

ASAP CONNECTIONS

Providing Research, Education and Support since 1988

2015 Barbara White Award

This year we are honored to name Mary and Fred Parker as the recipients of the 2015 Barbara White Award. It is given in recognition of outstanding contributions to further the efforts of our founder. Recipients demonstrate long-term commitment to the cause by being active in many areas of the organization.

Mary was diagnosed with syringomyelia in 1987. After several years working with health professionals who had never heard of the condition, she contacted the National Institutes of Health for information. Although the information was limited it connected her with ASAP.



During the years, Mary and Fred have been active in many volunteer initiatives. Their involvement with a number of conferences included not only serving on the committee to plan but volunteering during the events.

As the result of a heart condition Mary became involved with yoga which she discovered also helped improve symptoms related to her syrinx. In conjunction with Rachel Green she created, produced and donated a CD called *Breathe, Relax and Heal* which is available through the ASAP store. Dr Roger Kula, of the Chiari Institute calls it the ‘best relaxation CD’ he has ever come across and highly recommends it to patients.

Mary’s favorite experience has been working with the KIDS For A Cure Club and enhancing their conference program. She hopes that the relaxation techniques she taught them will continue to help them throughout their lives.

After receiving the award, Mary wrote, “We always love to help people in whatever way we can. That was so kind of you to give us this honor. We are very appreciative.”

These are just the highlights of the Parker’s involvement over the years. Congratulations and thank you Mary and Fred for all you have done for the Chiari and syringomyelia community.

2015 ASAP Volunteer Awards

Helping Hand Volunteers

Our Helping Hand volunteers keep ASAP running smoothly! By giving their time, energy and/or talents, they help us to further our mission.

- Michelle Dumsar
- Jessica Griffith
- Kathleen Hall
- Angela Holley
- Shananne Hutter
- Rebecca Jones
- Molly Lichtenstein
- Kaleena McNabb
- Lisa Dunton-Roy
- Kurt Schauburger

Visionary Award

These volunteers are committed to furthering the goals of ASAP. Their vision keeps ASAP moving forward.

- Amber Barnes
- Margaret Leisenheimer

Shining Star Volunteers

Volunteers whose continuous efforts go above and beyond, they are a shining example of volunteering at its best!

- Michael “Yogi” Borys
- Doug Kindlon
- Karen Kindlon
- Melissa Sanders

Key Volunteer Award

Given in recognition of exceptional service and contributions, these volunteers play a vital role in helping ASAP open new doors!

- Julie Jarvis
- Annette Johnson

Barbara White Award

- Mary & Fred Parker

*Life is not about waiting for
the storm to pass but learning
to dance in the rain.*

KIDS For A Cure Club

What is it?

KIDS For A Cure Club is designed for children and teens ages 5 to 19. Some of the goals include helping children find ways to cope with chronic illness, providing an outlet for kids to meet and share with others, encouraging good citizenship and empowering young people by providing materials and support for those interested in promoting awareness or undertaking fundraising projects.

We hope you are enjoying the new KIDS Connection. You can be a part of the fun by contacting Lauri or Kaylee and sharing your thoughts and suggestions.

Contact Info:

Laurie Swihart - kidsclub1@ASAP.org

Kaylee Tutrow - kidsclub2@ASAP.org

If you attended an ASAP conference in recent years we would love to hear your thoughts. How did the program help you? Was there something you expected but did not find? Do you have suggestions for future meetings?

Chiari Awareness Month

September is Chiari Awareness Month! If you are doing a special project let us know and we will recognize your efforts in the next newsletter.

Need ideas to promote awareness in your area? Here are a few possibilities:

- Contact your local media (newspaper, radio and television) and share your story.
- Talk to a local service club and share information.
- Start a local support group.
- Contact the ASAP office for brochures and take them to doctor's offices, clinics and hospital.
- If you have a child in school who has been diagnosed, ask the school to do a short walk and presentation.
- Create an awareness poster and ask stores to display.

