

Academy's 9th Annual Medical Imaging Technology Showcase

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Good evening to you all. And thank you for giving me the opportunity to speak with you. I hope you won't mind if I ask a few questions to start. How many of you have children? ... How many of you have ever had an MRI or a CT scan? ... I ask these not to put you all on the spot, but rather to better gauge how to tell my story. So, what is my story? How did I end up here in front of you all and why should you give weight to anything I am going to say? All good questions. To start, it is not my story. It is the story of my daughter, my hero, Abigail. In a soundbite: My twins were born when I was 25 weeks and 2 days pregnant. In other words, before my third trimester even began. My son weighed in at 11lb 14oz, and my peanut tipped the scale at 11lb 3oz. Any of you like to bake? That is just more than 4 sticks of butter. Abigail suffered a pulmonary embolism on her second day of life which led to bilateral bleeds in her brain. This was discovered by a head ultrasound and reported to me in a nonchalant sort of way, in the quiet of a late night NICU. It was surreal. I was new to the world of micropreemies and NICUs, but I knew that the news I was being given was not good and the casual way in which it was given belied the gravity of the information.

Abigail had a pretty exhausting and invasive next 80 days. Then we were told that the radiologist felt that her latest head ultrasound showed thinning of Abigail's brain matter. We were advised to transfer her to Children's Hospital for a pediatric MRI. The neonatologist did not entirely agree with the assessment of the radiologist which made our decision to split up the twins and transfer Abigail to a hospital we had no connection with that much harder. I kept wondering why two doctors could see the same images and come to two different conclusions.

We were not permitted to go into the room with her, though we had been privy to the complicated back and forth with the nurses regarding the oxygen needs of our daughter. When the MRI was over, the same nurse casually told us that Abigail had stopped breathing during the procedure, but they thought they got what they needed. Lovely.

The neurologist who read the MRI report told us that our daughter had hydrocephalus and that she would need brain surgery in the near future. Have any of you ever heard of hydrocephalus? Well I hadn't. It is a condition in which, for a variety of reasons, the brain cannot absorb the cerebrospinal fluid that we all have circulating around our brain. As such, the fluid builds up and puts pressure on the brain itself. If left unchecked, coma and death occur. Right now, there is no cure and the only treatment option involves brain surgery, and more often than not, and as with my daughter, the placement of a shunt that redirects the fluid out of the brain, and through a catheter that drains into the abdominal cavity. But shunts clog and break regularly. Sadly, shunts have not advanced much since they were created in the '50s.

Over the last six years, Abigail has had 12 shunt-related brain surgeries, including 2 shunt infections which landed her in the hospital for a month each time, and many, MANY MRIs and CT scans. So many, that I sometimes wonder, in all seriousness, if we have compounded her condition by adding in the possibility of cancer later in life from all of the exposure to radiation.

At some point in our journey, we learned about Fast MRIs. These offer imaging without radiation, but don't provide the same level of detail as a CT. Prior to the availability of this technology, we were stuck having to read the tea leaves and decide in an ER, while accompanied by a screaming-in-pain child, whether or not to have a CT. On no less than two occasions, ER

attendees advised us not to unnecessarily expose Abigail to the radiation, sent us home, only to have her symptoms worsen, and for us to return, get a CT and confirm that, yes, her shunt was malfunctioning. But fast MRIs are not always available even when hospitals have them.

The MRI and CT experience are far from ideal for a variety of reasons. Set up takes far too long to get a child who is scared and in intense pain situated. And for all the technology, why are we using rolled up towels or whatever else we can get our hands on to anchor her in place and try to keep her ear plugs in which have usually fallen out because she is squiring in fear and agony?

The other side of imaging is the reporting. In the case of hydrocephalus, the imaging reports literally stand between a decision to operate or not. But the report is subjective and images capture a moment in time and do not take in the history of a patient. With hydrocephalus, that history is critical information needed in order to accurately read the images. Often, radiologists focus just on the size of ventricles. BUT, as those of us on the hydrocephalus journey know far too well, the ventricles are never the full story.

You are here to hear about how innovation has helped us and about what we need for it to help us further. Innovation brought us the shunt that allows for my daughter to be among the living. The MRI and CT scan have allowed us to see if her shunt is working by gauging the size of her ventricles. The Fast MRI has allowed us to have imaging performed without the added bonus of radiation exposure. But surely this is not where we stop. We need imaging machines that do not scare a child to death so much so that they must be sedated in order for them to be still long enough to capture the images needed. We need more sophisticated imaging that does NOT involve radiation but which can go beyond revealing the size of the ventricles. Imaging that could show if there is a clog in the shunt tubing would be a game-changer, as well. While what I really want is a cure for hydrocephalus, right now I will settle for a daughter who does not glow at night from all of the radiation she has been exposed to in order to save her life.

Thank you for listening.