

## ASAP Chiari & Syringomyelia Conference Chicago, Illinois July 22-25, 2020

### Konstantin Slavin MD To Host ASAP Conference

Professor of Neurosurgery, Dr Slavin heads the Stereotactic and Functional Neurosurgery section at the University of Illinois Chicago (UIC). A Board certified neurosurgeon, he completed residency in neurosurgery at the Department of Neurosurgery, UIC and the Department of Neurosurgery of the Central Institute of Post-Graduate Training of Physicians, Moscow, USSR.

Dr Konstantin Slavin's clinical interests are diverse applications of surgical neuromodulation and functional neurosurgery. This includes movement disorders, epilepsy, psychiatric diseases and treatment of pain. He has a particular interest in Chiari malformation, stereotactic radiosurgery, brain tumors, spinal problems and the treatment of facial and cancer-related pain. Among his many clinical and professional awards, are "Most Compassionate Doctor" and the prestigious "Top Surgeons" and "Best Doctors" lists for many years. He is Past-President of the American Society for Stereotactic and Functional Neurosurgery, and Director-at-Large of the North American Neuromodulation Society and the International Neuromodulation Society. He also serves on Medical Advisory Board of the Facial Pain Association (formerly Trigeminal Neuralgia Association).

Dr Slavin has authored and co-authored more than a hundred chapters and peer-reviewed articles, edited three books on peripheral nerve stimulation, and presented at countless educational events and professional conferences worldwide. He is now an associate editor of Neuromodulation, Neurosurgery, Surgical Neurology International and a member of editorial boards of several other professional journals. Dr. Slavin's research interests parallel his clinical expertise and include practical aspects of neuromodulation, a multitude of prospective clinical studies and pioneering research in spinal cord stimulation for cerebral vasospasm, surgical treatment for migraines, and deep brain stimulation for tremor, Parkinson's disease, and depression.

Dr Slavin will work with the ASAP Medical Advisory Board to develop a multi-level program for the ASAP Chiari & Syringomyelia Conference which will be held in Chicago, Illinois July 22-25, 2020.

#### Conference Hotel

*Classic Style on Magnificent Mile*

Millennium Knickerbocker Hotel Chicago is the epitome of classic Chicago style, located just off Magnificent Mile – a famous stretch that's home to over 400 retailers and high-end shops. Established in 1927, the hotel has had many identities, including a Penthouse casino and speakeasy once run by the Capone family. You'll find markers of this iconic history all around the hotel as the old world meets the new. One of the most timeless aspects of the hotel is its commitment to its guests – you can expect 4-star service every moment of your stay.

ASAP has contracted a room block with the hotel for a base guest room rate of \$149 per night. The hotel will require a one night room and tax deposit at the time of reservation. The individual's deposit is refundable if the reservation is cancelled by 4 PM EST the day before scheduled arrival.

Make hotel reservation by calling 1-800-621-8140 Monday – Friday 8:30 AM – 5:30 PM EST or online at [www.millenniumhotels.com](http://www.millenniumhotels.com), Group Identification Code # ANNUALCHIA

Valet parking is available for \$73 per night (overnight based on 12 PM arrival - 2 PM departure). Early arrival and late departure fees will apply. Daily event parking is \$32 for non-overnight guest. Rates are subject to change. Other nearby parking facilities may be available at a lower rate. Recommended parking apps are Park Chicago, Park Whiz and Spot Hero. The hotel is located at 163 East Walton Place.



## A Word From Our President

*Eric J Berning*

Welcome to 2020!

A new year, and a brand new decade! To ring it in, we are thrilled to announce some very exciting changes going forward. First off, ASAP has just relaunched our website with a fresh, streamlined user interface that provides easier access to information and services across our multiple platforms. If you haven't yet, go to [www.ASAP.org](http://www.ASAP.org) and check it out! I'm confident you will enjoy the redesign as much as we do—please be sure to let us know what you think!

This year will also see ASAP partnering on some promising new research projects to continue to advance our mission to seek a cure for CM/SM and related conditions. And, of course, we would be remiss if we didn't mention how much we're looking forward to ASAP's 32nd annual conference, hosted by Dr. Konstantin Slavin in Chicago, Illinois, July 22-25, 2020! Mark your calendars now!

