

# ASAP CONNECTIONS

*Providing Research, Education and Support since 1988*

## Targeting Brain Cells to Deal With Neuropathic Pain

August 8, 2016 by Rutgers University

Neuropathic pain could be reduced or even eliminated by targeting brain cells that are supposed to provide immunity but, in some instances, do the opposite, causing chronic pain that could last a lifetime.

“The general thought has been that these cells are supposed to be beneficial in the nervous system under normal conditions,” said Long-Jun Wu, a professor of cell biology and neuroscience at Rutgers University. “But, in fact, in those with this neuropathic pain, these cells known as microglia have proliferated and instead become toxic.”

In new research, Wu and his team discovered that chronic neuropathic pain, caused by nerve damage as a result of an injury, surgery or a debilitating disease like diabetes or cancer, could be greatly reduced in animals if the injury was treated targeting microglia within a few days.

“If we can catch that window within one to five days to inhibit microglia after nerve injury, we can partially reverse the development of chronic pain,” Wu said. “If we were able to deplete the microglia cells causing the condition before nerve injury occurs, we can permanently prevent it.”

Neuropathy occurs when nerves are injured from trauma or disease and can also be the result of a surgical procedure. This type of pain, unlike physiological pain, persists even after the injured nerve has healed and is often resistant to pain relievers like

acetaminophen and naproxen. While opiates are used to alleviate pain, they have side effects and are not always effective for neuropathic pain patients.

In laboratory studies on mice, Wu and his colleagues used chemotherapy drugs to prohibit the microglia brain immune cells from proliferating, similar to the treatment used by oncologists to prevent cancer cells from multiplying. The results from Wu’s laboratory showed that this chemotherapy drug reduced the amount of pain the mice experienced after the injury occurred.

“What needs to be done is prevent the microglia cells from multiplying in the first place,” Wu said. “It had been thought that these cells were beneficial in a normal brain, but our research discovered how these cells function under neuropathic pain condition and initiate the problem.”

Although scientists have studied microglia cells in relationship to neuropathic pain for the past two decades, Rutgers is the first to pinpoint the exact role the cells have in the initiation and maintenance of the condition. Wu and his colleagues found that the proliferation of these types of cells is one of the major contributors of microglial pain.

This discovery could lead to the development of more effective painkillers with fewer side effects, he said.

## FDA Approves New Dysport Indication

SILVER SPRING, Maryland — The Food and Drug Administration has approved a new indication for Ipsen Biopharmaceuticals’ Dysport (abobotulinumtoxinA), the company announced. The drug can now be used to treat lower limb spasticity in pediatric patients ages 2 years and older.

“This approval means that, for the first time, physicians have a FDA-approved botulinum toxin with recommended dosing guidance for the treatment of children two years of age and older with lower limb spasticity based on a large registrational study,” said Dr. Ann Tilton, professor of clinical neurology and chief of the section of child neurology at Louisiana State University School of Medicine.

The drug comes with a boxed warning stating that the effects of the botulinum toxin may spread from the injection area to other areas of the body, causing symptoms akin to those of botulism.

*“You just do it. You force yourself to get up. You force yourself to put one foot before the other, and... you refuse to let it get to you. You fight. You cry. You curse. Then you go about your business of living. That’s how I’ve done it. There’s no other way.”*

*Elizabeth Taylor*

## 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

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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.

## Peer Support

Peer support occurs when people provide knowledge, experience, emotional, social or practical help to each other. ASAP volunteers provide peer support through local support groups, social media groups and telephone outreach. Groups currently offering regularly scheduled meetings are:

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

Meets the first Sunday each month, 2:00 pm, at Broadway Dysarts, 110 Broadway, Bangor, ME

For more information contact Lisa Dunton-Roy by email Maine\_Support@ASAP.org or call 207-570-6428.

### ASAP's Reading, PA Chiari/Syringo Support Group

Meets the first Sunday each month, 2:00 pm, at Reading Hospital & Medical Center in R Lobby Conference Room #8

For more information contact group leader, Stacie Nein by email neinemtet@aol.com.

