be informed and to get the help you need. You can email me at Patrice_Schaublin@ASAP.org to learn more.

Our 1st Kicks and Licks Walk is being held in Arlington, VA with neuro veterinarian Lauren Talarico as our host along with Robert Keating, MD. We are excited to be uniting man and his best friend for a common cause. Lauren Talarico will be updating us this summer on her research with the dogs and how it may translate into better treatment for all. We hope you will all come out and join us with or without your dogs for a fun and educational day. We will have things to do for everyone. (Date is April 16 at Bluemont Park Arlington VA)

Many of you have known me for years. I have been involved with ASAP since I picked up that phone and asked for help for myself over 23 years ago. In those years my journey has been one that has been filled with many life challenges including watching my children get diagnosed, losing loved ones, dealing with my health, moving four times, etc. I have also

watched so many changes within the CM/SM communities. I have learned from all of this that I can be the messenger but it takes a group of people to make things happen. Not just one person but a team of the right people.

ASAP has a very strong dedicated group of people who make things happen but additional help is always appreciated. We depend on volunteers. We only have two full-time and one part-time employee. The work is endless. Even though we encourage balance I have seen job and volunteer burnout too often. So in the spring, the Board will be holding our next strategic planning meeting. It's an opportunity to regroup and share thoughts face-to-face so we can be more effective for the community we serve.

ASAP has been strong in many areas. Support is one of our biggest. In the last few months we have been receiving more calls for syringomyelia and Chiari patient support. I am stepping back to our roots and going back to our webinars. We are also working on revitalizing our support groups with additional training for our support group leaders.

As I write, Valentine's Day is just around the corner. Please remember those you love.

Love is friendship that has caught fire. It is quiet understanding, mutual confidence, sharing and forgiving. It is loyalty through good and bad times. It settles for less than perfection and makes allowances for human weaknesses.

Ann Landers

Thank you to all for your continued support!

Gentle Hugs always,
Patrice
Patrice_Schaublin@ASAP.org

**Sometime my cross is hard to bear
for there is darkness everywhere,
and troubles pile around my door
like autumn leaves forevermore.**

**The morning light seems far away,
like I am stuck in yesterday.
My heart is beating like a drum.
I try to pray, but words won't come.**

**But then the sun begins to rise
and Hope is born within my eyes.
A rainbow forms among my tears
my faith is stronger than my fears!**

GMAN

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Living with a spinal cord injury for 50 years and counting!

by Leland Olson

I am a 50 year SCI 'spinal cord injury' survivor. I wrote this hoping it might encourage someone or help them get diagnosed.

Life is pretty much what we make of it, change is constant in a body and this world, but we can cope with those changes.

Stuff happens; we must cope with what comes our way. We just need a combination of faith, good doctors and medical technology, hard work and some luck.

In June of 1964 at twenty three years old and almost two years out of the US Air Force, I was running over with youthful energy. I was a truck driver, working on highway construction. We had just moved to a new job site near Sisseton, South Dakota and I was in my car driving back to be at work the next morning. I fell asleep at the wheel; the car left the road and hit the approach to a farmer's field. That heavy old Pontiac went through the air a long distance and ended up in a cornfield. I was wedged under the bent steering wheel. I could see headlights go past off to my left, behind a little hill.

I realized getting out of the car was the only way to find help. I'm pretty sure God doesn't play Let's Make A Deal but I was praying loudly for help, making promises that couldn't be kept, stuff like that. The front fenders of the car had been pushed back keeping the front doors from opening. Couldn't open either door more than a couple inches. I got out from under the steering wheel and crawled over the seat to get out of a rear door. My right leg wasn't working so thought it was broken. It was very hard getting over that seat.

I got out and found myself lying in the mud. It was raining hard. I pulled myself toward the road by grabbing onto cornstalks and pushing with my good leg. It was the middle of the night and there were few cars. They went by without seeing me. I got right up on the edge of the road and waved my handkerchief. Finally a car stopped. The woman in the car was a nurse, she kept me warm and sent her husband for help.

I woke up in the Sisseton Hospital and saw a doctor holding an x-ray of my back up to the light. I thought, how dumb, it's my leg, not my back! Then I realized finally what happened, must have gone into some type of shock.

I spent the next three days there on my back with the bed cranked up in the middle. The pain was very, very bad. I imagine that was a type of prehistoric traction to put the T-12 and L-1 vertebrae back in place.



Later, I was moved to the Sioux Valley Hospital in Sioux Falls, South Dakota where I spent three months on a stryker frame so they could turn me periodically. I drove the stryker frame to physical therapy. I would go by myself with two canes in my hands like ski poles pushing it down the halls. The people in PT were great. They got my right leg working again. The doctor did a spinal fusion in September and I walked out of there in a body cast that I wore for six months. A loving aunt and uncle let me stay at their house while I recuperated and got my

strength back.

