

Olivia

Born January 2012 | Kansas City, KS

Living with CMD

“Come on! Let’s play,” exclaims Olivia, her enthused, high-pitched voice trailing behind as she races down the road in her hot-pink power wheelchair. At age six, she’s got the energy of a hummingbird, and her rare condition of congenital muscular dystrophy (CMD) does not stop her from going where she wants, at top speed. Olivia lives with CMD LAMA-2, a type of muscular dystrophy related to a specific mutation in the laminin protein. The condition takes two forms: either a severe, early-onset form or a milder form that appears later in life. Olivia’s condition was early-onset, though when she was born, her health appeared to be fine.

Olivia was placed in daycare as an infant, as her parents, Matt and Sara, both worked full-time in finance and marketing. During this time, the differences between Olivia and the other children began to appear. “She didn’t have the same forcefulness of movements and projection of cries and screams as the other children,” recalls Sara. “I wasn’t sure what was going on, but my mother’s intuition said, ‘Something’s not right.’”

When Olivia was three months old, Matt and Sara embarked upon the difficult odyssey of finding a diagnosis. “Most people do a muscle



biopsy, but we felt it was very dangerous to give her anesthesia," says Sara. They preferred to get genetic confirmation through blood tests. The genetic testing revealed that Olivia had a high creatine kinase (CK) level, indicating muscle damage. After waiting weeks for the blood results and additional testing, Olivia was officially diagnosed with CMD LAMA-2 at six months old.

Receiving the diagnosis for their first-born baby was surreal. "You think everything's normal, and then your whole world gets flipped upside down," says Sara. All of a sudden the family had to shift into envisioning a new reality—one including a wheelchair, an adaptive vehicle, and an

accessible house. Up until that point they had planned on living, working, and raising Olivia in a fourth-floor, walk-up apartment in downtown Chicago. Reckoning with the change in plans, Matt and Sara decided to sell their apartment and move back to Kansas City, where they could be near supportive family and find a house that would accommodate Olivia's needs.

Although Olivia's diagnosis came early, at times it was deceiving, as she showed to be advanced in many ways. Not only was she a very early talker and excellent communicator, but around age two, she

taught herself how to read. "Her reading was wild," remembers Sara. "She literally learned to read, self-taught, out of the blue. She memorized words immediately."