Both the present and the future hold great promise for us. There are so many amazing things happening in our world right now, and if you look back across history we have come quite a long way in a very short time. The other day I got to thinking about the reality of the advancement of humankind after my wife, who is a nut about genealogy and history, showed me old footage she found on YouTube of a 103-year-old man being interviewed in 1929 about the things he saw and remembered throughout his life. At 103, he would have been born in 1826—decades before the American Industrial Revolution began—and he lived to see the advent of electricity, motor cars, transcontinental flight, and telephones.

My wife's grandmother recently passed away at 103. While she was with us we had wonderful conversations about her life and all the amazing advances she saw and progress she experienced, from women's suffrage to smart phones. This really hit me...imagine life 100 years ago. Could Chiari and Syringomyelia be treated in 1920? Yes, but treatment and care were very different, almost "primitive" by today's standards. Just a diagnosis itself proved very difficult, because the presence of CM/SM was often only revealed upon autopsy. MR images of the brain were first done in 1993. 1993! Just 27 years ago. Barbara and Don White started ASAP in 1988. Look how far we have come. We still have a long way to go until we find a cure, but in perspective, we certainly have come a very long way.

As we move forward into 2020 and beyond, ASAP will continue to welcome and reach out to fellow organizations that share and wish to pursue our goal of research, education, and support for the CM/SM community. We will continue growing our partnerships with like-minded international organizations as well as enhance our domestic partnerships. I firmly believe that as a community we need to band together to utilize our resources in the best way possible and to unify a voice for the advocacy of those affected by these conditions. My pledge to you is to continue to lead ASAP with inclusivity and support for the betterment of our overall community.

My "door" is open to you—don't hesitate to contact me at [eric\\_berning@ASAP.org](mailto:eric_berning@ASAP.org). We are in this together! As I always say, remember that you may have to live a life within limits, but you can lead a limitless life. That's my motto, and I'm sticking to it!

### Stamp Project

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

Please send cancelled postage stamps that are in good condition (attached to envelope and trimmed with a 1/4 to 1/2 inch border around undamaged stamp). Forever, special occasion and foreign stamps are accepted as well as postcards. Nonprofit, postage meter and presort stamps are not collectable.

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



**Please Note: Articles in this newsletter are not intended as a substitute for medical advice and do not necessarily represent the viewpoints of the editor, Medical Advisory Board or Board of Directors. Please contact your doctor before engaging in any new therapy or medication.**

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

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

# Outcomes Study Report

## INTRODUCTION

A grant provided by the American Syringomyelia & Chiari Alliance Project to study the outcomes in children undergoing posterior fossa decompression and duraplasty with and without tonsillar reduction for Chiari malformation type I and syringomyelia was a multicenter cohort study. Centers involved include:

- Department of Neurological Surgery, University of Wisconsin, Madison, Wisconsin; Joyce Koueik, MD, MS, Carolina Sandoval-Garcia, MD and Bermans J Iskandar, MD
- Department of Neurosurgery, University of Utah, Salt Lake City, Utah; John R W Kestle, MD
- Department of Neurosurgery, Children's of Alabama, Birmingham, Alabama; Brandon G Rocque, MD, MS, W Jerry Oakes, MD and R Shane Tubbs, PhD, PA-C
- Section of Neurosurgery, Department of Surgery, University of Chicago, Chicago, Illinois; David M Frim, MD, PhD
- Department of Pediatric Neurosurgery, Stanford Health Care, Palo Alto, California; Gerald A Grant, MD
- Department of Neurosurgery, Children's National Health System, Washington, DC; Robert F Keating, MD
- Department of Neurosurgery, Duke University Medical Center, Durham, North Carolina; Carrie R Muh, MD
- Department of Neurosurgery, UPMC Children's Hospital of Pittsburgh, Pennsylvania; Ian F Pollack, MD
- Department of Neurological Surgery, Oregon Health and Science University, Portland, Oregon; Nathan R Selden, MD, PhD
- Department of Neurosurgery, Johns Hopkins All Children's Hospital, Tampa, Florida; Gerald F Tuite, MD
- Department of Neurosurgery, Boston Children's Hospital, Boston, Massachusetts; Benjamin Warf, MD
- Departments of Biostatistics and Medical Informatics University of Wisconsin-Madison; Victoria Rajamanickam, MD and Aimee Teo Broman, MA
- Radiology, University of Wisconsin-Madison, Wisconsin; Victor Haughton, MD and Susan Rebsament, MD
- Department of Neurosurgery, Dell Medical School, Austin, Texas; Timothy M George, MD

## OBJECTIVE

Despite significant advances in diagnostic and surgical techniques, the surgical management of Chiari malformation type I (CM-I) with associated syringomyelia remains controversial, and the type of surgery performed is surgeon dependent. This study's goal was to determine the feasibility of a prospective, multicenter, cohort study for CM-I/syringomyelia patients and to provide pilot data that compare posterior fossa decompression and duraplasty (PFDD) with and without tonsillar reduction.