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

Meets the second Saturday each month, 10:30 am at Southwest Oklahoma City Public Library, 2201 SW 134th Street, Oklahoma City, OK

For more information contact support group leader Ann Humphries by email OKsupportgroup@ASAP.org.

### AZ Chiari/Syringo Support Group

Meetings held quarterly at 11:00 am, Mercy Conference Room at St. Joseph's Hospital and Medical Center, 350 W Thomas Rd., Phoenix. Parking in the 6th or 3rd Ave Garage at a reduced rate. Next meeting will be October 8.

For more information contact Kathleen Hall at 623-570-5945 or email arizonasyringochiari@gmail.com.

### SMNW Puget Sound Support Group

Holds monthly meeting at various times and places. Next meeting is Saturday, October 1.

For more information contact Michele McGraw via email MicheleIm@frontier.com.

### ASAP Telephone Outreach

Meets the third Thursday each month via teleconference. Contact the ASAP office for more information.

## A Word From Our President



Hard to believe that conference 2016 is barely behind us, and planning for conference 2017 is already underway.

Let me first say that our deepest gratitude and thanks goes to Dr. Gerald Grant for hosting such an outstanding 2016 conference. He and his amazing team of presenters gave so much and again demonstrated the importance of this annual event.

Many of you experienced this year's conference, and know first hand, the impact it can have for individuals affected by, or connected to our community. Several of you took advantage of the LEARN points program and were able to attend for little or no cost. These programs, LEARN points, scholarship and the annual conference, have served to improve the lives of persons affected by syringomyelia, Chiari malformation and related disorders while we find the cure as outlined by our mission statement.

I am proud to be part of an organization that makes a difference, everyday.

Gentle Hugs always,  
Patrice  
Patrice\_Schaublin@ASAP.org

## 2016 Volunteer Awards

Each year we take time to honor those who truly make ASAP shine – our volunteers!

### Our 2016 recipients are:

**Barbara White Award** – ASAP's most prestigious award is given in recognition of outstanding contributions to further the efforts of our co-founder, Barbara White. Recipients demonstrate long-term commitment to the cause by being active in many areas of the organization. This year we are honored to give the award in memory of a woman who served as a support group leader, Board Director and parent of a child with these disorders. She was a true example of strength in gentility, courage in grace and lovingly loyal.

#### Renee Tobias

**Key Volunteer Awards** – These volunteers play a vital role in helping ASAP open new doors through their service and contributions.

#### Michael "Yogi" Borys

#### Bridget Borys

**Shining Star Volunteers** – A shining example of giving at its best, these volunteers continuous efforts go above and beyond.

#### Molly Lichtenstein

#### Sheila Rainey

**Visionary Awards** – Volunteers who are committed to furthering the goals of ASAP by donating their time and talents to keep ASAP moving forward.

#### Lisa Dunton-Roy

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

#### Patti Davis

#### Ann Humphries

#### Staci Nein

#### Wendy Schwoyer

#### Lauren Talarico, BS, DVM, DACVIM

#### Christine Grabowski

#### Michele McGraw

#### Austin Rodriguez

#### Connor Yung

**Outgoing Board Members** – The Board of Directors is the final authority on operations of the American Syringomyelia Chiari Alliance Project, Inc. ("ASAP"). Directors serve a 3-year-term and can serve two continuous terms.

**John Heiss, MD – term: 2008-2015**

**Lori Tutrow – term: 2012-2015**



**visit us on the web**

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

**check out our online videos**

## 2016 Conference Speakers

A very special thank you to the speakers who made the ASAP Chiari and Syringomyelia Conference world class! The meeting was recorded and videos will be available online later this year or early 2017.



