

ASAP CONNECTIONS

Providing Research, Education and Support since 1988

Can Light Replace the Use of Opioid Drugs

Medical Design Technology recently published an article about new research that shows it is possible to activate opioid receptors with light. This discovery at Washington University in St Louis could lead to new ways to relieve severe pain without the addictive properties and side effects of drugs like morphine, OxyContin and Vicodin.

Keep in mind that much additional research is needed. First they must learn the most effective ways to activate and deactivate the opioid receptors' pathways in brain cells. Opioid receptors have multiple functions in the body. Not only do they interact with pain-killing drugs but they are also involved in breathing, are found in the gastrointestinal tract and play a role in the reward response.

When a person takes an opioid drug to relieve pain it interacts with receptors in the brain to blunt pain sensations. But over time the patient can develop tolerance and sometimes addiction. It can also slow a person's breathing and typically cause constipation.

In theory, receptors tuned to light may not present the same danger. It may be possible to activate or deactivate nerve cells without affecting any of the other receptors that pain-killing drugs trigger. Although achieving this goal will be difficult, it is encouraging to know that additional studies are planned.

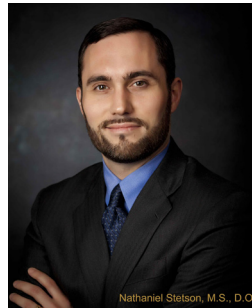
World's Smallest Spinal Cord Stimulation System Approved by FDA

Chronic pain affects more than 100 million Americans, an incidence rate higher than heart disease, cancer and diabetes combined. In total, the condition costs the American population 515 million workdays annually and generates upwards of 40 million visits to physicians each year.

Spinal cord stimulation (SCS) is a proven therapy used to manage chronic pain. It uses a small implanted generator to deliver electrical pulses to the nerve fibers of the spinal column via thin wires, known as leads, with electrodes. These electrical pulses mask or interrupt pain signals as they travel up the spinal cord to the brain, reducing the sensation of pain.

SCS therapy can offer proven, meaningful chronic pain relief for many patients while improving quality of life and reducing or even eliminating a patient's use of pain medication. Yet

Dr Nate Stetson Joins ASAP Board of Directors



Nate Stetson, MS, DO, is a private practice neurosurgeon at Neuroscience Specialists, PC in Oklahoma City, Oklahoma.

Dr Stetson received his undergraduate degree in biological sciences with honors from the University of Vermont. He completed a Masters Degree in healthcare

quality improvement and outcomes research at The Dartmouth Institute in Hanover, New Hampshire. After attending the New England College of Osteopathic Medicine he subsequently went on to complete neurosurgical training at the Cushing Neuroscience Institute in the North Shore Long Island Jewish Health System in New York. He has extensive experience in the surgical treatment of Chiari malformations secondary to his involvement with the Chiari Institute at North Shore LIJ.

In 2013, Dr Stetson established his practice with Neuroscience Specialists. Licensed by the State of Oklahoma, Dr Stetson is board certified and has a special interest in minimally invasive and complex spinal surgery, cranial micro neurosurgery and Chiari malformation and associated conditions and an interest in clinical outcomes research.

for some patients battling chronic pain, the possible need for future MRI scans has acted as a barrier to SCS therapy.

St Jude Medical has secured FDA approval for the Protégé MRI system. It is the smallest MR-conditional SCS implantable pulse generator (IPG) available in the United States. It is also the only upgradable IPG on the market. It will allow patients to safely undergo head and extremity MRI scans.

Upgradable technology allows patients to access future SCS technology from St. Jude Medical, once approved, through software updates rather than surgical device replacement. Historically, most patients would need additional surgery to receive new product features and benefits.

Kids For A Cure Club at the ASAP Conference

Annie Chapman has planned an exciting time for children ages 5--16 who will be attending ASAP's Chiari and Syringomyelia Conference in Michigan July 22 - 25.

Along with volunteer Annette Johnson, Annie has scheduled a pizza party, relaxation classes, art, music and pet therapy, a special session with a child life specialist and more.

A teacher will work with the kids on different techniques during Meditation Made Easy Day to help them cope with chronic pain.

Julie R. Piazza, MS, CCLS, BS with Patient Family Centered Care / Child & Family Life at C.S. Mott Children's & Von Voigtlander Women's Hospital will hold a session regarding how children deal with their medical treatment. She will also conduct a workshop for adults.

In addition, there will be arts and craft projects, games and much more.