In addition to our brochure, ASAP has bookmarks and awareness cards with short, generic descriptions of Chiari and syringomyelia that are easy to hand out and bring awareness to the general public.

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.

Fundraising Summer 2015

Fundraisers utilize multiple volunteer hours planning, soliciting and organizing. They raise awareness in addition to funds that support research and programs. The best part is that they touch lives, teach others about our cause and create new friendships.

Lisa Dunton-Roy wanted to do something different. **ASAP 1st Annual Cruisin' for CM & SM** is a scavenger hunt and game of skill August 22 in Bangor, Maine.

Lisa's symptoms started as a child. Debilitating headaches left her bedridden for days, Told they were migraines, the pain continued to increase as she got older. Lisa recalls, "I had sprains and broken bones. I was *clumsy* and would drop things. I was getting worse and the tests showed nothing. I was told it was *psychosomatic*, that it was all in my head."

Now 47, after many years of frustration with her situation, she consulted with a doctor who referred her to a specialist. It did not go well. After going through some old medical records, she came across an old MRI report. One word stood out, SYRINX. Lisa consulted with her primary care physician and he notified the neurologist. After another MRI, she was off to see a neurosurgeon where surgery was scheduled. Lisa want to spread awareness and education in both the medical field and general public.

Molly's ASAP Walk and Roll for a Cure is September 19 at Bretton Woods Recreation Center, Germantown, Maryland.

Molly Lichtenstein was diagnosed at 16 with Chiari and syringomyelia. After her first surgery that same year she realized there was a huge lack of knowledge in the medical community and that needed to be changed.

"Since my first surgery in 2009 I have had over 24 brain and spine surgeries and have been diagnosed with many other underlying issues: Ehlers- Danlos syndrome, hydrocephalus, and 4th nerve palsy. My life is a bit different, but I try as hard as I can to live as normally as possible. I am a student, I will be finishing my BA degree this summer working towards obtaining my degree in Early Childhood Education. I hope to be a kindergarten teacher one day!," Molly writes.

ASAP members organize and hold fundraising events in many areas of the United States to raise awareness about syringomyelia and Chiari malformation. Monies raised go to support research and programs for support, education, and awareness. Interested in holding a fall event? Please contact Patrice at Patrice_Schaublin@ASAP.org.

www.ASAP.org

A Word From Our President



Thanks to everyone who participated in making ASAP's conference a success. Due to family obligations and health issues causing us to be short-staffed, we had our challenges. However the core group pulled together to deliver our 27th annual conference without a hitch. I have said this in the past and I will say it again, ASAP is truly like an extended family. Every year patients at the conference tell me they feel like they are at home. They are provided with a source of comfort and leave with a source of empowerment and a new group of family and friends.

Thank you to our host Dr Cormac Maher and all of the professionals who donated their time. The doctors feel privileged for the opportunity to spend time with so many adults and children affected by the disorders in a unique setting. But we are truly blessed for the opportunity to interact with them. This conference also offers the doctors an opportunity to share and learn from each other.

The children had a wonderful program this year. They enjoyed art and music therapy, a bird of prey exhibition, medical play, pet therapy, meditation and so much more. They made new friends and learn they are no longer alone. The program is growing yearly.

Thanks to Annette Johnson; with her special efforts, the University of Michigan Department of Neurosurgery was presented with a flag which was flown over the White House on July 4.

On another note I am looking for volunteers to help on committees. If you have a few hours a month to spare and are interested in publicity, marketing, awareness, support, fundraising, etc, please send me an email. ASAP is run by a small group of people. I would love to extend our reach and share our love for this community with others.

ASAP fundraises year round in an effort to minimize requests for donations from our membership. If you have an idea for a fundraiser please feel free to contact me. It is our members' fundraising efforts that allow us to fund research, provide educational materials, run our annual conference, etc. For those who fundraise and would like to attend the national conference we have a program to help you attend. Please go to our website and read about the L.E.A.R.N. Points Program. We hope to see you all next year in California, the location for the 2016 annual conference.