**Ulrich Batzdorf, MD** - Professor of Spinal Neurosurgery, UCLA School of Medicine, Los Angeles, CA

**Sumit Bhargava, MD** - Clinical Associate Professor, Pediatrics - Pulmonary Medicine, Stanford University, Stanford, CA

**Nancy Block, PT** - Silicon Valley EDS Support Group

**Paolo Bolognese, MD** - Neurosurgeon, Director of the Chiari Neurosurgical Center NSPC, Lake Success, NY

**Ian Carroll, MD, MS** - Assistant Professor of Anesthesiology, Perioperative and Pain Medicine at the Stanford University Medical Center, Stanford, CA

**May Casazza, NP** - Neurosurgery, Stanford Children's Health, Stanford, CA

**Sam Cheshier, MD PhD** - Assistant Professor of Neurosurgery, Stanford University, Stanford, CA

**Brian Dlouhy, MD** - Assistant Professor, Neurosurgery, University of Iowa Children's Hospital, Iowa City, IA

**Michael Edwards, MD** - Lucile Packard Children's Hospital Professor in Pediatric Neurosurgery, Stanford University, Stanford, CA

**Karen Friday, MD** - Cardiac Electrophysiologist, Stanford University, Stanford, CA

**Timothy George, MD** - Medical Director of the Pediatric Neurosurgery Center of Central Texas at Dell Children's, Austin, TX

**Brenda Golianu, MD** - Associate Professor of Anesthesiology, Perioperative and Pain Medicine (Pediatric) at the Stanford University Medical Center, Stanford University, Stanford, CA

**John D Heiss, MD** - Head Clinical Unit, Surgical Neurology Branch, NINDS/ NIH, Bethesda, MD

**Nicole Hodgeboom, CPNP, CNS** - Pediatric Nurse Practitioner, Integrated Pediatric Pain and Palliative Care Team Stanford University, Stanford, CA

**David Hong, MD** - Clinical Assistant Professor, Neurosurgery, Stanford University, Stanford, CA

**Bermans Iskandar, MD** - Director of the Pediatric Neurosurgery Program, University of WI, Madison, WI

**Line Jacques, MD** - Professor of Clinical Neurological Surgery, Chief of Peripheral Nerve and Pain Surgery University of California, San Francisco, CA

**Susy Jeng, MD** - Clinical Assistant Professor, Neurology & Neurological Sciences, Stanford University, Stanford, CA

**Robert Keating, MD** - Chief of Neurosurgery, Children's National Medical Center, Washington, DC

**Roger Kula, MD** - Director, the Chiari Institute, Great Neck, NY

**Jeff Lazarus MD, FAAP** - Pediatrician, Medical Hypnosis Specialist, Menlo Park, CA

**AnhThu, Lewis, NP** - Pain Management, Stanford University, Stanford, CA

**Dave Limbrick, MD** - Chief, Pediatric Neurosurgery, Associate Professor, Neurological Surgery, Associate Professor, Pediatrics Neurosurgeon-in-Chief, St. Louis Children's Hospital, Washington University, St. Louis, MO

**Tina Loven, DO** - Neurological Surgeon, Mercy Hospital, Springfield, MO

**Arnold Menezes, MD** - Vice Chairman, Professor of Neurosurgery, University of Iowa Carver College of Medicine, Iowa City, IA

**Harold ReKate, MD** - Professor, Hofstra Northwell School of Medicine, Great Neck, NY

**Doug Sidell, MD** - Associate Professor Pediatric Otolaryngology/Head Neck Surgery, Stanford, Palo Alto, CA

**Aintzane Urbizu, PhD** - Postdoctoral Research Fellow, Duke, Durham, NC

**Anand Veeragavu, MD** - Stanford University, Stanford, CA

**Erol Veznedaroglu, MD, FACS, FAANS, FAHA** - Director, Drexel Neurosciences Institute; Robert A. Groff Chair in Neurosurgery, Philadelphia, PA

**Selda Yildiz, PhD** - Georgia Institute of Technology, Atlanta, GA



## Together We Can... Events Spread Awardness

### Yogi's Community Fun Day and Ziti Luncheon

On May 21, a crowd turned out to enjoy a Ziti lunch at the Seneca Falls Elk Lodge in Seneca Falls, New York. With visits from the local fire and police departments, the Wildlife Defenders a little education was mixed in with all the games for kids of all ages.



