

Sept. 15, 2021

Dear News Reporters —

I have a story that I think you may be interested in—which could also help other children and adults in the Brazos Valley. Next Month, October, is AVM Awareness Month. According to the Brain Foundation, AVMs occur in approximately 3 out of every 10,000 people. They are rarely genetic (it is a random thing that happens during fetal development) and bleeding from a Brain AVM most often occurs between the ages of 10 and 30. The average age of rupture is 17 years old. Approximately 10% of cases which have hemorrhage as the first symptom are fatal. A Brain AVM is the most common reason in children for having a brain bleed not caused by trauma. I had no idea what a Brain Arteriovenous Malformation (AVM) was — I had never even heard of it, until my family's life changed forever on April 10, 2020.

On April 10, 2020 my son, College Station High School Student Kyler Lewis, was riding in the car with me on HWY 6 at Rock Prairie Road when he turned to me very confused. He told me he didn't know where he was or how he got in the car and all of a sudden his head hurt very, very badly and his vision was blurry. Suddenly, he couldn't remember anything for more than a few seconds. Scared of COVID-19 at the time, I rushed him to the pediatrician who was near by. The pediatrician diagnosed Kyler with an acute migraine headache, gave him a shot, and told me I should take him home and put him to bed. I had personally had a migraine before, and this didn't seem right, so I asked the nurse to have the pediatrician to come back in the room after the shot was given and look at Kyler again. I then called my husband and we made the decision for me to drive Kyler, who was 15 at the time, to Texas Children's Hospital in the Woodlands for a 2nd opinion. We arrived 1.5 hours later and, by this time, Kyler was in what they medically called a “severely altered mental state.” I kept insisting to the ER Staff he was not a teen on drugs; he was not that kind of kid. There was something very, very wrong with my son!

A brain CT scan revealed my son was bleeding in his brain and required emergency transportation to Texas Children's Main hospital for brain surgery to stop hydrocephalus (brain swelling) from damaging my son's brain. He was diagnosed with an Acute Spontaneous Intracranial Hemorrhage. I never knew this was a thing—that kids could suffer from a ruptured vessel in their brain (like an aneurysm) which you hear about with much older people who suffer from a stroke. But IT IS something parents should know exists and should be aware of the symptoms to look out for.

We had always thought Kyler was perfectly normal and healthy. He passed every yearly wellness exam with flying colors, was always signed off on by doctors to participate as he wished in sports; he had never even had a headache a day in his life. The night of April 10th, however, we discovered our son was born with an Arteriovenous Malformation (Brain AVM) and it had ruptured. An MRI later revealed Kyler's AVM is inoperable. It is a Spetzler-Martin grade 5 in the Parietal/Occipital lobe of his brain. It is about the size of a hen's egg. (Photos included.) Brain AVM's are graded from 1-5. They are called “Ticking Time Bombs” by the medical community because they can rupture at anytime.

My son has undergone 3 rounds Gamma Knife Brain Radiation to treat his AVM. He is one of the lucky who survived his first brain hemorrhage and has almost fully recovered from the bleed. You would not know by looking at him or talking to him that he has this life-threatening condition. When Kyler woke up after the first procedure when he initially had the bleed, he suffered from memory loss. It was very hard because he would ask where his dad was, but because of COVID-19, they would only allow one parent in the hospital and you could change parents only every 4 days in ICU. The 2nd day after the bleed, I ordered Kyler some Lucky Charms from the hospital menu. I was trying to get him to eat and talk. I said, "What is this?" And held up a star marshmallow. "A Star!" I said. I then ate it and held up a diamond Marshmallow and said "What is this, A Diamond!" The Third marshmallow I held up was a heart. "What is this?" I said. but before I could reply, Kyler said "A Butt!" It did, in fact, look like a small pink butt, and Kyler smiled. I saw his personality return. It was at that moment — I knew — my 15 year old's brain was still okay. The brain swelling was going down, the bleeding had stopped with very minimal leakage to the surrounding tissue and my son was back. The doctors could not believe how fast and fully he recovered. They said he is a walking miracle. Unfortunately, when Kyler left the ICU 8 days later, his Brain AVM remained untreated.