I got married in 1970, instantly had a wife, four daughters and a grandson. After working at several different jobs, I started driving a tanker truck in Tucson Arizona. When driving with my arm out the window, the air hitting my arm would sting, my left hand was losing sensation and I couldn't tell hot and cold apart. By 1985 the numbness had taken over all my left side from my waist to the top of my head and I was biting my tongue when I ate.

In April of 1985 a young resident doctor at the Sioux Falls VA Hospital was the first to diagnose my syringomyelia. It has been learned that the disorder can follow a spinal injury. A spinal shunt was put into my spinal cord at T-3 about a week later at the Minneapolis VAMC. The numbness in my tongue went away but everything else stayed pretty much the same.

Then in October 1985 my left shoulder joint disintegrated (Charcot Joint). A new joint was mentioned but I was told it may not heal after being numb so long. I still get some use out of that arm even though it hurts a lot. I finally quit driving, my walking was getting worse and I had a brace on my right leg.

In 2000 a disk and half of a vertebra was taken out of my cervical/thoracic region of the spine for stenosis surgery. The vertebra was put back with bone dowels. A plate with six screws was put in to hold my head on. I've had two low-sodium episodes since then, they were pretty bad. I thought for sure I was at the end of life's checkout lane. We sold our forty three year collection of stuff and moved into a small apartment.

In October 2014, I had a new thoracic shunt put in. I am anxiously waiting to see what changes take place. I can walk with a walker, balance is bad. Need some help showering and getting dressed. I try to exercise every day with stretch bands.

I'm very thankful for my 50 year SCI survival. I turned 75 on December 1, 2015. I've always tried to stay busy. It is just a little harder to do these days. My wife and I are each other's caregivers. Memories from four daughters and their families, boating, hunting, fishing, gardening and our church family all help in these 'Great Golden Years'.

Steps to Being an Effective Self-Advocate, Part I

In the following issues we will be breaking down steps in a journey to be an effective self-advocate. You will discover how to believe in yourself again. Maybe you have forgotten that you have the same rights as other people. Or you feel that you have lost the power to ask for what you want and need. Do you struggle so much that you have become discouraged? Now is the time to take back control of your life.

Being a good self-advocate means taking personal responsibility for your own life. Put yourself back in charge. Many people who have been disabled for years have taken back responsibility for their own lives. As they have done this, their lives have changed dramatically.

Believe in Yourself

The first step to become an effective self-advocate is to believe in yourself. Believing in yourself means you are aware of your strengths, know that you are worthwhile, and are willing to take good care of yourself. Many people who have troubling emotional symptoms or who have a disability struggle with self-esteem. To ask for what you need and want and to protect yourself when others treat you badly, you will need to support your self-worth.

You will want to assess, appreciate, support, and improve the way you feel about yourself

- **Assess:** On a 1-10 scale, what is your self-esteem? If you're undecided, give yourself a 5.
- **Appreciate:** Give yourself credit for as much self-esteem as you do have. It can be really hard to hold one's own in the world, and you deserve appreciation for every point you've been able to hold on to. Forgive yourself for the points that lie between you and a 10. You've done the best you can. Also give yourself credit for taking steps to being an effective self-advocate. **Support:** What do you do for yourself that supports your well-being? Write down those things, like eating well, making sure you have fun regularly, or pursuing your goals. Write only the good things you do right now, appreciate yourself for them, and vow to continue.
- **Improve:** Think of something you'd like to change to improve your well-being. It can be just one small thing

that's easy for you that you'd like to stop doing or begin to do such as exercising more, signing up for a class, or watching less television. It may even be getting out of bed. Sometimes deciding is enough, but here, it is helpful to make a step-by-step plan of how you are going to change if you need to.

Exercises to Raise Self-esteem

- Get together with a trusted friend. Divide a block of time in half, for instance, 20 minutes divided in half would be 10 minutes each. Then, take turns telling the other person everything good about them. Just think, 10 minutes of compliments!
- Go to the library and get a book on building self-esteem. Do any of the suggested activities that feel right to you.
- Repeat over and over the affirmation: I am a unique and valuable person. I am worth the effort it takes to advocate for myself to get what I want and need for myself to protect my rights and to insist that others treat me well. Think of other affirmations that you could say to yourself.
- Set a timer for 10 minutes. Then, write everything good you can think of about yourself. After your time is up, read what you have written. Then, fold it up, and put it in a convenient place, like in your pocket, purse, or next to your bed. Then, read it over before you go to bed, when you get up in the morning and every time you have a spare moment. If you can't think of enough things to write in this exercise, ask your friends for ideas before you begin.
- Do something nice for someone else or for your community. Take fresh flowers to a friend, visit a person in the hospital or in a nursing home, or clean up the trash in a park.