### Connor's ASAP Awareness and Fundraising Event

The Heckscher Playground in Central Park was the site for Connor's Kids For A Cure Club awareness event on May 22 in New York.



### Jessica's 1st Annual ASAP Walk and Roll for a Cure

Jessica Griffith wasn't about to let a little rain put a damper on her awareness event so everything was moved indoors. On August 13, people turned out at the Gouverneur's fairgrounds to enjoy music, food, children's events, a bake sale and vender booths.



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**

Donor

#### **Alana Ficco**

Donalda Wolfe

#### **Dr Paolo Bolognese**

Ann Hood

#### **Jacqueline Babitts**

Steven & Rosa Babitts

#### **Michael Kirlin's 24th**

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Diane Mullens

#### **Diane Strauser**

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#### **Marjorie Walzer**

Mr & Mrs Stephen Sharkey

#### **Chip Vierow**

Ann Hood



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### **ASAP History**

During the summer and fall of 1993, a few persistent ASAP members roamed the halls of Congress on behalf of ASAP. Under the guidance of Ann Charnley, an ASAP board member at the time and experienced lobbyist, a provision in the 1994 federal appropriation bill was included for an NIH conference to set a research agenda for syringomyelia. Representative Steny Hoyer of Maryland spearheaded the effort with help from Senators Robert Byrd, West Virginia, Tom Harkin, Iowa and Alphonse D'Amato, New York.

The NIH Conference was held June 20-21, 1994. The meeting was chaired by Dr Ulrich Batzdorf, UCLA School of Medicine and attended by 19 neurosurgeons, neurologist, radiologist and researchers. ASAP members were active participants in the workshop expressing the patient's point of view and concerns. Not only was a research agenda developed, but important connections were established between the doctors, the government institutes and ASAP.

ASAP members have been helpful in many different research projects over the years. One of the first studies was in 1993. A questionnaire was developed by Dr Colin Kanar to define the most common symptoms and develop a demographic database. It was distributed to 450 members with SM and 250 responses were received. Dr Kanar submitted a successful abstract based on those responses to the American Association of Physical Medicine.

In November 1996, ASAP announced its first sponsorship of a Research Fellow, Dr Ian Heger at the SUNY Health Science Center under the leadership of Dr Thomas Milhorat.

To strengthen the ties between ASAP and the research community, the ASAP Board of Directors voted to establish a Medical Advisory Board in January 1996. With the help of that Medical Advisory Board, ASAP was able to better evaluate the merits of research projects, encourage awareness of SM and Chiari and boost government sponsorship of projects. It also inspired awareness of syringomyelia and Chiari among medical professions.

Dr Thomas Milhorat chaired the first Medical Advisory Board that also included:

Dr Henry Barnett, Ontario, Canada

Dr Ulrich Batzdorf, Los Angeles, California

Dr Arnold Menezes, Iowa City, Iowa

Dr Richard Ellenbogen, Seattle, Washington

Dr Robert Stanton, Wilmington, Delaware

Dr Marcy Speer, Durham, North Carolina

# POTS

Postural Orthostatic Tachycardia Syndrome (POTS) is a form of dysautonomia that is estimated to impact between 1,000,000 and 3,000,000 Americans, and millions more around the world. The term POTS was coined in 1993 by a team of researchers from Mayo Clinic. However, Postural Tachycardia Syndrome (POTS) is not a new illness. It has been known by other names throughout history, such as DaCosta's Syndrome, Soldier's Heart, Mitral Valve Prolapse Syndrome, Neurocirculatory Asthenia, Chronic Orthostatic Intolerance, Orthostatic Tachycardia and Postural Tachycardia Syndrome. In the past, it was mistakenly believed to be caused by anxiety. However, modern researchers have determined that POTS is not caused by anxiety. It is caused by a malfunction of the patient's autonomic nervous system.