Lastly, I would like to give a special thank you to Dr Batzdorf who celebrated his birthday with us once again.

Gentle Hugs always,
Patrice
Patrice_Schaublin@ASAP.org

Paying It Forward

ASAP is looking for motivated individuals with good communication skills, special talents and a willingness to make a difference. Past experience is a plus but not mandatory. The position requires as much time as you are willing to give. It is exceedingly rewarding.

What we need first is someone who can coordinate the organization's needs with the individuals willing to donate their time and experience. It is not an easy position and one that probably will offer less rewards than others. You must be flexible because everyone will have different times they are available. You will need to be creative and often use your imagination to solve an issue or find a position for those willing to work. A sense of humor will often come in handy. Still reading? We would love to hear from you. Please complete our online volunteer form and contact the ASAP office.

Here are some of the qualities needed:

- Enthusiasm – a positive attitude is vital
- Common sense – knowing the difference between right and wrong, good and bad
- Non-judgmental – being able to take an objective view of a person's problems – even if they're of their own making
- Awareness – being able to recognise other people's needs and able to look for ways to meet those needs as a result of training and your own life experiences
- Reliable – willing to devote a set amount of time regularly
- Committed – demonstrating your passion for a cause
- Self-confident – able to work both autonomously and as part of a team where necessary
- Good communication – able to relate to both fellow workers and those you are trying to help and a willingness to make suggestions for improvements
- Self-assured – able to take constructive criticism on board to improve one's own skills and ability to help others

SPECIAL THANKS

**2015 ASAP Chiari & Syringomyelia
Conference Host**

Dr Cormac Maher

**FOR AN OUTSTANDING AGENDA AND
GREAT CONFERENCE!**

Physical Activity Guidelines Summary (edited)

Being physically active is one of the most important steps that Americans of all ages can take to improve their health. The 2008 Physical Activity Guidelines for Americans provides science-based guidance to help Americans aged 6 and older improve their health through appropriate physical activity.

Regular physical activity can produce long-term health benefits.

The Physical Activity Guidelines for Americans describes the major research findings on the health benefits of physical activity:

- Regular physical activity reduces the risk of many adverse health outcomes.
- Some physical activity is better than none.
- For most health outcomes, additional benefits occur as the amount of physical activity increases through higher intensity, greater frequency, and/or longer duration.
- Most health benefits occur with at least 150 minutes (2 hours and 30 minutes) a week of moderate intensity physical activity, such as brisk walking. Additional benefits occur with more physical activity.
- Both aerobic (endurance) and muscle-strengthening (resistance) physical activity are beneficial.
- Health benefits occur for children and adolescents, young and middle-aged adults, older adults, and those in every studied racial and ethnic group.
- The health benefits of physical activity occur for people with disabilities.
- The benefits of physical activity far outweigh the possibility of adverse outcomes.

Key Guidelines for Older Adults

The Key Guidelines for Adults also apply to older adults. In addition, the following Guidelines are just for older adults:

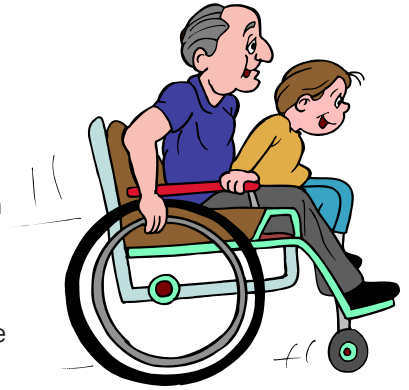
- When older adults cannot do 150 minutes of moderate-intensity aerobic activity a week because of chronic conditions, they should be as physically active as their abilities and conditions allow.
- Older adults should do exercises that maintain or improve balance if they are at risk of falling.
- Older adults should determine their level of effort for physical activity relative to their level of fitness.
- Older adults with chronic conditions should understand whether and how their conditions affect their ability to do regular physical activity safely.