Register now online. On the ASAP home page, look for the gray section below the pictures. When you click 'Register for the Conference' you will be directed to the conference page.

Syringomyelia Awareness Month

In preparation for May being decreed Syringomyelia Awareness Month volunteers solicited their state governors for proclamations. This year we received proclamations from many states but we would like for every state to recognize it next year. If you are interested in participating please contact Jamie Mayhan by email at info@ASAP.org or call the ASAP office. They want your request about six weeks out so we will be pushing the drive in mid March 2016. You will be provided with instructions and wording for the proclamation. Thank you to everyone who participated this year.

Support Group Update

Interested in starting a support group in your area? Contact Lori Tutrow (Lori_Tutrow@ASAP.org) for more information. Or call the ASAP office.

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 Spring 2015

Thank you to all the volunteers who held fundraisers and awareness events for Chiari and syringomyelia.

Michael "Yogi" & Bridget Borys held the **2nd Annual Yogi's Walk and Roll for a Cure** at Seneca Lake State Park in New York. The event took place on April 25.

Yogi was diagnosed with syringomyelia and Chiari in 2001 while attending the Finger Lakes Law Enforcement Academy in Hopewell, NY.

He tried to look away from his two surgeries and pursue a part of the life that he wanted. At first, not being able to be a Police Officer/Deputy Sheriff shattered his lifetime dreams. Though, he has been able to work in the criminal justice field as a dispatcher. He worked at the Seneca Falls Police Department for just a little less than 5 years. On May 1, 2006, he transferred to the Seneca County E-911 Center. He has also been a volunteer fire police officer with the Red Jacket Fire Department in the town of Seneca Falls since September of 2001.

Margaret Leisenheimer is currently finishing up her senior year at LaGuardia Arts High School. Diagnosed at the age of 15 she underwent surgery in the middle of her sophomore year.

April 2014, Margaret held her first **Syringo My What? Steps Across the States** walk and raised over \$5,000 which helped her to attend the ASAP Chiari & Syringomyelia Conference in Princeton, New Jersey.

This year Margaret's walk took place on April 26 in Middle Village, New York. She is doing well since her surgery but realizes everyone is not as lucky. She joined ASAP because she wants to help others who are struggling.

Her advice for people who are afflicted with syringomyelia and/or Chiari malformation would be to stay strong and take advantage of the good days. These disorders may be a large part of you, but they don't define you.

Melissa Sanders is holding her annual golf tournament in Auburn, Illinois on June 19. 100% of the net proceeds will be donated to ASAP. You can participate in a round of golf and dinner for \$90 per person. If you don't play golf come for the open bar and dinner for only \$25 a person. For more information on **Swing Fore The Cure** go to Great Expectations on www.ASAP.org or contact the ASAP office.

Interested in holding a fall event? Please contact Patrice at Patrice_Schaublin@ASAP.org.

www.ASAP.org

A Word From Our President



Another spring is here; it's hard to believe how fast time flies. We will be celebrating 28 years as a non profit soon. I am thrilled to be a member of ASAP for over 20 years.

As you will see in this issue, the conference is approaching quickly. We are honored to have Dr Cormac Maher as our host. As the Associate Professor, Neurological Surgery of

The University of Michigan, he was a natural fit for the ASAP annual conference. We have chosen the Ypsilanti Marriott at Eagle Crest as this year's location. Just outside of Ann Arbor, Michigan, its scenic grounds and resort feel offer a relaxed environment. Dr Maher has brought back many familiar faces this year and added a few new ones. We are thankful for all of the medical professionals who selflessly donate their time to help and support this community. Read about it in this issue and book your spot before it's too late.

Being affected by these disorders makes every day challenging. Many of you reading this know. We all share this experience. We do what we can to help. ASAP is always looking to form new support groups. Support, education and research has been our mantra for many years. Would you like to help others get through the rough spots? Please contact us if you are interested in starting a support group in your area. Make the call, find out how. There is no harm in asking and its vital to our community to know we have a place to turn in times of need. ASAP works with our leaders.

ASAP is always looking for volunteers, example (grant writers, development writer, volunteer coordinator, etc.) If you have some time and can give something to ASAP, we would love your help. It can be making an item for auction, helping obtain auction items, joining a committee, etc.

Lastly, I would like to thank all of you who visit us online. Our website, facebook pages, youtube channel, etc. are there for you. Past conference videos, a support network, educational materials and ongoing research are all on the web. Share the links with others in your network. ASAP is there for all of us. This is a great way to support others. Your small efforts can mean so much in someone else's life. We all know how hard it can get; extend a hand, lets all support each other!