Kyler is now working on recovering from the effects of the Gamma Knife Radiation treatment he started August 28th, 2020 with the last round March 24, 2021. His dad and I traveled with him to San Francisco, California for each treatment at UCSF because finding someone with experience at *successfully* treating large pediatric Brain AVM's has proven very difficult. Renowned places like Texas Children's Hospital and the Mayo Clinic told us they didn't want to treat Kyler because Kyler's AVM was so large and surrounded by "eloquent" (important for functioning) brain tissue. I created a "Doctor Information and Treatment Recommendation" PDF that became so extensive it caught the attention of "The Aneurysm and AVM Foundation." Kyler met with over 16 neurosurgeons throughout the United States and 1 even from overseas in Germany, before we decided on a course of action for treatment. (This has been one of the few blessings created by COVID-19—Telemedicine doctor appointments.) Kyler's first brain surgery was 18.5 grays of radiation for several hours to 1/3 of his AVM. Two more radiation treatments followed each one 3 months apart. He has neuro-fatigue so he is considered intermittent Homebound. He goes to College Station high school on days he can, and works from home when he is too tired or the headaches too great. Brain AVM's are tricky. Each one is unique — like a snowflake. You can choose to treat or choose to not treat and still have the possibility of ending up with the same outcome. It has all been very hard for a now 17 year old, to process and accept. Kyler knows what he can lose, and he is so very grateful for every day he has.

We have been told that the best hope for Kyler, and other's like him, is through research for a cure that has not yet been discovered. It is has been very hard for charities to raise money for research with everything happening with COVID-19. In 2020, Kyler was a top fundraiser for the Aneurysm and AVM Foundation raising \$5,844.00. He also raised 5,000 for the AVM research foundation. This year, he is participating with Century 21 in an "Awareness Walk" (with the help of Aggieland Outfitters) selling shirts that say: "*On rough days, I remind myself*

my record for getting through bad days so far is 100% and that's pretty good.” It is a tough road to be diagnosed with a rare disease at age 15 and we are so, very, very proud of him.

Kyler reaches out when we find parents of other children online who suddenly find themselves in the hospital with this diagnosis— so they know they are not alone. He has sent "get well" videos, blankets and socks (because he was always cold in the hospital) and even his AVM Awareness t-shirts to other children diagnosed with AVM ruptures. It all started when he reached out to the mom of a boy, his age, who did not survive their brain AVM rupture. The mom sent Kyler an Amazon gift card with the sweetest letter thanking Kyler for reaching out, and he turned around and used the card to send things to other kids who are recovering AVM survivors. Even with his medical diagnosis and situation, Kyler is trying to help others however he can.

Kyler has a Facebook page created to tell his story and the story of other survivors (as well as of those that do not survive) and provide information on doctors, treatment options, bring awareness of this condition and more. (<https://www.facebook.com/groups/cure4kyler>) It is a community of support that has grown and helped Kyler so very much. It is called “A Cure for Kyler” and the support of our local community has helped Kyler unimaginably. He actually told the doctors right before his first Gamma Knife Procedure that he thought he could go through the Brain Radiation, and do well, because he had such support behind him and so many people praying for him — that he had hope because he never knew this kind of support for him could possibly exist. People here in BCS we barely knew sent Kyler food via grub hub in California while in the hospital’s “Family House” as well as and notes, letters and well-wishes to Kyler, both before and after his radiation treatment trips. The community of support makes such a difference to his outlook! Even people in California, from Kyler’s Facebook page, met us when we arrived in San Francisco and helped our family. Kyler spent the entire day before his surgery with a boy his age named Andrew who had also had a bleed and gone through Gamma Knife Treatment. The local BCS community made sure Kyler knew he was being thought of and prayed for during his radiation treatments and our wonderful community continues to help him so very much. It is a huge blessing to our family.

Kyler has made connections with many people through social media, from all over the world. As an example, a man named Osman Mehinagic who lives in Bosnia, Herzegovina with his wife, Emina who had a grade IV AVM reached out to me via Facebook messenger and spent all hours of the night his time on multiple occasions helping me get large medical files on my computer in a way that I could send to doctors to review. He also took time to educate me about his research on AVM treatment options and what doctors he had found to be helpful. I think it is just beyond amazing that a stranger on the other side of the world would randomly reach out and help a mom in Bryan-College Station. I also want to let you know about a man in College Station who reached out to me and met with Kyler —He had a Brain AVM that was removed, but it left him with the loss of 1/2 his vision in both eyes. He wanted Kyler to see that even if this does happen to Kyler later on, he could still function quite well.