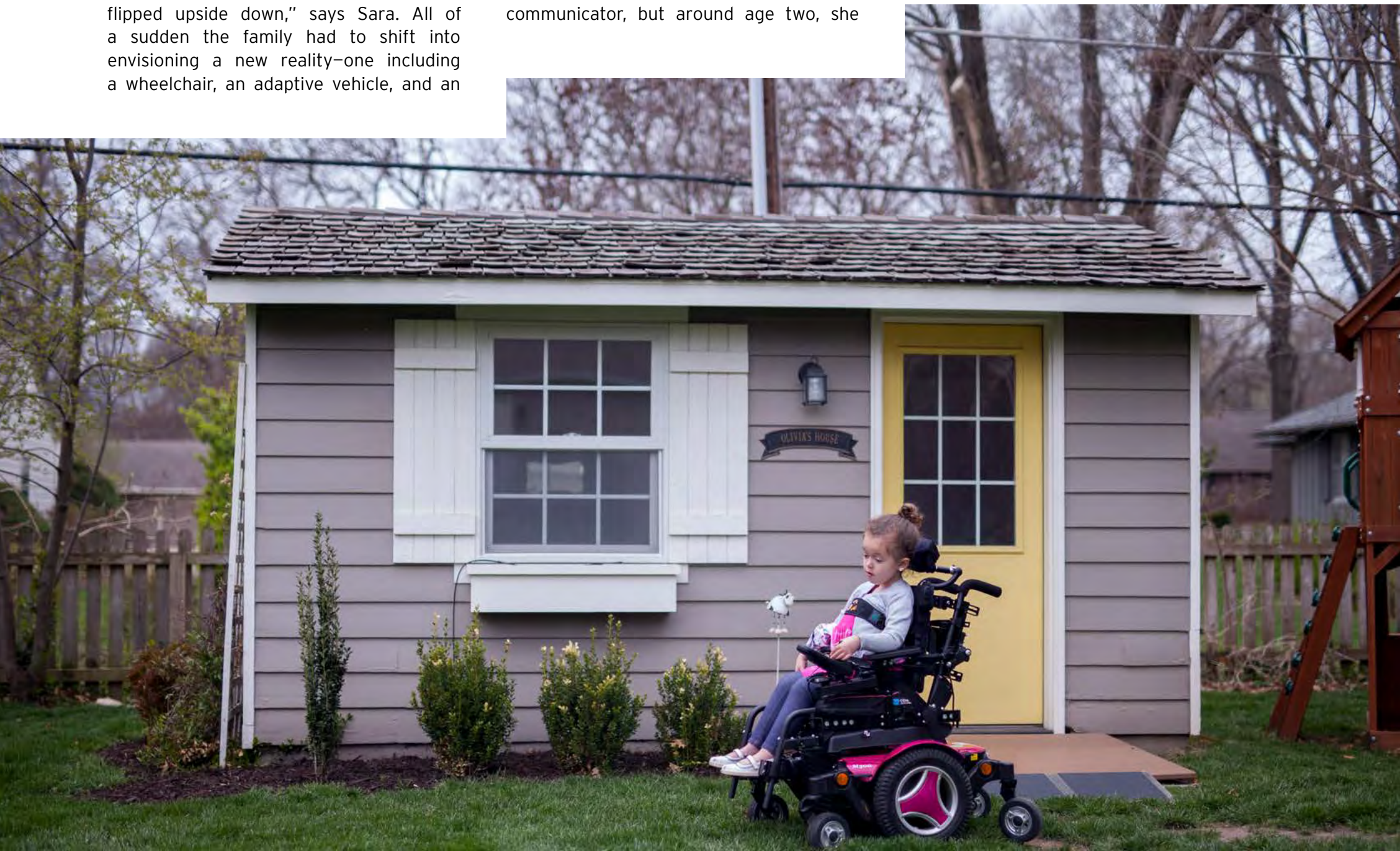
As Olivia grew older, Matt and Sara realized that she had no arena to explore her burgeoning imagination and her unquenchable desire to play. They wanted to build her an accessible playhouse, but were met with legal restrictions. "Living in a historic neighborhood, there are many

building regulations and constraints," explains Matt. "There was no playspace for her. Not a spot for her." Olivia couldn't go to her friends' houses because they weren't wheelchair accessible, and due to housing regulations, the family wasn't allowed to build another structure big enough for her to have a playhouse. Taking matters into their own hands, they organized a meeting with the building commission, where Olivia, at just two-and-a-half years old, showed up in true form. "In the middle of the

meeting Olivia started beeping the horn in her chair. 'I'm bored, I'm bored, I'm bored. I am so bored,' she exclaimed in her sweetly adamant voice. 'I have nowhere to play! Can I just have my playhouse?'" After witnessing young Olivia, the building commissioner approved, and the family was permitted to build a playhouse large enough for her to play in.

"Olivia is unique because she is so verbal," reflects Sara. "Olivia speaks up. We do this

for Olivia and for all the other kids too." Furthering her knack for civic engagement, Olivia helped redesign a playground in her neighborhood. The plan for the playground was to have mulch and woodchips on the ground beneath the structures, in which case, Olivia wouldn't have been able to access it. So she spoke out to be included, rallying for a soft rubber surface instead. "Our neighbors were really great about standing up," says Sara. "They'd say, 'We need to be looking out for kids like this.



We need them in our neighborhood.” The communal camaraderie moved Sara to tears. “People care, but they don’t know what they don’t know. Once we started talking, we’ve been surprised by the support we’ve been given.” With this support, Olivia’s family was able to accomplish major milestones with accessibility to public spaces, and not just for Olivia, but for other children as well.

Managing Olivia’s medical needs have also proved challenging. “We are lacking an integrated team,” explains Matt. “The doctors are good but they don’t communicate with one another. Instead of having a neuromuscular clinic, for instance, we have to be the communicators between specialists.” This lack of integration takes extra time and is a cause of frustration. At

some point in the future Olivia will need a spinal fusion. But it’s really when her spine will start impacting her lungs that concerns Matt and Sara the most. They will have to go back and forth from pulmonologist to surgeon—requiring precious time and energy—to figure out what is best.