If you don't believe in yourself because you are feeling so badly, have a trusted friend or health care provider remind you that they believe in you.

Part II will cover deciding what we want or what we need to change in our lives. We will cover steps from making list to planing a strategy, setting goals and meeting objectives.

Conference Scholarships

ASAP offers scholarships to assist with the expense of attending the conference: registration is waived plus 50 percent of room cost for those who qualify. To apply for the scholarship you must be an ASAP member for longer than one year.

To receive an application email info@ASAP.org or call 903-236-7079.

*Out of suffering have emerged the
strongest souls;
the most massive characters are
seared with scars.*

Kahlil Gibran

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.

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Avoid Caregiver Burnout

By taking care of yourself you will become a better caregiver.

Caring for others takes time, work and effort. Stress and anxiety can often get the best of you, not to mention the emotion and physical health problems that occur. Avoid burnout by using the following tools to keep you in check.

Ask for and accept help. If you have other family members, develop a plan for dividing up responsibilities. Consider how much time each person can realistically give. How long-distance loved ones can contribute. Also seek out and use community resources, both for yourself and the person you are caring for.

Consider respite care. Respite care offers a temporary break to caregivers. It can range from a few hours of in-home care to a short stay in a nursing home or assisted living facility. This will give you a chance to take care of other responsibilities or a much needed vacation.

Know your limits. Guilt can play on your ability to say no. Be realistic with yourself about what you can and cannot handle, based on your other responsibilities to your spouse, children, work, school, etc.

Talk about your caregiving experience. Research has shown that counseling and support groups, in combination with respite care (see above) and other services can help caregivers maintain their role longer, with less stress and greater satisfaction. Join a support group for caregivers in your area, see a therapist or just talk to a trusted friend.

Take it one day at a time. Recognize that you will have good days and bad. Even when you're feeling resentful or angry, know that this is normal and doesn't define you for eternity. It doesn't make you a bad person or a bad caregiver.

Stay in touch with friends and family. Social activities can help you feel connected and can provide emotional outlets for stress.

Get enough sleep. It sounds so simple, but a good night's sleep can make facing any challenge seem all the more manageable. Make getting at least seven hours a priority.

Eat well & exercise. Eating a sugary snack because you have no time to eat will only make you crash later, making you more vulnerable to irritability, stress and fatigue. Choose snacks like nuts or fruit to keep you on an even keel longer.

Make time for yourself. This is not a luxury, but essential for caregivers. If nothing else, set aside five minutes each day to meditate or simply be still. This is time just for you.

Educate yourself. The more you know about both your loved one's condition and the resources available to you, the more effective you will be in taking care of the both of you. Look online or check out books at your local library.

Ehlers-Danlos Syndrome

Ehlers-Danlos syndrome (EDS) is an umbrella term for a growing group of hereditary disorders of the connective tissue. The main symptoms include:

- loose joints
- highly elastic, velvety skin
- fragile skin
- skin that bruises easily
- redundant skin folds on the eyes
- muscle pain
- muscle fatigue
- benign growths on the pressure areas (such as the elbows and knees)
- heart valve problems

Most EDS patients share a nearly normal life span, but are severely limited by disabling features, such as pain, fatigue and headache. Parents are often silent carriers of the defective gene that causes EDS. This means the parents may not show any signs of the condition, and are unaware that they are carriers.

A series of tests may be used to diagnose EDS. They include genetic tests, skin biopsy, and echocardiogram.

- An echocardiogram uses sound waves to create moving images of the heart. This will show the doctor if there are any abnormalities present.
- A blood sample is taken from your arm and tested for mutations in certain genes. A DNA test can confirm if the gene is present in embryos as well. This form of testing is done when the woman's eggs are fertilized outside of her body (in vitro fertilization).
- A skin biopsy is used to check for signs of abnormalities in collagen production. This is performed by removing a small sample of skin and checking it under a microscope.

Current treatment options for EDS include:

- physical therapy (used to rehabilitate those with joint and muscle instability)
- surgery to repair damaged joints
- drugs to minimize pain
- Additional treatment options may be available depending on the amount of pain you are experiencing or any additional symptoms.

You should take these steps to prevent injuries and to protect your joints:

- Avoid contact sports.
- Avoid lifting weights.
- Put adequate padding on your child before they ride a bike or when they are learning to walk.
- Use sunscreen to protect the skin.
- Avoid harsh soaps that may over-dry the skin or cause allergic reactions.
- Use assistive devices to minimize pressure on your joints.



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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