Key Guidelines for Safe Physical Activity

To do physical activity safely and reduce the risk of injuries and other adverse events, people should:

- Understand the risks and yet be confident that physical activity is safe for almost everyone.
- Choose to do types of physical activity that are appropriate for their current fitness level and health goals, because some activities are safer than others.

- Increase physical activity gradually over time whenever more activity is necessary to meet guidelines or health goals. Inactive people should “start low and go slow” by gradually increasing how often and how long activities are done.
- Protect themselves by using appropriate gear and sports equipment, looking for safe environments, following rules and policies, and making sensible choices about when, where, and how to be active.
- Be under the care of a health-care provider if they have chronic conditions or symptoms. People with chronic conditions and symptoms should consult their health-care provider about the types and amounts of activity appropriate for them.



Key Guidelines for Adults With Disabilities

- Adults with disabilities, who are able to, should get at least 150 minutes a week of moderate-intensity, or 75 minutes a week of vigorous-intensity aerobic activity, or an equivalent combination of moderate- and vigorous-intensity aerobic activity. Aerobic activity should be performed in episodes of at least 10 minutes, and preferably, it should be spread throughout the week.
- Adults with disabilities, who are able to, should also do muscle-strengthening activities of moderate or high intensity that involve all major muscle groups on 2 or more days a week, as these activities provide additional health benefits.
- When adults with disabilities are not able to meet the Guidelines, they should engage in regular physical activity according to their abilities and should avoid inactivity.
- Adults with disabilities should consult their health-care provider about the amounts and types of physical activity that are appropriate for their abilities.

Key Messages for People with Chronic Medical Conditions

- Adults with chronic conditions obtain important health benefits from regular physical activity.
- When adults with chronic conditions do activity according to their abilities, physical activity is safe.
- Adults with chronic conditions should be under the care of a health-care provider. People with chronic conditions and symptoms should consult their health-care provider about the types and amounts of activity appropriate for them.

[Editor's Note: The Physical Activity Guidelines is a free download available at <http://health.gov/paguidelines/>]

Occipital Neuralgia

What is occipital neuralgia?

Most of the feeling in the back and top of the head is transmitted to the brain by the two greater occipital nerves. There is one nerve on each side of the head. Emerging from between bones of the spine in the upper neck, the two occipital nerves make their way through muscles at the back of the head and into the scalp. They sometimes reach nearly as far forward as the forehead, but do not cover the face or the area near the ears; other nerves supply these regions.

Irritation of one of these nerves anywhere along their course can cause a shooting, zapping, electric, or tingling pain very similar to that of trigeminal neuralgia, only with symptoms located on one side of the scalp rather than in the face. Sometimes the pain can also seem to shoot forward (“radiate”) toward one eye. In some patients the scalp becomes extremely sensitive to even the lightest touch, making washing the hair or lying on a pillow nearly impossible. In other patients there may be numbness in the affected area. The region where the nerves enter the scalp may be extremely tender.

What causes occipital neuralgia?

Occipital neuralgia may occur spontaneously, or as the result of a pinched nerve root in the neck (from arthritis, for example), or as the result of prior injury or surgery to the scalp or skull. Sometimes “tight” muscles at the back of the head can entrap the nerves.

How is occipital neuralgia diagnosed?

Occipital neuralgia can be diagnosed—and temporarily treated—by an occipital nerve block. For patients who do well with this temporary “deadening” of the nerve, a more permanent procedure may be a good option. These treatments include cutting the nerve surgically, “burning” the nerve with a radio-wave probe, or eliminating the nerve with a small dose of an injected toxin.

Obviously any procedure that deadens the nerve permanently is likely to leave some degree of permanent numbness in the scalp. A few patients may do well with procedures that “spare” the affected occipital nerve—a surgeon could decompress the nerve by removing any impinging muscles or scar tissue, or a pain specialist could implant an occipital nerve stimulator, a pacemaker-like device that stimulates the nerve with electricity resulting in tingling rather than pain.

