

September is Chiari Awareness Month

What are Chiari malformations

Chiari malformations are structural defects in the base of the skull and cerebellum, the part of the brain that controls balance. Normally the cerebellum and part of the brain stem sit above an opening in the skull that allow the spinal cord to pass through it (called the foramen magnum). When part of the cerebellum extends below the foramen magnum and into the upper spinal canal, it is called a Chiari malformation (CM).

CMs may develop when part of the skull is smaller than normal or misshapen, which forces the cerebellum to be pushed down into the foramen magnum and spinal canal. This causes pressure on the cerebellum and brain stem that may affect functions controlled by these areas and block the flow of cerebrospinal fluid (CSF)—the clear liquid that surrounds and cushions the brain and spinal cord. The CSF also circulates nutrients and chemicals filtered from the blood and removes waste products from the brain.

What causes these malformations?

CM has several different causes. Most often it is caused by structural defects in the brain and spinal cord that occur during fetal development. This can be the result of genetic mutations or a maternal diet that lacked certain vitamins or nutrients. This is called primary or congenital Chiari malformation. It can also be caused later in life if spinal fluid is drained excessively from the lumbar or thoracic areas of the spine either due to traumatic injury, disease, or infection. This is called acquired or secondary Chiari malformation. Primary Chiari malformation is much more common than secondary Chiari malformation.

How common are Chiari malformations?

In the past, it was estimated that the condition occurs in about one in every 1,000 births. However, the increased use of diagnostic imaging has shown that Chiari malformation may be much more common. Complicating this estimation is the fact that some children who are born with this condition may never develop symptoms or show symptoms only in adolescence or adulthood. Chiari malformations occur more often in women than in men and Type II malformations are more prevalent in certain groups, including people of Celtic descent.

How is Chiari Diagnosed

Chiari malformations can be difficult to diagnose, since the symptoms can vary, or there may be no symptoms at all. A definitive diagnosis is generally made after an MRI scan, where the abnormal protrusion of the cerebellum toward the spinal cord can be seen. In some cases, the diagnosis may be incidental, meaning that a patient who undergoes an MRI scan for another reason may be diagnosed with Chiari when the scan reveals the abnormality – in these cases the patient may not have experienced any symptoms.

Anyone who receives a tentative diagnosis of Chiari should always be referred to a neurosurgeon, who will conduct an evaluation and recommend a course of treatment.

In addition to an MRI scan of the brain, an MRI of the entire spinal column is useful. In some patients with Chiari, a cyst (known as a syrinx or syringomyelia), forms within the spinal column. Symptoms of leg numbness or scoliosis are more likely when a syrinx exists. There are also special MRI studies that can measure the direction and degree of fluid motion around the Chiari malformation. This MRI can help in the decision-making process regarding treatment.

To diagnose your condition, your doctor will review your medical history and symptoms and conduct a physical examination. He will also order imaging tests to determine the cause of your condition and make a diagnosis.

Tests may include:

- Magnetic resonance imaging (MRI) uses powerful radio waves and magnets to create a detailed view of your body. This safe, painless test produces detailed 3-D images of structural abnormalities in your brain that may be contributing to your symptoms. It can also provide images of your cerebellum and determine whether it extends into your spinal canal. An MRI can be repeated over time, and it can be used to monitor the progression of your disorder.
- Computerized tomography (CT) scan. Your doctor may recommend other imaging techniques such as a CT scan. A CT scan uses X-rays to obtain cross-sectional images of your body. A CT scan can help to reveal brain tumors, brain damage, bone and blood vessel abnormalities, and other conditions.

Chiari Awareness

September is Chiari Awareness Month! Do something special during the month to promote awareness of Chiari! Take photos of your event or project and email to the ASAP office (info@ASAP.org).

Suggestions for promoting awareness:

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

Contact Information

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Alliance Project

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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

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



A Word From Our President

Eric J Berning

Greetings all,

We are coming into my favorite time of the year, FALL. The leaves change, we get cooler weather, and watching football returns to my weekends! Having been born and raised in Ohio, I have a fondness for THE Ohio State Buckeyes and the Cleveland Browns. Both teams have a long and beloved pigskin history, and one of them is (finally!) on the precipice of returning to that historic level of greatness. While I never played football myself, I have always loved the sport.

Why do I bring up football in an article for the ASAP newsletter? Well, for one, it's that time of the year and I love the sport! And two, it's a TEAM sport and a perfect analogy for our organization...just follow me here...