Gentle Hugs always,

Patrice
Patrice_Schaublin@ASAP.org

Fall Fundraising Events

Patrice is setting up fundraisers for the fall. We have 4 different walks - Kicks and Licks (with or without your canine friends), Heads up for Chiari and Syringo (color your hair blue or purple), Syringo My What? Steps Across the States and our Walk & Roll For A Cure.

But you don't have to limit your event to a walk. Members have hosted celebrity dinners, yard sales, write-a-thons, bowl-a-thons, concerts, poker runs, galas, golf tournaments. They have collected coins, used stamps and pop tops. Let your imagine soar.

Patrice has been working with volunteers for many years to hold successful events. She will help you get started and ensure your event runs smoothly.

Contact: Patrice Schaublin

Email: Patrice_Schaublin@ASAP.org

Phone: 585-747-9651

ASAP Educational Video

The ASAP educational videos are now available on our YouTube channel, **Chiari & Syringomyelia ASAP.org**. A variety of topics are available from the leading experts. You can also view videos on our website www.ASAP.org in the Video Library.

ASAP's Chiari & Syringomyelia Conference July 22-25, 2015

Exploring New Frontiers

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

Host: Dr Cormac Maher

Neurological manifestations of Ehlers-Danlos syndrome(s): A review

Marco Castori and Nicol C. Voermans

Abstract

The term “Ehlers-Danlos syndrome” (EDS) groups together an increasing number of heritable connective tissue disorders mainly featuring joint hypermobility and related complications, dermal dysplasia with abnormal skin texture and repair, and variable range of the hollow organ and vascular dysfunctions. Although the nervous system is not considered a primary target of the underlying molecular defect, recently, increasing attention has been posed on neurological manifestations of EDSs, such as musculoskeletal pain, fatigue, headache, muscle weakness and paresthesias.

Here, a comprehensive overview of neurological findings of these conditions is presented primarily intended for the clinical neurologist. Features are organized under various subheadings, including pain, fatigue, headache, stroke and cerebrovascular disease, brain and spine structural anomalies, epilepsy, muscular findings, neuropathy and developmental features. The emerging picture defines a wide spectrum of neurological manifestations that are unexpectedly common and potentially disabling. Their evaluation and correct interpretation by the clinical neurologist is crucial for avoiding superfluous investigations, wrong therapies, and inappropriate referral. A set of basic tools for patient’s recognition is offered for raising awareness among neurologists on this under diagnosed group of hereditary disorders.

Conclusion

This overview on neurological manifestations of EDS demonstrates a largely unrecognized set of central and peripheral nervous system features in patients with heritable connective tissue disorders. The familiarity that any neurologist has with some of these manifestations when reported in the general population, such as cerebrovascular

disease, headache, myalgia and fatigue, poses neurologists in a privileged position for promptly recognizing EDS. Although the global assessment of EDS patients is, by definition, multisystem and often managed by other specialists, such as rheumatologists and clinical geneticists, the neurologist has a high chance of evaluating still undetected EDS patients with a neurological presentation.

In addition, while the pathognomonic features of EDS are not historical heritages of neurology, now, we know that a great proportion of the increased mortality and morbidity of EDS patients is linked to the reverberations that a primary connective tissue derangement has on nervous system development and functions. Hence, all practitioners occasionally or constantly involved in the management of EDS should be better aware of the neurological manifestations of this condition on both clinical and research perspectives.

On a practical point of view, the group of EDS types is large with a wide spectrum of manifestations and possible complications. Nevertheless, in this paper reviewing neurological features in EDS, the variability at presentation may be narrowed to a discrete list (Table 4).¹²⁰ Figure 3¹²⁰ illustrates the procedures for assessing generalized JHM by the Beighton score¹²¹ which is currently included in both Villefranche and Brighton criteria, as well as the alternative Bulbena score, which has proved to be equally efficient in discriminating hypermobile and non-hypermobile subjects.¹²² Both sets have limits and are not ideal in all situations, but may be considered useful first-line screening methods. A positive scoring as illustrated in figure 3 should prompt the clinical neurologist to refer the patient to an expert in the field for diagnosis confirmation and appropriate multidisciplinary management.

