Riley Kid, Jocelyn Renee Meggenhofen

Jocelyn was born March 14, 2004. She is a happy 20-year-old that loves Benson Boone, Taylor Swift, Justin Bieber and One Direction. She loves to play UNO, so much so that she has about five different decks of UNO….Trolls, Barbie, Emoji, GIANT, mini….you name it. She loves babies and children and loves to socialize. She has a 17 year old brother and a 10 year old sister and she LOVES to spend time with family. Though Jocelyn has been diagnosed with a progressive illness, Jocelyn has remained fairly healthy over the past couple of years thanks to the wonderful doctors and nurses at Riley Children's Hospital; however, this is was not always the case.

At the age of three, Jocelyn suffered a 45-minute seizure and less than a year later, a second one. After each, she was rushed to the hospital and MRI's were done. Little did we know how much these seizures would change our lives. The results of the MRI's showed that there had been changes in the white brain matter from the time she had the first seizure to the second one. We were informed by the neurologist that she had a form of Leukodystrophy, a progressive, degenerative disease in the brain. As the changes happened in her brain, so too would her functioning level. She would eventually lose some of the skills that are taken for granted by most; walking, eating, writing, speaking. We had a name for what was happening but did not learn the specific form of the illness until 3 years later at the age of six.

We were advised to see a neurogeneticist at Riley and it was at that point that our relationship with Riley began. Thanks to Dr. Walsh, we learned that she had Alexander's Disease, a very rare disorder of the brain. The odds of being born with it are the same as being struck by lightening. There is no treatment for it, you can only treat the symptoms.

For the next several years Jocelyn did very well and we, as well as her Neurologist questioned if maybe she was misdiagnosed because the disease did not seem to be progressing like we had been told it would. She did have some challenges such as unsteady gait, and speaking clearly.

In 2017, our lives changed as the reality of Jocelyn's disease started to become evident. She started having numerous falls, was struggling with muscle control and motor coordination. She has a fall of this loss of coordination and ended up inpatient at Riley with Cellulitis to her knee; however, she began having difficulties keeping her O2 levels up and was rushed to the PICU with a collapsed lung. This was the beginning of all the pulmonary issues. It was during this time that we started to see the knowledge, care and compassion that the Riley

In 2018, Jocelyn got pneumonia, which again resulted in a collapsed lung. This time however was more severe as she had to be intubated. The same experience of professional staff who took the time to learn about Jocelyn's disease were back again caring for her and comforting us.

In 2019, Jocelyn was hit with pneumonia again, but both of her lungs collapsed, her blood pressure dropped and her already low O2's were declining. She was in Septic Shock and her body was shutting down. The doctors told us how sick she truly was and informed us they did not think she would make it through the night. They put her on a Rotoprone bed and an Oscillator (a last resort when a normal ventilator isn't working) while intubated to try to help her lungs heal. After being on the Rotropone she was able to progress to a normal ventilator and eventually extubated; however, this was short lived and she ended up back on the vent. Finally, six weeks later her lungs were healed up enough for her to be discharged.

In 2022, we officially became frequent flyers at Riley with 9 PICU admissions, all for respiratory failure. By this point, Jocelyn had been to Riley so may times that many of the PICU nurses and doctors knew her and us on a first name basis. Thankfully, since 2022 Jocelyn's number of hospitalizations has slowed down. We attribute this to all the wonderful staff at Riley, from the client facing desk staff to the Child Life staff, to the Respiratory/Occupational therapists to the doctors and nurses. It is always nice when a doctor or nurse comes in and already knows Jocelyn's story so it doesn't have to be retold. There have been several times with the nurses from the PICU will see Jocelyn's name of the admissions list and come up to the floor just to say "hi" to her or staff will play music from her favorite artists while doing her medications, feeds etc. Riley (and God) have saved Jocelyn's life so many times!

Every time Jocelyn has been at Riley the staff have been wonderful. They have been compassionate and listened to what we, as parents, had to say. They included us in their morning rounds each morning and night when discussing her care and never made us feel as though we were being pushed out.

As much as it hurts that she has this horrible disease, we have learned so much on this journey. She has taught me so much and made me a more patient person. She has made me realize that even when I think I am having a bad day, things can always be some much worse. She has taught me to appreciate everything I have been given and to slow down and appreciate everything in life because we are not promised tomorrow.

Jocelyn is currently in a wheelchair, is on a lot of medications to manage her symptoms, is incontinent, receives all nutrition through a feeding tube, has poor motor skills and is difficult to understand when speaking and yet, she is always happy and delighted by the simplest of things. She enjoys just being around people, having people acknowledge her and say “hi” and offer to play a game of UNO with her. We have been able to develop a lot of new relationships with people we probably would not have met if not for Jocelyn. We are blessed to be able to shar her story with others and offer encouragement and hope to other families going through similar circumstances. Jocelyn has touched so many lives in her short time on this earth.

Had it not been for Riley, she may not be here today and our story could have been very different.