There are three separate "teams" that comprise a football team: the Offense, the Defense, and Special Teams. If you watch the sport you will notice that teams that lack a solid foundation in each of these three critical areas typically don't perform as well as the ones that have developed, employed, and strengthened theirs. The New England Patriots is an organization that consistently elicits very strong, effective results from each of their teams' components. Tom Brady and the Offense are formidable, the Defense dominant, and Special Teams can be relied upon to both create field advantages for the Offense and put points on the board by rarely ever missing a field goal opportunity. Time and again, each component wields impressive individual strength, but combines that strength to work together for that common goal, to bring home a "W."

So how is that related to ASAP and Chiari/Syringomyelia? ASAP is, truly, a historic team. At over thirty years, we are the oldest organization in the USA that funds research, education, and support for these conditions. Over the years we have chased the "Trophy" (A Cure), and yet it still eludes us. But, through it all we continue, wipe the sweat from our brows, and cheer for our small victories.

As the President of the Board of Directors I'm kind of the "General Manager" of the team. I help direct ASAP's game plan with the strategic advice of our team's "Coaching Staff" (the Board, Staff and the Medical Advisory Board). I get to lead the conversation on how the team's resources are deployed to "win" (research, education, and support) and determine whose strengths are best-suited for each of our organization's Offense, Defense, and Special Teams

(the various committees that contribute to the overall effectiveness of ASAP). But I'm not doing this alone—in fact, I'm just a small cog in the greater whole. To truly be successful, we all work in conjunction, recognize each other's contributions, and continue to recruit new "players" (you!).

The ASAP team needs you. We have a wonderful Board of Directors, Staff and Medical Advisory Board, but just like our favorite sports teams, we are always looking for fresh talent. We have multiple opportunities for you to join us. As with any team, not everyone can be a coach or a player—like me with football, some of us can only be fans. Does that make the fans any less important? Heck no! What's a great team without loyal fans? My Browns wouldn't be the team they are without us "diehards"! The same goes for ASAP. We are the powerhouse we are because of our Members! So consider this a call for all Fans, Players, and Coaches to step up and step forward to let me know how you want to participate in our team's success. Would you like to be a:

- Coach: Apply to Join the Board or head up a committee, help call the plays (direct the future of ASAP).
- Player: Join a committee (Defense), lead a support group (Offense), or head up a fundraiser (Special Teams) and help us win every game.
- Fan: Continue to get out there and support the team by raising funds, donating time or monies, wear the "team jersey" (i.e., create awareness), etc.

Let us know how you want to participate. Applications for the Board and Committees are available online or from the ASAP office and are regularly reviewed and considered by the Board of Directors. (Please keep in mind that if you are not selected to fill a coach or player position, you are still very important to our team, and our success would not be possible without you!)

As always, "You may have to live your life within limits, but you can still lead a limitless life!"

Let's get this season rolling!
Eric Berning, President

<https://ASAP.org/index.php/volunteer/>

Duke DMPI Research on CM1/S

The Duke Molecular Physiology Institute (DMPI), formerly the Duke Center for Human Genetics, is investigating the hereditary basis of Chiari type I malformation with or without syringomyelia (CM1/S). Our research is aimed at learning if CM1/S is indeed caused by factors inherited through the family and, if so, which genes are involved. The long-term goal is to find out how these genetic factors cause or contribute to CM1/S, with the hope that this knowledge will lead to improved diagnosis and more effective treatments.

Several lines of evidence point to a genetic contribution to CM1/S. This evidence includes families with multiple individuals all diagnosed with CM1/S. Observations of identical twins (genetically the same) have shown that if one twin is diagnosed with CM1/S, the other twin often also has CM1/S. Finally, CM1/S is known to co-occur with a number of different genetic syndromes.

This research has been supported in part by grants from the National Institutes of Health, Bobby Jones Open Fund, American Syringomyelia & Chiari Alliance Project (ASAP), Chiari & Syringomyelia Foundation (CSF) and Conquer Chiari.

Publications Chiari Type 1 Malformation/Syringomyelia

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CM1/S Study Participation

The DMPI is actively recruiting families who have TWO OR MORE family members with CM1, with or without syringomyelia. They must be related by blood, and BOTH must be willing to participate.