[Neurological manifestations of Ehlers-Danlos syndrome(s): A review - www.ncbi.nlm.nih.gov]

Every Dollar Counts

Donations made to ASAP not only support research they also fund our education and support programs. When you first contacted ASAP, you received an information package through the mail with general information about the disorders and organization. We send out several thousands of those packages every year. Your donations make this possible.

Your support also funds this newsletter. Every issue is read by over 10,000 persons. ASAP’s presence on social media has expanded in recent years with multiple FaceBook group pages. They are monitored to prevent spam and inappropriate posts.

Video recordings of speakers during our annual conference is an educational program made possible through public support. We stream them on our website and YouTube channel free of charge.

ASAP’s website, telephone support group, and research projects are all made possible because of our generous donors. These are only examples of how your donation dollars are spent. If you would like to receive a copy of our annual 990 or audit please contact the ASAP office.

Annual Conference Auction and Raffle

Our annual conference auction and raffle need your help to be successful. You can send donations to the ASAP office in Longview or bring them to the conference in July.

Suggestions for items include but are not limited to paintings, quilts, aprons, baby items, toys, arts and crafts and jewelry. Timeshares, airline miles and unused gifts are a few other suggestions. It is always fun to see the many items displayed and even better when you win that special item through the raffle or auction.

Let your imagination free and support the organization with a donation of your choice. Please include the value of donated item(s).

Mailing address for donations:

ASAP, Inc
300 N Green St Ste 412
Longview TX 75601



Tips for the Caregiver

Most of what ASAP does is to provide support and information for the person diagnosed but we also realize the needs of those who provide daily care to these individuals. We know that it is important to you to give your loved one the best possible care. The following are a few guidelines that should make everything run smoother.

Listen

It is important to make time to talk in order to find out how your loved one feels and what they want you to do for them. Losing one's independence is hard. It is important to realize even though a person may no longer be physically able to provide for themselves, they still need to be respected.

Set a Schedule

A schedule will provide structure for both parties involved. Set times for meals, personal care, household chores, exercise, activities, and relaxation. When you make the schedule, think about your loved one's needs. Consider how he/she organized their day before you got involved.

Get Organized

Paperwork can pile up. To keep things running smoothly, put prescriptions, insurance info, doctor contacts, and health history in one place, like a multi-pocket folder. Keep track of appointments in a paper, computer, or smartphone calendar.

Keep Track of Medicines

A person with these disorders may take five or more drugs to treat different symptoms. All those meds can lead to mix-ups and mistakes. Go over the list with your loved one's doctor and pharmacist to make sure every medication and dose is correct. Store all medicines in one place for easy access. Use a pillbox to keep organized by day and time. Do an inventory every few months, and throw out any expired pills.

Simplify Meals

It takes time to prepare three meals a day. Planning ahead can help. Do all the week's grocery shopping in one trip. Cook a big batch of meals and freeze them. Ask friends and family members to chip in. Set up a rotating schedule where each person shops for groceries, or brings over a whole cooked meal. When you cook, adapt dishes to your loved one's taste as well as calorie and dietary needs.

Ask for Advice

If you're a first-time caregiver, you probably have a lot to learn. Get help from an expert like a geriatric care doctor, nurse, or therapist.

27 Years and Strong

On May 31, ASAP will complete its 27th year of service to the syringomyelia and Chiari community. The organization was founded by Barbara and Don White. Barbara was diagnosed with SM in May 1983.

One of their main goals was to identify persons with SM. They began by sending a brochure and letter to 15,000 doctors across the nation asking them to please contact their patients with SM and direct them to the organization for support and information.

In 1989 Barbara wrote, "Every victim we have found with SM has also gone through the same fruitless search that we have gone through. We have had people tell us that they wished they had started the organization instead of us. I, myself wish someone had started it many years ago, but they didn't. Possibly my deficits would not be as great as they are today."

Thanks to the efforts of two people 27 years ago, those diagnosed today have a greater source of information and support.

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 Person

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ASAP History

On March 30, 1989, Dr Bernard Williams, a noted neurosurgeon from Birmingham, England, visited with Barbara White in Longview Texas during his vacation/lecture tour in the United States. A presentation on his research with syringomyelia was attended by five persons with SM, one who traveled from Raleigh, North Carolina to attend.

Candace Morse wrote, "We believe this is the largest group of Syringomyeliacs that has ever been together in the US. For myself, it was the first time I had ever met someone else with SM and that was as exciting as hearing Dr Williams' lecture."