## METHODS

Participating centers prospectively enrolled children suffering from both CM-I and syringomyelia who were scheduled to undergo surgical decompression. Clinical data were entered into a database preoperatively and at 1–2 weeks, 3–6 months, and 1 year postoperatively. MR images were evaluated by 3 independent, blinded teams of neuro-surgeons and neuroradiologists. The primary endpoint was improvement or resolution of the syrinx.

## RESULTS

Eight clinical sites were chosen based on the results of a published questionnaire intended to remove geographic and surgeon bias. Data from 68 patients were analyzed after exclusions, and complete clinical and imaging re-records were obtained for 55 and 58 individuals, respectively. There was strong agreement among the 3 radiology teams, and there was no difference in patient demographics among sites, surgeons, or surgery types. Tonsillar reduction was not associated with > 50% syrinx improvement (RR = 1.22, p = 0.39) or any syrinx improvement (RR = 1.00, p = 0.99). There were no surgical complications.

## CONCLUSIONS

This study demonstrated the feasibility of a prospective, multicenter surgical trial in CM-I/syringomyelia and provide pilot data indicating no discernible difference in 1-year outcomes between F=PFDD with and without tonsillar reduction, with power calculation for larger future studies. In addition, the study revealed important technical factors to be an important consideration in future investigations.

To review the full report:

<https://thejns.org/doi/abs/10.3171/2019.8.PEDS19154>

## ABBREVIATIONS

ASAP = American Syringomyelia and Chiari Alliance Project;

CM-I = Chiari malformation type I;

PFDD = posterior fossa decompression;

PFDD = PFDD and duraplasty;

PFDD-T = PFDD with tonsillar reduction.

### Dr Timothy M George

On Sunday, November 10, 2019 it was with a heavy heart that we received the news of Dr Tim George's unexpected passing. He is a man that was openly admired and respected by many. A true friend to this organization, he was a blessing to the Chiari and Syringomyelia community. He will be greatly missed by all who knew him. A special presentation in his honor will be presented at the 32nd annual ASAP conference this July.

## How to Qualify for Social Security Disability Benefits with Syringomyelia

Syringomyelia is a condition in which the individual develops a fluid-filled cyst in the spinal cord. The cyst, also called a syrinx, may enlarge. This may cause damage to the spinal cord. It can result in a variety of symptoms, such as pain, stiffness, and weakness. The most common cause is Chiari, a malformation where brain tissue may protrude down into the spinal canal. It can also be the result of inflammation around the spinal cord, a spinal cord injury, or tumors either near or on the spinal cord. Some cases are mild and cause minimal symptoms, but other cases have severe symptoms, which may require surgical intervention.

The condition may develop slowly, especially when it was caused by an accident. Symptoms can include bowel functioning problems, bladder issues, muscle spasms, facial pain and numbness, curvature of the spine, and pain of the neck, arms, and back. It can lead to motor difficulties and chronic pain that makes performing daily tasks difficult – or even impossible. Usually, an MRI is required to confirm the diagnosis. When surgery is needed, it is done to relieve the pressure on the spinal cord. If you are unable to work because of the condition, you may qualify for disability benefits from the Social Security Administration (SSA).

### Meeting The Medical Criteria

The SSA uses a medical guide called the Blue Book. This book has sections for different systems of the body. Every section list conditions that may be disabling. Each of these has specific criteria that must be met for a claimant to qualify for disability benefits. Section 11.00 of the Blue Book refers to neurological disorders and Listing 11.19 of the Blue Book is used for syringomyelia claims. To be approved with this listing, you must meet at least one of these criteria:

- A diagnosis of syringomyelia with the loss of motor function in two or more extremities.
- Diagnosis of syringomyelia with significant signs of bulbar, which is a bulbous mass of tissue, which is the fluid-filled cyst in this case.

You will need to provide supporting medical documentation to have your claim approved.