Study participation involves these steps:

- Contact the study coordinator.
- Provide blood samples from family members both with and without CM1.
- Answer questions about family and medical history.
- Complete a medical questionnaire.
- Review of medical records and MRIs to confirm the diagnosis of CM1.
- Potentially ask other degree family members to participate in the study.

If your family meets the criteria and is willing to participate in the study, please contact the study coordinator.

CM1/S Study Coordinator
E-mail: chg_chiari@dm.duke.edu
Phone: (919) 684-0655

How are Chiari Malformations Classified?

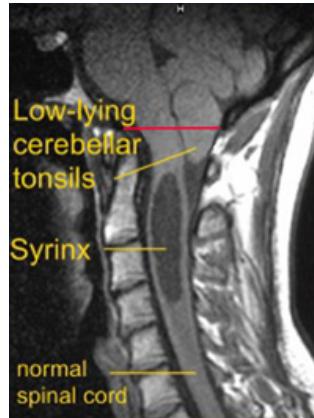
Chiari malformations are classified by the severity of the disorder and the parts of the brain that protrude into the spinal canal.

Chiari malformation Type I

Type 1 happens when the lower part of the cerebellum (called the cerebellar tonsils) extends into the foramen magnum.

Normally, only the spinal cord passes through this opening. Type 1—which may not cause symptoms—is the most common form of CM. It is usually first noticed in adolescence or adulthood, often by accident during an examination for another condition.

Adolescents and adults who have CM but no symptoms initially may develop signs of the disorder later in life.



Chiari malformation Type II

Individuals with Type II have symptoms that are generally more severe than in Type 1 and usually appear during childhood. This disorder can cause life-threatening complications during infancy or early childhood, and treating it requires surgery.

In Type II, also called classic CM, both the cerebellum and brain stem tissue protrude into the foramen magnum. Also the nerve tissue that connects the two halves of the cerebellum may be missing or only partially formed. Type II is usually accompanied by a

myelomeningocele—a form of spina bifida that occurs when the spinal canal and backbone do not close before birth. (Spina bifida is a disorder characterized by the incomplete development of the brain, spinal cord, and/or their protective covering.) A myelomeningocele usually results in partial or complete paralysis of the area below the spinal opening. The term Arnold-Chiari malformation (named after two pioneering researchers) is specific to Type II malformations.

Chiari malformation Type III

Type III is very rare and the most serious form of Chiari malformation. In Type III, some of the cerebellum and the brain stem stick out, or herniate, through an abnormal opening in the back of the skull. This can also include the membranes surrounding the brain or spinal cord.

The symptoms of Type III appear in infancy and can cause debilitating and life-threatening complications. Babies with Type III can have many of the same symptoms as those with Type II but can also have additional severe neurological defects such as mental and physical delays, and seizures.

Chiari malformation Type IV

Type IV involves an incomplete or underdeveloped cerebellum (a condition known as cerebellar hypoplasia). In this rare form of CM, the cerebellum is located in its normal position but parts of it are missing, and portions of the skull and spinal cord may be visible.

[“Chiari Malformation Fact Sheet”, NINDS, Publication date June 2017. NIH Publication No. 17-4839]

How Can I Find a Chiari Specialist?

The American Association of Neurological Surgeons (AANS) does not recognize Chiari as a sub-specialty. However most neurosurgeons are easily found in a google search. See if they list Chiari as a speciality.

Each person must find a doctor they are comfortable with. Don't be afraid to ask them how many Chiari surgeries they do a year, are they involved in Chiari clinical trials or stay up-to-date on research. Read their on-line bio and check patient reviews. Everyone is different and will have different needs, so find the doctor who works best for you!

Thank You
American Syringomyelia
& Chiari Alliance Project's
31st Annual Conference
Speakers!

Remember ASAP...

When It's Time to Remember Loved Ones

Our appreciation to everyone who made a recent donation to ASAP on behalf of their friends and loved ones.

We will send an acknowledgement card to individuals or families when you make a \$5 (or more) donation to the organization. Please indicate whether the gift is 'in honor of' or 'in memory of' and provide name and mailing address of the recipient.

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Bits and Pieces

2019 conference videos are available online at www.asap.org. Click on the YouTube icon in the upper right corner which will take you to our YouTube channel. Click on videos in the menu bar.

ASAP began as a grassroots organization in the White's spare bedroom due to the frustration they encountered when Barbara was diagnosed with syringomyelia. Since then, ASAP has grown tremendously but our fundamental goals of research, education and support remain the same.