As she speeds around the house in her pink wheelchair, her little sister, Emily, hops on for a ride. Emily sneaks a sip out of Olivia’s water cup that’s held behind the seat. Matt and Sara catch it and quickly move to the kitchen sink to wash the cup. “It takes her three times longer to get over any illness,” remarks Sara. “So we have to be really careful she doesn’t share with other children to keep her healthy.” When Olivia was two, she contracted pneumonia and

was taken to the hospital where they found that half of her lung had collapsed. She was put on respiratory-support for a week. Two glucose crashes also led to more hospital visits. Through observation by a feeding specialist, they discovered that every time Olivia was taking a sip of water, she was silently aspirating—breathing in the water. “The feeding therapist was a saving grace because after that, she started doing so much better,” recalls Sara.

Time is the main ingredient in caring for Olivia. “It used to take us an hour-and-a-half per meal to feed her. Doing that three times a day takes almost a whole day.” With the support of Olivia’s grandmothers, nannies, nurses, and specialists, the time obligations are shared. Sara’s mom has been the biggest help with babysitting and feeding, but soliciting her help was easier when Olivia was smaller. “Our moms are older now and Olivia’s getting heavier, so it’s difficult to find people who can pick her up and transport her in a way that they are safe and she is safe,” explains Sara.

Despite their support network, Matt and Sara still find themselves missing work quite often for illness, doctor’s appointments, IEP meetings, and swimming for physical therapy. “It’s a different level of tired that we operate at,” says Sara. And step by step, they are always learning. Their greatest resource is connecting with other families online. “Even our family members don’t really understand on a day-to-day, hour-by-hour basis what’s going on. If we didn’t have access to other families with CMD-LAMA2, I don’t know what we would do,” expresses Sara. “Connecting with other families is critical. They can give you a glimpse of what’s next. We rely on them more than anybody else. There’s so much more information I can get from them, more than doctors. That helps with not being so overwhelmed.”



Matt and Sara try to focus on the areas they can help. Sara assists with fundraising and social media efforts for the Cure CMD organization. "You do feel helpless," says Sara. "There's so much you can't do. We can't fix it or change the diagnosis, but we can change certain things to make her life and others' lives better. That helps." Olivia's resilience in itself is an aid. She has been a spokesperson for organizations like the Variety Children's charity, a national organization with a Kansas City chapter. Olivia has appeared on commercials for the local grocery store, and even at cinemas across the midwest, on an advertisement before each film supporting Variety's efforts to build inclusive playgrounds. Her lively spirit brightens up any room. "Being around Olivia makes my day better," says Sara, with a smile.

A social butterfly since she was very little, Olivia is always talking to people. "She'll go zip up to all the neighbors, or anyone, and talk," says Matt. When people ask Olivia about her wheelchair, she replies, "My muscles don't work, so I have a wheelchair that helps!" For Olivia, it's as plain and simple as that. "Kids should be able to be included and be able to play with their friends," says Matt. "It's all stuff we never thought about before, and a lot of people in the community

don't think about either, until they meet Olivia, and see her firsthand."

Matt and Sara keep up with the hurdles of learning how to best care for their daughter. "We need her to be here, and we need her to be healthy. And healthy doesn't mean you have to walk." They are focusing now on her spine and breathing support, to keep her lungs strong. "She's currently very healthy, in good weight. We want her to maintain independent eating and breathing," says Sara.

Olivia picks out another color from her set of fifty markers. "Will you pass me eggplant purple please?" she asks. She knows the full name of every color, and rotates between ten as she fills in the gemstones on a paper tiara. When asked to pose for a picture, she obliges, but only for a moment. "But I'm coloring! Can I go back to my very important coloring now?" On the one hand, Olivia is focused on typical six-year-old stuff—making art, playing with friends, and playing games. But she also does the extraordinary—she speaks out about her condition and advocates for herself. "We talk about resilience. Olivia is the epitome of it," says Matt. "She's the most resilient kid, and human, I've ever been around."

"Being around Olivia makes my day better."

—Sara