### Using A Medical Vocational Allowance

If you cannot be approved using the Blue Book, you can still be approved with a medical vocational allowance that includes a thorough review of your medical records. This approach uses your medical conditions, symptoms, side effects, treatment plans, age, educational background, work history, and transferrable skills to determine if you are capable of working. A residual functional capacity (RFC) is filled out to indicate what you can do and to what extent.

### Applying For Disability Benefits

You can start the application process by calling 1-800-772-1213 and speaking with a representative, schedule an appointment at one of the 1,300 field offices located across the country or online at SSA.gov. Remember, documentation and hard medical evidence are needed for a successful disability claim.

### More on SSDI

<https://www.disabilitybenefitscenter.org/social-security-disability-insurance>

### Medical Vocational Allowance

<https://www.disabilitybenefitscenter.org/glossary/medical-vocational-allowance>

### Residual Functional Capacity

<https://www.disabilitybenefitscenter.org/glossary/residual-functional-capacity-rfc>

### SSA Field Offices

<https://www.ssa.gov/locator/>

## Arthrogram

Joints can go wrong in a lot of ways. You might fracture a bone, wear down cartilage or tear a ligament. Sometimes standard imaging, like an X-ray, doesn't show enough detail to pinpoint the problem. That is when you might need an arthrogram.

Also known as arthrography, it is another type of imaging that uses a contrast dye to detect problems such as unexplained pain. The doctor may check for a small tear in a ligament or for damage from dislocating a joint several times.

Risks include allergic reactions to the contrast dye, infection and radiation. It is best to avoid this test if you have a joint infection or arthritis that is acting up. If you are scheduled for this test be sure to tell your doctor about:

- All medical devices you have such as cochlear implants, pacemakers, and man-made heart valves
- Allergies to contrast dyes, iodine, medicines, latex and tape
- Medicines, herbs and supplements
- If you are pregnant or might be

## Relaxation Tips

### Breathe

We're not just talking about an automatic reflex but actually paying attention to your breathing. Count your breaths. If you are breathing too fast, slow it down. Try to average about six breaths a minute.

### Enjoy an Aquarium

If you don't own one, it could be a smart investment. You can start small but studies show watching fish swim can lower blood pressure and heart rate.



### Exercise

When you exercise, your body releases endorphins which can improve mood, help you to focus and even provide better sleep. Exercise should improve your life, not make you feel worse. Be sure to find a program that is right for you!

### Listen to Music

We've talked before about music therapy used in pain management. Focusing on the music not just having it in the background will take your mind off your own thoughts.

### Help Others

Helping others helps lower stress and loneliness. It can help you feel more connected to your community as well.

### Enjoy the Outdoors

Being around nature will help you feel more relaxed and refreshed. Spending time outdoors can bring down your heart rate, lower blood pressure, reduce stress hormones and even muscle tension.

### Practice Muscle Relaxation

It is a simple technique you can practice when you go to bed. Pick a part of the body and tense the muscles for a few seconds then relax them for about 10 or so. Move from section to section for your entire body. Not only can this improve sleep it may ease headaches.

### Hang Out With a Dog

When you pet and play with a dog, it seems to lower levels of stress hormones. If you do not have a pet, consider volunteering at a local shelter. It has not been studied as much but cats can also calm you.

### Guided Imagery

This is a simple exercise where you concentrate on your happy place. Focus on details like the smells and sounds. It can be real or imagined, like a beach at sunset, a comfy chair in front of a fireplace, or a stream in the forest.

### Get Creative

Activities like coloring books, knitting, scrapbooking, and pottery offer an escape for a busy mind. Simple, repetitive actions can help you redirect your thoughts and tune out the chatter in your head. The key is to enjoy the process and not worry so much about the result.

### Take a Break

Sometimes we just need to take 5 minutes to recharge and reset. When you find your mind racing full-speed, change your focus: stretch, daydream, walk around, get a snack, or chat with a friend. You'll be more centered and clear-headed.

### Plant a Garden

Did you know gardeners are less depressed and anxious? It's not just the great outdoors and the exercise. The soil itself has microorganisms that might help you focus and lift your mood.



Taking the time to relax can encourage the increase of blood flow to the muscles. This provides more energy, better metabolism and improves memory. Relaxation helps you to achieve a clear and calm mind. Your thought process is more positive and helps you in making better decisions.

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 person you would like to honor.

#### In Honor of Donor

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### In Memory of...