In addition to Facebook, Kyler has a caring bridge page that is regularly updated and also is used to share his story: <https://www.caringbridge.org/visit/kylerlewis>

Additional Take Away Information:

- A Brain AVM is a tangle of abnormal blood vessels connecting arteries and veins in the **brain**. The arteries are responsible for taking oxygen-rich blood from the heart to the **brain**. Veins carry the oxygen-depleted blood back to the lungs and heart. A **brain AVM** disrupts this vital process because the arteries are connected directly to veins- they look like tangled yarn. In some cases they can be hereditary, but in most cases, like Kyler's they are random congenital occurrences.
- Brain AVM's effect less than 1% of the United States Population
- They tend to be discovered in children between the ages of 10-18 or later in life as an adult between the ages of 30 - 40. And most often they are discovered because the rupture and cause a bleed. Typically, you don't know you have an AVM until you either have a bleed or you get really bad headaches and go for a CT or MRI scan, or an angiogram. Kyler never had a headache prior to his AVM bleed. It can be a silent and deadly killer.
- Kyler's AVM is located in the parietal / occipital lobe. **Parietal Lobe**- This means - strength of memory is diminished, details of complex events become harder to retrieve, (sometimes he has a hard time finding words, sometimes he tells me to slow down because he doesn't understand what I am saying (For example: pick up your clothes and put them in the utility room so I can wash them caused him great confusion this week and this scared him), and sometimes he is told something but truly does not remember the conversation or what was just told to him. (For example: "Remember the words, puppies, hat, boat and tell them to me when I ask in 1/2 an hour" more often than not, he can not do this.) His subjective confidence in his memory is very low. **Occipital Lobe** - the occipital lobe is the visual processing center of the brain. Damage can cause [homonymous hemianopsia vision loss](#) from similarly positioned "field cuts" in each eye (photo of chart explaining attached). This is the biggest problem we have for Kyler currently that we are trying to avoid. He has already lost this twice (Medically called Recrudescence--once with his first bleed and then right after his first Gamma Knife treatment) , but we have been very blessed that it came back. This article does an excellent job of explaining Homonymous Hemianopsia with photos and videos. https://www.brainrecoveryproject.org/parents/brain-surgeries-to-stop-seizures/hemispherectomy/vision-hemispherectomy-occipital-lobectomy-tpo-disconnection/fields-of-vision/homonymous-hemianopia/?fbclid=IwAR1tgyM9gZOVaksKb_c0LYZ8C0BfkriTb-xiH_AT3TDURLtY0o5-zizuCAg
- Because Kyler's AVM is inoperable, we have chosen for him to have **Gamma Knife** Radiosurgery. He had 3 treatments 3 months apart for each all in San Francisco, California. With each treatment, they attach a metal halo to his skull and target the blood vessels in 1/3 of Kyler's Brain AVM. They shoot 18.5 grays of radiation into his head for approximately 3 hours each time. The hope is this will cause the AVM to shrink. The hope is that we can shrink the AVM without damaging the good and very needed brain tissue that surrounds the AVM. Brief Gamma Knife Explanation: <https://youtu.be/7ScVu-ZGfu8?t=86>
- Side Effects from the Gamma Knife treatment for Kyler thus far have been *vision loss* (temporary), *blurry vision* (temporary), *migraine headaches* (more problematic currently)

and *neuro fatigue* (more problematic currently--Kyler has to sleep for several hours after "thinking hard to do each assignment or attending class"). "*Swelling* in the brain at or near the treatment site is also a possibility and can cause a variety of symptoms depending on what areas of the brain are involved (in this case, parietal / occipital). Kyler has had some post-treatment swelling from the Gamma Knife treatment, called Cerebral Edema. These symptoms showed up almost exactly at the one year mark as predicted (*approximately six months to one year after treatment* is normal rather than immediately after the procedure like with conventional surgery") We had already been warned brain swelling was a real possibility due to the amount of hours Kyler has to have GK each treatment. He has currently been on steroids for several weeks thus far as a result. Kyler also developed Epilepsy as a result of the gamma knife radiation. *With this treatment, you can slowly get worse before you get better, and of course you can have a spontaneous bleed at anytime while you are waiting for the AVM to shrink away—without any guarantees that it actually will.*

October is AVM Awareness Month

AVM Survivor Symbol: Green Butterfly

AVM Awareness Ribbon Color: Maroon

Additional helpful resources:

- <https://brainfoundation.org.au/disorders/arteriovenous-malformation/>
- <https://www.aans.org/en/Patients/Neurosurgical-Conditions-and-Treatments/Arteriovenous-Malformations>
- <https://www.stroke.org/en/about-stroke/types-of-stroke/hemorrhagic-strokes-bleeds/what-is-an-arteriovenous-malformation>
- <https://taafonline.org/>
- <https://www.research4ryan.org/>

Thank you so very much for your time.

Regards,

Raylene Lewis

Kyler's Mom

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