Because all of these procedures are invasive, carrying some degree of risk of permanent complication, they generally first try to use medications to “calm down” the over-active nerves. Some patients respond quite nicely to non-invasive therapy.

[Information source - Johns Hopkins Medicine]

What We Really Want to Hear

If you could tell others how to respond to your situation, what would you want them to say?

“You look good, but how are you really feeling?”

We all try to look our best and put up a strong front. People on the street would never know the daily struggles caused by invisible symptoms. But what we all need is someone who cares enough to ask how we really feel.

“I’m going to the store. Do you need me to pick anything up for you?”

Most people have a hard time asking for help. We don’t want to be a bother to others and often do without, hoping tomorrow will be better.

“Do we need to stop visiting so you can rest?”

It is nice to have company and we do not want to offend them by saying we need rest. Or may even be afraid they won’t come back so we just tough it out. If only people could really see what is going on so we don’t have to tell them.

“Don’t feel bad if you have to cancel our plans at the last minute. I’ll understand.”

How often have you forced yourself to keep commitments even when you do you should cancel? Invariably, you pay the price for days. Or cancelled an outing and them felt guilty? Understanding friends and family make it much easier to say, “I’m not going to make it today.”

“Would you like to hear about our trip?”

Even when we are denied our own fun times, hearing about someone else’s allows us to share the enjoyment and take our mind off our pain. Just because we are sick, doesn’t mean we don’t care how our friends are feeling and what they have been doing.

“I can see you’re not feeling well, why don’t I check back in a day or two?”

If someone asks you to call when you are feeling better, you would probably never call. When they take the initiative and you are expecting the invitation, you can be better prepared.

People with any disorder or disease don’t want others to feel sorry for them, they only want understanding. We did not choose this life. It is the life we were given and we are just trying to make the best of it.

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

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ASAP History

In September 1996, ASAP co-founder Don White wrote:

My vision for the future of ASAP is to identify the thousands of people out there who don't know where to turn, what questions to ask to know who is qualified to treat them, or if he/she is the only person in the world who has this disorder.

The organization was founded on these goals:

- Providing a clearinghouse for information regarding syringomyelia.
- Identifying people with syringomyelia and offering them a support network.
- Increasing public awareness of the existence of the disorder and its devastating effects.
- Urging research efforts and raising funds to find all causes, to develop new treatments, and to improve existing treatments.
- Coordinating the efforts of organization working towards improving the lives of people with syringomyelia.

Prior to ASAP there was no concerted effort toward these goals. We have helped literally hundreds by answering their many questions, providing them the names of others in their area who share in their problems, and furnishing them with a list of medical professionals who have a good track record in dealing with this insidious disorder. More importantly than anything, we are here, ready to help.

It has not been an easy task. There have been roadblocks, setbacks, and disappointments but with your encouragement we have continued to fight. You know that through the efforts of our members and the respect for the organization, the NIH/NINDS has allotted funds for syringomyelia research. Until we have enough members and are recognized by the general public we cannot hope to raise these types of funds. In the meantime I think we should do what we do best, provide information. (Aren't you glad we were here for you?)

For now I believe we must concentrate on developing what we have worked so hard to establish. I know that with your continued support we will succeed.

Thank you Lori Tutrow for you service to ASAP and the Chiari & Syringomyelia Community.

Lori served on the Board of Directors from April 2012 - April 2015. She also ran a support group in the Indianapolis area, held numerous walks and multiple other duties during her term. She offers support and shares her experience with other parents on the ASAP Parent Page on Facebook. We are indebted and grateful to Lori for her past and future service to the Chiari and syringomyelia community.

St. Luke's Performs First Live Feed Surgery With Medtronic, World's Largest Medical Device Company

St. Luke's University Health Network's functional neurosurgeon Steven Falowski, MD, has partnered with Medtronic medical device company to promote faster and better product development within the field of neuromodulation for patients with pain and disability related to nerve disorders. Many of the patients' pain and disability is a result of brain tumors, Parkinson's disease and head and spine injuries.

