Jadyn Kietzer

NOTHING SLOWS HER DOWN

by Ruth Klossner

Ten-year-old Jadyn Kietzer is wise beyond her years. After all, she’s experienced so much more than the average youngster—four full-on surgeries and being under anesthesia more than 20 times. You wouldn’t know it as Jadyn is a growing, thriving, beautiful 10-year-old girl.

Mom, Sara, describes her daughter, saying, “She is tough as nails, wise beyond her years, a playful girl, is always laughing, dancing and singing. She loves her big brother and they also like to pick on each other. She has taught us more in 10 years than anything we have learned in the school of life.”

“It is a privilege to be raising this little miracle,” Sara continued. “We are thankful every day that she continues to thrive. Her journey is ongoing and, of course, is an ongoing, long-term support system in our family and friends. We are so fortune for everyone that has been with us through the thick and thin.”

The daughter of Sara and Lucas Kietzer of rural Vernon Center, Jadyn was born with health problems that weren’t even given a name until she was five or six years old—and then only in a general way. She has lymphedema—that’s the way God made me,” Sara explained.

Jadyn just started fifth grade at Lake Crystal-Wellcome Memorial where big brother Gabe is a freshman. She enjoys hanging out with her friends and loves to bake (and eat) cookies and cupcakes.

As Jadyn and her family look ahead, Sara commented, “We kind of operate on ‘one day at a time.’ We maintain and monitor.”

Jadyn continues to have yearly MRIs, along with regular visits to specialists, with her immune system messed up, she’s susceptible to infections and is unable to fight viruses. She’s also started another experimental medicine. While her main doctor is in Rochester, she receives additional treatment at the Mayo Clinic.

When Sara started Jadyn on CBD (cannabidiol from the cannabis plant) a year ago, she didn’t tell her why she was taking it. Within a week, Jadyn had no more complaints about her belly hurting and—about a year ago, she didn’t tell her why she was taking it. Within a week, she was four weeks in—Jadyn pointed out that she could see her ankle bones—little bony bits—appear.

Sara added, however, “I think I look fine.”

The active little girl scrambles around the family’s home and farm and doesn’t let anything stop her. She cuddles cats Mack and ChaCha, climbs the climbing wall in their home, and jumps on the trampoline outside.

The trampoline—along with running, basketball and volleyball—might require the use of an inhaler but, don’t kid yourself, Jadyn is very active.

“Nothing much slows her down. She really doesn’t have limitations. For the most part, Jadyn wears a daytime compression garment. It does distinguish her a bit and she sometimes gets questions. She’s diplomatic, she just tells people, ‘I was born with lymphedema—that’s the way God made me.’”

Jadyn and Sara Kietzer

Sara Kietzer

Jadyn’s Story

We welcomed Jadyn on June 24, 2009 at full-term and after a relatively normal pregnancy and delivery. I had terrible edema in my legs and feet during my pregnancy. One of the first things I heard after she was delivered was my mom saying, “Look, she has a sweater foot, like her mom.” It didn’t really register at first but things changed pretty quickly thereafter.

Jadyn had her first X-ray before she was 12 hours old to see if her right foot had somehow been broken during delivery. Thankfully it had not, but it meant we had a challenge ahead of us to figure out what was going on with our little girl. You know how moms are, their instincts and the eyes and ears to notice when something is “off” with their children. After snuffling and soaking in her thick dark hair, and once the exes, it began to notice some asymmetry in her face. The right side was a little fuller and her tongue didn’t completely fit in her mouth. And her breathing—I called her my “little piggy” because she was such a noisy breather. I shared my observations with the nurses and they passed them along to the on-call pediatrician.

My husband and I will never forget the doctor coming in at one o’clock in the morning when Jadyn was just 22 hours old, to tell us he had been on Google and found a condition to explain her symptoms. It doesn’t involve much confidence when your daughter has something a doctor has never heard of or heard of, and his last resort was Google. His guess was Milroy’s Disease/Lymphangiomatosis. He showed us some photos he had printed and our concerns mounted. He had several more X-rays and many blood draws from her tiny little body. We had few answers and were kind of in an exhausted fog. We thought we were headed home that Friday as none of her issues seemed to cause any immediate danger. As discharge papers came, so did the instructions that we were headed to the NICU at Children’s Hospital in Minneapolis. She had chemical testing done that afternoon and we were admitted as they had also observed some fluid around her heart.

We spent three days in the NICU and honestly didn’t learn much more except that she tested negative for Milroy’s so they had tested her for a few other genetic conditions, which were also negative. We continued doctoring at Children’s for the first six months of her life. Specialist after specialist, appointment after appointment, and really no clear answers. We eventually decided to take her care to Mayo Clinic where we have doctoring ever since.

At one point, I believe we had 17 different doctors at Mayo involved in her care as more and more things kept popping up that would warrant a specialist for another anomaly. Jadyn spent about a month in the hospital our various illnesses and surgeries. She spent about seven days in an isolated room to come from two airway surgeries. She has had countless X-rays, about nine CT scans before the age of one, 10 or so MRIs, six sleep studies, and was under anesthesia about 19 times before her fourth birthday. The procedures seemed never-ending and she was scoped and biopsied more times than we can count. She is involved in three separate research studies out of Baltimore, Wisconsin, and San Francisco. Our Mayo doctors frequently have “round tables” about Jadyn with other doctors from all over the country and world.

Being Jadyn’s mom and dad was—and still is—a very scary journey, especially when your daughter has something a doctor has never heard of and has never seen. Not only do parents worry that someday a shoe will never fit as a her size grows but, of course, there is inherent anxiety. Our future is filled with more and more things kept popping up that would warrant a specialist for another symptom. I can’t even remember the last time Jadyn was able to have a normal day—part, Jadyn wears a daytime compression garment. It does distinguish her a bit and she sometimes gets questions. She’s diplomatic, she just tells people, ‘I was born with lymphedema—that’s the way God made me.”

Sara explained.

We didn’t really receive a diagnosis until she was about five or six and it really is just a blanket description more than a diagnosis—genetic and symptomatic abnormalities. She has lymphedema in her face, tongue, airway, lungs, digestive tract, labia, and right foot and also has a large inoperable lymphangiomatosis mass in her abdomen. (See sidebar for Jadyn’s story.)

As Jadyn described it, “Basically everything on my right side is a little bit swollen—a little bit puffy—except my arm.”

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We’ve seeing it as impacting her health in a positive way now,” Sara said.

Jadyn’s most recent MRI results came back early in September. ▶
Sara noted, “Thankfully, although she has grown considerably this last year, the large mass in her abdomen has not! The jury is still out if this is related to the CBD as she is such a rare case, that it would be pretty difficult to verify with certainty. However, we see this as a win in her ‘journey’ and are so thankful that the pain is now controlled without resorting to ibuprofen, etc.”

Jadyn’s maturity and independence is evident in many ways. “She’s 10 but goes to appointments and fills out her own questionnaires,” Sara said.

While some twice a year tests and MRIs have been cut back to once a year, there’s still a lot of blood work. There are some things that Jadyn doesn’t like but, when it comes to blood work, she said, “I just tell them ‘Here’s my arm, do your thing.”’

Jadyn’s journey has made a big change for the Kietzer family. They’re tackling a new way of farming—with Lucas partnering with his parents Jeff and Jane Kietzer raising eight acres of hemp on their farm and doing some custom planting and drying for others. Sara became an entrepreneur, opening Journey Organics in the mall, and is on the board of the Minnesota Hemp Association and doing some consumer education talks.

Jadyn loves the family’s two cats, Mack (pictured) and ChaCha.