ASAP holds an annual conference in a different geographical location each year. Sites are determined by the availability of a volunteer host, previous year location and available speakers in the area.

ASAP.org has over 2,000 pages of information about Chiari, Syringomyelia and related disorders.

ASAP was incorporated in 1988 and held its first conference in Colorado Springs, Colorado the following year.



Together Making Changes

Together Making Changes a 501(c)(3) organization created for the purpose of supporting initiatives of interest to TMC team members, residents and patients presented ASAP with a special donation check on August 21 in Longview, Texas.

Heather Guin, Senior Director of Claim Integrity, traveled from Minden, Louisiana to make the presentation. Pictured with Heather are Patrice Schaublin, ASAP Executive Director; Patricia Maxwell, Operations Director; and Eric Berning, ASAP Board of Directors President.

Related Disorders/Conditions of Chiari

Arachnoiditis

Inflammation of the arachnoid membrane in the spinal canal, it can be caused by trauma, spinal surgery, hemorrhage or infection. It can result in severe pain.

Basilar Invagination

A condition in which a portion of the C2 vertebra (called the odontoid) compresses the brain stem.

Ehlers-Danlos Syndrome

A group of inherited disorders marked by extremely loose joints, hyperelastic skin that bruises easily, and easily damaged blood vessels.

Hydrocephalus

A buildup of fluid in the ventricles of the brain. This condition is usually treated by placing a ventricle-peritoneal shunt to drain the fluid.

ICP (Intracranial Hypertension, Pseudotumor Cerebri)

Increased intracranial pressure can be due to a rise in cerebrospinal fluid pressure. It can also be due to increased pressure within the brain matter caused by a mass (such as a tumor), bleeding into the brain or fluid around the brain, or swelling within the brain matter itself.

An increase in intracranial pressure is a serious medical problem. The pressure itself can damage the brain or spinal cord by pressing on important brain structures and by restricting blood flow into the brain.

Many conditions can increase intracranial pressure.

Nystagmus

Nystagmus is a vision condition in which the eyes make repetitive, uncontrolled movements. These movements often result in reduced vision and depth perception and can affect balance and coordination. These involuntary eye movements can occur from side to side, up and down, or in a circular pattern.

Spina Bifida

The incomplete closing of the backbone and membranes around the spinal cord. In babies with spina bifida, the bones around the spinal cord do not form properly, causing defects in the lower spine. While most children with this birth defect have such a mild form that they

have no neurological problems, individuals with Type II Chiari malformation usually have myelomeningocele, and a baby's spinal cord remains open in one area of the back and lower spine. The membranes and spinal cord protrude through the opening in the spine, creating a sac on the baby's back. This can cause a number of neurological impairments such as muscle weakness, paralysis, and scoliosis.

Scoliosis

There are many types and causes of scoliosis, including:

- Congenital scoliosis. Caused by a bone abnormality present at birth.
- Neuromuscular scoliosis. A result of abnormal muscles or nerves. Frequently seen in people with spina bifida or cerebral palsy or in those with various conditions that are accompanied by, or result in, paralysis.
- Degenerative scoliosis. This may result from traumatic (from an injury or illness) bone collapse, previous major back surgery, or osteoporosis (thinning of the bones).
- Idiopathic scoliosis. The most common type of scoliosis, idiopathic scoliosis, has no specific identifiable cause. There are many theories, but none have been found to be conclusive. There is, however, strong evidence that idiopathic scoliosis is inherited.

Tethered Cord

A condition where scar tissue forms and tethers, or holds, the spinal cord to the dura, the soft tissue membrane that surrounds it. This scar tissue prevents the normal flow of spinal fluid around the spinal cord and impedes the normal motion of the spinal cord within the membrane.

Syringomyelia

A disorder in which a CSF-filled tubular cyst, or syrinx, forms within the spinal cord's central canal. As a syrinx expands it can cause damage to the central nervous system, resulting in pain, weakness, and stiffness in the back, shoulders, arms, or legs. Other symptoms may include a loss of the ability to feel extremes of hot or cold, especially in the hands. Some individuals also have severe arm and neck pain. These are the most recognized symptoms but keep in mind there are others that some doctors might not be aware of at this time.

Editor's Note: Although these are some of the more common disorders that may accompany Chiari malformations, the list is not complete. Also keep in mind not all conditions may be related as individuals can have one without the other.



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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