In a first of its kind undertaking, live video feed taken while Dr. Falowski performs neurosurgical procedures to implant spinal cord stimulators, deep brain stimulators and pain pumps is sent through a specialty camera system to Minneapolis, MN where Medtronic engineers witness how their products are being used in live time. During the surgical procedures, Medtronic engineers have the ability to ask questions to best make modifications to enhance and improve their devices for the future. The first surgery using this technology and Medtronic engineer-St. Luke's surgeon interaction occurred, Thursday, August 6.

Dr. Falowski is the Lehigh Valley region's only fellowship-trained, functional neurosurgeon, and Medtronic is the world's largest medical device company. The relationship between the company and Dr. Falowski has been long-standing and has resulted in a number of technological strides that ultimately benefit patients.

"We've been working to develop this capability for several years," said Dr. Falowski. "The live feed, which includes a specialty camera attached to my surgical headlamp, allows Medtronic engineers to see a surgery from my visual perspective and allows the engineers to see exactly how I am using their equipment."

The partnership is extremely valuable to Medtronic, due in part to Dr. Falowski's implantation history and success rates. A national leader in neurostimulation implantation, Falowski implants 150 neurostimulators annually and implanted nearly 50 deep brain stimulators last year. Because of the large number of cases performed of a single procedure, St. Luke's Neurosurgical Associates' success rates are higher and complications are lower compared to other, non-specialized facilities.

Participating patients will remain completely anonymous. The camera system is engaged when the patient is completely draped and only the operative field is recorded through the technology.

According to Dr. Falowski, "The technology at St. Luke's is really on the leading edge, especially for neuromodulation. As a result of this partnership, St. Luke's patients will have access to new technology before any other health care center in the country." After FDA approval, new medical products are typically not available for up to six months but Dr. Falowski is one of a handful of physicians in the country with pre-market release access.

For now the Medtronic products being utilized as part of this program are those related to neuromodulation including spinal cord stimulators, deep brain stimulators and pain pumps. But with the technology investment already made Falowski suggests other medical device companies may look to forge similar relationships not only with the neurosurgery department but other surgical as well. Said Falowski, "The possibilities are truly endless."

[Re-Printed by permission from St Lukes University Health Network. For more information call 1-866-STLUKES.]

Spinal Cord Stimulation and Spinal (Pain) Pumps

When oral medications and/or nerve blocks do not sufficiently control the pain, advanced pain therapies or implantable systems may be effective for treating neuropathy. These systems are designed to interrupt transmission of pain signals from the spinal cord to the brain. If the neuropathic pain signals do not reach the brain, then the patient does not actually feel the pain.

Spinal cord stimulation (SCS) for pain control introduces low levels of electrical current to the dorsal portion of the spinal cord to block the sensation of pain. The device is implanted during a surgical procedure, and may include a fully implanted system or a system with an external power source.

Spinal cord stimulators may be used to manage pain from radiculopathy (sciatica or leg pain). Literature indicates that 50 to 60 percent of patients will get a 50 percent or better pain relief with this procedure that has lasted up to 20 years.

Spinal (or pain) pumps delivers pain medication directly to the intrathecal space around the spinal cord via an implanted pump. The pump is implanted during a surgical procedure, and medication in the pump is added periodically (e.g. monthly) by injecting medication through the skin into the pump reservoir.

Spinal pumps may be used to manage chronic pain are also used to treat painful spasticity. Often multiple medications are put into the pump to treat certain specific situations. That is, morphine to treat the nociceptive pain and local anesthetics (such as bupivacaine) to treat a neuropathic pain component.

For each of the above procedures, a trial is first performed to see if it is effective and how the patient reacts before the surgery is performed. Both of the procedures are reversible and the implantable system can be removed.



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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