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Linc 101 Cultivating Main Character Energy

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EXPLORATION OF CHIARI MALFORMATION

Background

If you have ever observed an MRI of the cranium, you see there is a gap at the base of the skull, in which the brain rests upon the foramen magnum (latin for “great hole”). Chiari Malformation (CM) is a rare neurological condition which causes your brain to grow abnormally large compared to most brains, which makes it grow through the opening of your skull. If you look at an MRI of the brain with Chiari, you see that the cerebellar tonsils grow into the spinal canal. This causes severe pressure on the spinal cord, causing the spinal fluid to back up in the brain which can lead to severe headaches, seizures, and/or dizziness.

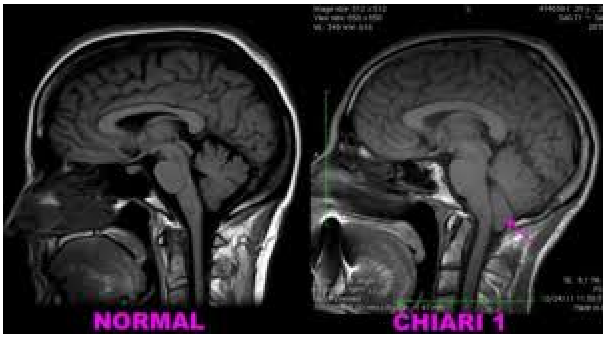

Image showing a brain without Chiari (left) and a brain with Chiari (right)

With this condition, comes a wide array of symptoms. The most common symptoms being occipital headaches (pain at the base of your skull), dizziness, fatigue, hearing problems , vision problems, sleep apnea, balance problems, and neck pain. You can either be born with Chiari Malformation or develop later on in life as a result of trauma to the head. There are four types of CM, today we will specifically discuss CM type I.

Chiari Malformation became a recognized medical condition in 1891 by Dr. Hans Chiari. Later named after him. CM I was first found in the autopsy of a 17 year old female who died from typhoid fever who also suffered from a hydrocephalus (cerebrospinal fluid leak in the brain's ventricles). Although there were no symptoms related to the cerebellum or medulla, the malformation found was "peg-like elongation of tonsils and medial divisions of the inferior lobes of the cerebellum into cone shaped projections, which accompany the medulla oblongata into the spinal cord." (Chiari 1172). Julias Arnold was also a part of the research which led Arnold and Chiari to find that this condition was complex and pathological. (Kular/Cascella).

With Chiari, you could also develop, or be born with, other disorders like spina bifida, syringomyelia, scoliosis, and multiple sclerosis (M.S.) All of these disorders are related but not linked together. Syringomyelia is a fluid filled cyst in the spinal cord, also known as a syrinx. These sacks can grow over time, causing damage to the cord leading to pain, dizziness, and weakness.(Mayo Clinic). Someone can be born with syringomyelia, and develop chiari while others can be born with chiari and develop syringomyelia. Though it is rare for this to happen, some people can be born with both chiari and syringomyelia, like me.

Statistics

Statistics show roughly 1 in 1000 people in the United States have a type of Chiari Malformation, most of the time it is CM I. The ratio of female/male with chiari is 1.3 to 1, female lead. It is also shown that approximately 10% of CM patients have Hydrocephalus. (Kular/Cascella). Similar to CM, Hydrocephalus can be fatal if it isn't treated. Things that can cause hydrocephalus are brain or spinal cord tumors, bacterial meningitis/ bleeding in the brain, or other traumatic injury to the brain. Some of the complications from Hydrocephalus can be learning, developmental, and/or physical disabilities.(Mayo Clinic). Syringomyelia is found in 20% to 85% of all CM1 cases. In up to 71% of symptomatic patients, there is a cervicomedullary “kink” found with MRI imaging. The cervicomedullary junction is where your brain meets your spinal cord.(Mayo Clinic)

My Background

There are a few treatments for CM but the ones we will discuss are different medications, therapy, and surgery. For instance, everything I have done to treat my CM1 ranges from different doctor appointments, many different medications, therapy (mental and physical), and unfortunately, I had to get two decompression surgeries. In the beginning, before being diagnosed with CM, I had seen multiple different doctors but none of them helped. It was until I saw Dr. Katherin Taub, a pediatric neurologist out of CHOP (Children’s Hospital Of Philadelphia). She had ordered an MRI to find answers as to why I had severe migraines, dizziness, and syncope. Dr. Taub later found my CM in the images. After being diagnosed with CM, I was prescribed Migraleif, but I was rushed into surgery because I had little to no cerebral spinal fluid flowing, which is extremely bad. I then went to see Dr. Shih-Shan Chen who performed my first CM decompression surgery.