Dianne Marie Aguirre was diagnosed with Syringomyelia in the spring of 1975 at the age of 28, when her first son Ryan was 3 years old. She underwent her first surgery on her neck in the early summer of 1975, and after recovering, she and her husband Rey visited Opryland, New Orleans and finally Mexico City where she climbed the Pyramid of the Sun in April 1976. In September 1976, she had her second son Brandon. She never let on how much pain she was in.

Subsequent surgeries occurred every year until 1982, culminating in a stint placed in her spine that drained excess fluid from her spinal column and relieved the pressure on her neck and spinal cord. Shortly after that, we took our first family vacation to Jamestown, Virginia, Washington DC and to the World's Fair in Knoxville, Tennessee. We knew Mom was sick, but she barreled forward, determined to give us the normal childhoods we remember. For 35 years, she endured the excruciating pain and health complication of the early progress of her diagnosis and she did it all with a smile, all while she and Rey raised two healthy boys. She went to Ryan's basketball and football games, track and wrestling meets. She took Brandon to gymnastics practice and out of town gymnastics meets. She also took yearly vacations with the whole family, never letting on how much everything hurt.

The early years were very rough on her, but within her bloomed a tenacity and perseverance that is rarely seen in a person. She took things one day at a time. Her progression mostly leveled off and we simply knew her as a mom, one who loved everyone deeply and would go out of her way for anyone in need.

The later years were not so kind. Despite all the injuries, hospital visits, doctor's appointments and medication, she lived fully, traveled often and saw places far and wide. She required of herself the ability to do what must be done to live.

Then, two years ago, the valve connected to her stint stopped working and the progression began again in earnest. She never told us. We saw it but didn't see it, lulled into a complacency that she'd always be there due to her sheer force of will, her indomitable spirit. We didn't know how good we had it, having her in our lives. But she was loved immensely and everyone feels the void. Syringomyelia may have finally won but only after Dianne fought, lived and loved for 73 years.

## Chicago Attractions and Entertainment

Chicago is home to:

- 26 miles of lakefront with 25 beaches.
- More than 8,800 acres of green space and 600 parks; the Chicago Park District is the largest municipal park manager in the nation.
- Over 200 miles of bike lanes, 19 miles of lakefront bicycle paths, and more than 13,000 bike racks and parking areas.
- 580 Divvy bike share stations and 5,800 Divvy bikes across the Chicagoland area.
- Art on theMART, the longest-running and largest permanent digital art installation in the world.
- One of the largest collections of Impressionist and Post-Impressionist paintings outside of Paris, housed at the Art Institute of Chicago.
- More than 500 public works of art displayed in over 150 municipal facilities around the city as part of the City of Chicago's Public Art Program. These works include installations by Picasso, Chagall, Miro, and Calder.
- Approximately 60 museums, nearly 200 art galleries, and 20 neighborhood art centers.
- More than 250 theatres, 225 music venues, and 200 dance companies.
- More than 7,300 restaurants and 167 breweries in the Chicagoland area — the most breweries of any metropolitan area in the nation.
- Seven free downtown and lakefront major music and dance festivals, more than 30 food festivals, over 400 neighborhood festivals, and more than 40 film festivals annually.
- The starting point of "Historic Route 66" at Grant Park on Adams Street in front of the Art Institute of Chicago.
- The Museum of Science and Industry is the largest museum of its kind in the Western Hemisphere. FYI: The museum is housed in the only remaining building constructed for the 1893 World's Columbian Exposition's "White City." It was originally built as the exposition's Palace of Fine Arts.
- Máximo the Titanosaur, the largest dinosaur known to man, and SUE, the largest and most complete T.rex specimen in the country, at the Field Museum of Natural History.
- The Chicago Cultural Center, built in 1897, which originated as the city's first public library, and became the first free municipal cultural center in the United States. FYI: The Center is home to the world's largest stained glass Tiffany dome.
- Lincoln Park Zoo, one of the oldest zoos in the country, and one of the few remaining free zoos in the U.S.
- Willis Tower (formerly Sears Tower) is the second-tallest building in the Western Hemisphere. FYI: Willis Tower held first place until the construction of New York's One World Trade Center in 2014. Also, the Willis Tower elevators are among the fastest in the world, operating at speeds as fast as 1,600 feet per minute.
- Wrigley Field (1914) is the second oldest ballpark in Major League Baseball.
- Approximately 16 examples of Frank Lloyd Wright designs in the city of Chicago, and a further 25 in nearby Oak Park. FYI: Frank Lloyd Wright's Prairie School of architecture originated in Chicago.



### Contact Information

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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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