Dr Williams late wrote, "I first spoke to Barbara through a telephone call. I immediately knew that this was somebody of importance for those of us who care about syringomyelia. We share much in common. It is true that my interest in syringomyelia has been chosen whereas Barbara's was thrust upon her, but she never seemed to resent this and when speaking to me she always seemed to be concerned with the practicalities of the situation rather than with complaining about it."



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Living Life with Chiari, Syringomyelia, Ehlers Danlos, POTS and Chronic Pain

Compiled by Shananne Hutter

Making it work for you.

Here are some techniques/ideas for transforming your life.

- Surround yourself with the right people. Seek ways to spend more time with the people that make you laugh and that enjoy your company. Life is too short to spend it with people who can only focus on the negative.
- Be proactive—manipulate your environment. Keep funny books, audios and toys within reach. Refer to them at least once a day.
- Be proactive—manipulate your mind-set. If you have a challenging situation, exaggerate it until you can laugh at the audacity of it. Practice looking for the humor around you.
- Take a risk—be willing to appear silly to others. No one ever died from looking foolish, and the benefits far outweigh the risks. Be willing to laugh at yourself.
- Be in the moment—play when the occasion arises. Don't wait until you feel better to play. Play and then feel better.
- Use meditation, prayer and the counsel of others.
- Find your passion and share it with others.
- Try new things (calculated risks); give yourself something else to talk about besides your conditions.
- Eliminate toxic relationships from your life. Forgive those who fail you and then move on.
- Determine who and what adds meaning to your life and invest in those relationships and activities.- Try volunteering. It builds self-esteem, adds value and worth, helps overcome social isolation & gives you a sense of belonging.
- Create a support network.
- Simplify your life.
- Let Go...Reduce Stress.
- Find the right doctor - The one who will listen, validate and work with you to help find answers to your questions.
- Protect your health by setting healthy boundaries in all areas of your life.
- SAY NO! It's ok to say no I'm sorry I can't do whatever.
- Create new traditions to reduce holiday stress.
- Have hopes and dreams and STRIVE for them.
- Enjoy the small victories!
- Be honest with yourself and others. Share how you feel. This lets others know what they can do to help you.
- Consider medication or counseling to help reduce pain and depression.
- Create new coping mechanisms especially if the old ones aren't working anymore.
- LEARN as much as you can about your condition(s). Knowledge is POWER. In order to get the best treatment for your condition(s) and it helps you keep a sense of power and control as well as maintain a sense of independence.

2015 Conference Speakers

The following is a list of speakers confirmed for the ASAP Chiari & Syringomyelia Conference June 22-25:

- Robert Keating – Children's National Medical Center - Incidental Chiari
- Tim George – Dell Children's Hospital, Austin, Texas - Embryology of Chiari
- Cormac Maher – University of Michigan – Identifying Chiari-associated syrinx
- John Heiss – NIH - Longitudinal Study of Pain and Functional Abilities in Chiari 1 Malformation and Syringomyelia
- Bermans Iskandar – University of Wisconsin/Madison
- Roger Kula – Long Island - The Neurological Work-up of Chiari I Patients
- Lance LaCerte, Psy D – Behavioral Medicine
- Nate Stetson – Oklahoma - TCS
- Andrew Ringer – University of Cincinnati- or Robert Bohinski (or both)
- Bryn Martin - University of Akron – CSF Flow Research
- Allison Ashley-Koch – Duke University– Genetics
- Dave Limbrick – Washington University – The Park-Reeves Registry
- Brandon Rocque – University of Alabama – Surgical Management of Pediatric Chiari
- Nick Wetjen – Mayo Clinic- Postoperative Syrinx Resolution OR Sports
- Paolo Bolognese – Long Island
- Ulrich Batzdorf – UCLA - Syringomyelia
- Dave Frim – University of Chicago- Treatment Outcome Scale
- Aintzane Urbizu – University of Akron – Imaging Features of Symptomatic Chiari
- Leon Dure – University of Alabama – Pediatric Non-surgical Management
- Julie Piazza – University of Michigan - Child Life
- Karin Muraszko – University of Michigan – Clinical CSF Flow Analyses Part I (neurosurgery)
- Rajiv Bapuraj – University of Michigan – radiology – Clinical CSF Flow Analysis, Part II
- Steve Leber – University of Michigan – Pediatric Neurology
- Wade Cooper – University of Michigan – Pain Management
- Vikram Shakkotai - University of Michigan – Adult Non-surgical Management

Make plans now to attend!



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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