After the surgery, Dr. Taub prescribed Gabapentin for migraines and nerve pain. I went about 1 year until my second surgery. I needed another surgery because the first surgery didn’t fully work, due to the fact that only half of my CM was removed, which didn’t help much. I still suffered from migraines, dizziness, syncope, but then I was discovering new symptoms, like shakey eyes. All of my symptoms came back after my first surgery but heightened, like I didn;t have the surgery in the first place. A year later, I had my second surgery at Weill Cornell Medical Center, in Manhattan, performed by Dr. Jeffrey Greenfield. After the second surgery, I was diagnosed with Postural Orthostatic Tachycardia Syndrome (POTS). With this diagnosis came more medications. As of right now, all together I take Levison, Cyproheptadine, Migrelieg, Vitassium, CoQ10, Collagen, Vitamin D3, and Atomoxetine, plus the medications I take for my mental health. All of these medications help my Chiari Malformation, POTS, and my stomach issues. I was diagnosed with Chiari Malformation 1 when I was 14, I had my first surgery when I was 15, then I had my second surgery when I was 16. Now, I am four months shy of 19 years old, living with Chiari Malformation type 1 among many other disorders.

Treatments

As was mentioned above, there are different treatments for Chiari Malformation, some people can go their whole lives without needing surgery, they might just need to take medications. There are multiple different facilities with programs centered around Chiari. For example, Weill Cornell has a program called Chiari Care Program, it has articles on different chiari cases, some medications they recommend, the different treatments they offer, ect. The main goal for Weill Cornell's Chiari Care Program is "address your individual medical and surgical goals. Evaluations and treatment at Weill Cornell Medicine Chiari CARE may also involve neurology, radiology, pain nutrition, management, ophthalmology, neuro-ophthalmology, ENT, sleep medicine, neuropsychology, genetics and/or immunology." The Chiari Care specialists recommend patients become educated with their disorder to better understand what they are going through. (Weill Cornell Medicine).

The surgery that is performed on Chiari patients is called a Chiari Decompression, the surgeon goes in and lazer's off the part of your brain that grows into your spine, sometimes they have to remove a part of your neck as well. For instance I had to have a Suboccipital Craniectomy for intradural Chiari Decompression with a C1 Laminectomy and duraplasty, all at the same time. Most patients don't have all these done. They usually have the decompression but mine was so severe that they had to do all of those surgeries together. Roughly 27.8% of chiari patients need a laminectomy, 28.3% of chiari patients need a decompression, and 2.2% of chiari patients need a spinal fusion.("Timing to surgery of Chiari malformation type 1 affects"). The surgery depends on the severity of the malformation. If the medications don't help, then you are told to try therapy, if that doesn't help, the last resort is surgery.

Resources

The top three resources recommended for Chiari patients is Weill Cornell MEdical Center, specifically Dr. Greenfield and his team, the UCLA Chiari and Syringomyelia Program, and CHOP Chiari Clinic. Weill Cornell was mentioned in above statements, so we won't discuss them much more. UCLA's Chiari and Syringomyelia Program is based in Los Angeles, California. They offer diagnostic and state-of-the-art treatment options. The specialists involved with this program have treated over 1,000 patients over the last twenty years. The program uses a team approach with dr from different specialties such as, neurology, neurosurgery, and rehabilitation. They have three high-resolution Tesla MRI scanners.(UCLA Health).

CHOP offers advanced care for all children/teens suffering from Chiari Malformation. They offer a full day experience where you meet with every doctor in their multidisciplinary program. They assess you with physical exams and they do MRI and CT imaging all on the same day. Their doctors get together and share everything each of them saw and will come back to you with a result and a care plan they think is best for you. They see every child with Chiari symptoms/diagnoses, this includes children who have not previously been seen at CHOP or those who need a second opinion. CHOP tries to use the least invasive approach when it comes to assessing your child.(CHOP Chiari Clinic).

Conclusion

Chiari Malformation is a highly invasive neurological disorder, causing severe symptoms like dizziness, migraines, and syncope. It is a rare condition that isn't well known. My mission is to spread awareness around the world, find others who suffer like I did for years and help them. I was a young teenager who loved sports, nature, and care-free activities. You might have called me a daredevil. When I started developing symptoms of Chiari, my whole life changed. I was outgoing and loud, but then I became a quiet introvert who slept all the time. I loved to wrestle and that dream was taken from me when I was told I was never able to participate in wrestling or any other physical sport because I could risk being paralyzed. Now, I have to live with the fact that at any given moment, I could get severely hurt and possibly paralyze myself. I live in fear of what would happen if I just so happen to get a paper cut. Chiari took away my childhood and I don't want Chiari to take away anyone else's life the way it did to me. There is no cure right now, but with the awareness that I spread, I believe we *will* find a cure. Every resource and treatment that was discussed in this paper, will be shared throughout the world, shining new light on the topic. People who suffer from this won't feel alone anymore. They will have the support system and resources that I didn't realize I had until after surgery.

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