## Signs and Symptoms

While the diagnostic criteria focus on the abnormal heart rate increase upon standing, POTS usually presents with symptoms much more complex than a simple increase in heart rate. It is fairly common for POTS patients to have a drop in blood pressure upon standing, but some POTS patients have no change or even an increase in blood pressure upon standing. POTS patients often have low blood volume and high levels of plasma norepinephrine while standing, reflecting increased sympathetic nervous system activation. Approximately 50% of POTS patients have a small fiber neuropathy that impacts their sudomotor nerves. Many also experience fatigue, headaches, light-headedness, heart palpitations, exercise intolerance, nausea, diminished concentration, shaking, fainting, coldness or pain in the extremities, chest pain and shortness of breath. Patients can develop a reddish purple color in the legs upon standing, believed to be caused by blood pooling or poor circulation. The color change subsides upon returning to a reclined position.

## POTS Classifications

POTS researchers have classified the disorder in various ways. Dr Blair Grubb has described POTS as *primary* or *secondary*. *Primary* refers to POTS with no other identifiable medical condition (also known as idiopathic POTS). *Secondary* refers to POTS with the presence of another medical condition known to cause or contribute towards symptoms. Dr Julian Stewart has described *high flow* and *low flow* POTS, based upon the flow of blood in the patients lower limbs.

Other researchers have described POTS based on some of its more prominent characteristics: hypovolemic POTS, which is associated with low blood volume; partial dysautonomic or neuropathic POTS which is associated with a partial autonomic neuropathy; and hyperadrenergic POTS which is associated with elevated levels of norepinephrine. These are not distinct medical conditions and many POTS patients have two or three of the different characteristics present. For example, one patient can have neuropathy, low blood volume and elevated norepinephrine.

## Who Develops POTS?

POTS can strike any age, gender or race, but it is most often seen in women of child bearing age (between the ages of 15 and 50). Men and boys can develop it as well, but approximately 80% of known patients are female.

## What Causes POTS?

POTS is a heterogeneous (meaning it has many causes) group of disorders with similar clinical manifestations. POTS itself is not a disease; it is simply a cluster of symptoms that are frequently seen together. This is why the 'S' in POTS stands for syndrome. Since it is not a disease, it is fair to say that POTS is caused by something else. However, figuring out what is causing the symptoms in each patient can be very difficult, and in many cases, patients and their doctors will not be able to determine the precise underlying cause. When doctors cannot pinpoint the underlying cause, it may be called primary or idiopathic POTS. Idiopathic simply means 'of an unknown origin.'

While researchers are still working to identify the root causes and pathology of POTS, there are several underlying diseases and conditions. Some disorders known to cause or be associated with POTS or POTS like symptoms in some patients are Chiari malformation, Ehlers Danlos Syndrome and multiple sclerosis.

## Treatment

Each patient is different, thus consulting with a physician who has experience in treating autonomic disorders is important. The most common treatments for POTS include increasing fluid intake to 2-3 liters per day; increasing salt consumption to 3,000 mg to 10,000 mg per day; wearing compression stockings; raising the head of the bed (to conserve blood volume); reclined exercises such as rowing, recumbent bicycling and swimming; a healthy diet; avoiding substances and situations that worsen orthostatic symptoms; and finally, the addition of medications meant to improve symptoms. If an underlying cause of the POTS symptoms can be identified, treating the underlying cause is very important as well.

## Prognosis

Currently, there is no cure for POTS, however researchers believe that some patients will see an improvement in symptoms over time. Detailed long term follow up studies on the course of POTS are sparse. With proper lifestyle adjustments, exercise, diet and medical treatments, many patients see an improvement in their quality of life. If an underlying cause can be identified, and if that cause is treatable, the POTS symptoms may subside. While the prognosis is good for most patients, researchers have noted that some patients will not improve and may actually worsen over time.





**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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