

Kids deserve the best.

# Children's Wisconsin provides specialty care to kids across the state and beyond

When Keegan was 7 years old, she loved spending time with family and friends and enjoyed cheering. One day, Keegan mentioned a sore shoulder and came home from school in pain. At a local walk-in clinic near their home, a doctor did X-rays and a blood draw, after which Keegan's pediatrician called them to come in immediately. He told Keegan and her parents that she had leukemia and needed to go to Children's Wisconsin. She was diagnosed with acute lymphoblastic leukemia and underwent two years of treatment, including chemotherapy, surgeries and more – with many severe side effects. Keegan's parents shared that everyone at Children's was so kind and comforting. They realized they were right where they needed to be and felt lucky that Children's Wisconsin was so close to home. Now, Keegan is 16 years old, is doing well and continues to return to Children's for yearly checkups. She and her family started a foundation to support other kids going through cancer treatment.



Keegan Genoa City, Wis.



Ayden Milwaukee, Wis. When Ayden was 4 years old, he began experiencing extreme tooth pain, impacting his ability to function. Ayden's dentist discovered he had cavities, but as his mom tried to schedule dental appointments, she found long waitlists or requirements for a referral. Meanwhile, Ayden was crying and suffering in pain, impacting his sleep, eating and daily activities. Finally, Ayden visited Children's Emergency Department in hopes of getting his pain addressed. There, Children's dental team found that several of Ayden's cavities had created infections in his mouth and several of his teeth couldn't be saved. Children's dental team provided safe and compassionate care to Ayden, using general anesthesia to remove the teeth. Now, Ayden is pain-free and has returned to being a playful, energetic and smiling young boy. He loves to play with his little brother and really likes dinosaurs and superheroes.

Never before in the United States had a baby survived when born without a trachea, called tracheal agenesis. That changed in 2016 when a team of doctors saved the life of now 7-year-old Thomas. Most children with this condition die within hours of being born but, amazingly, the doctors at Ministry St. Joseph's Children's Hospital in Marshfield stabilized Thomas so he could travel to Children's Wisconsin. Children's expertise and resources enabled specialists to create a treatment plan that hadn't been done before. Physicians did a procedure to use Thomas' esophagus to get air into his lungs and then surgeons divided his

esophagus into two pieces. A breathing tube connected to a ventilator was

inserted down Thomas' esophagus. Now, Thomas breathes on his own through a tracheotomy and is able to eat, make many noises and is full of energy. Thomas loves to play with his siblings, loves Spiderman and moose and enjoys playing t-ball and making art.

**Thomas** Wisconsin Rapids, Wis.



A few years later, and not far from where Thomas was born, mom Rachel was pregnant with baby Tennison, who had some diagnosed birth defects. When Tennison was born, the Children's team was shocked to find that, like Thomas, Tennison was born with tracheal agenesis. Thanks to Children's recent experience caring for Thomas, the specialists knew what to do and were able to save Tennison's life. Tennison, now 3 years old, continues to defy the odds. He recently started school, uses sign language and attends speech, physical and occupational therapy. Tennison loves Mickey Mouse and playing with his siblings and family dog. He is working on walking and recently started loving to read books. Both Thomas and Tennison are living, breathing, thriving testaments to the incredible care and medical expertise at Children's Wisconsin. Today, their families are close and share the common bond of being the only children in the United States to live with this diagnosis.



### Tennison Black Creek, Wis.



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17-year-old Nick was born in China and was adopted when he was 2 years old. He was born with several heart defects and had multiple surgeries before and after his adoption. As he grew, Nick was operating with about 70 percent oxygen, which limited his participation in

### **Nick** Menomonee Falls, Wis.

physical activities and sports; however, he enjoyed participating in musicals, art and served as the manager of the boys' basketball team. Nick visited the Herma Heart Institute several times a year for regular checkups, scans and stress tests. While in high school, his heart wasn't improving, and his provider recommended Nick for heart transplant. After four months on the transplant list, Nick's parents got the call that he had a heart match, and he immediately went to the hospital to prepare for surgery. After the 13-hour surgery, Nick pushed hard to go home 17 days later. Nick's recovery is going well, and he's enjoying getting back to his regular activities and keeping up with his friends.





### Ellie

#### Seymour, Wis.

When 9-year-old Ellie and her twin brother were born, her parents had expected complications – in fact, they were prepared that Ellie wouldn't survive. Ellie's mom went into labor early and as soon as Ellie was born, she was transferred from a local hospital to Children's. Ellie was born with her bladder outside her body and several other GI and kidney challenges. During her first year, she had surgery to create a colostomy, a G-tube inserted for feedings, two bladder repairs and a flight

to Children's Intensive Care Unit. Her second bladder surgery was part of a multi-hospital symposium, so doctors from other children's hospitals could learn how to care for other kids like Ellie. While Children's providers were able to repair function in one of Ellie's kidneys, she needed a transplant. After traveling to Children's for dialysis three times a week, Ellie received a kidney from her mom when she was 3 years old. Ellie returns to Children's regularly for coordinated follow-ups with several specialists. Today, Ellie loves playing with her brothers, enjoys swimming and is obsessed with dogs.



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When Vince was first born, his parents took him to the pediatrician, where they heard a loud heart murmur. At a local hospital, he was diagnosed with two holes in

his heart: both atrial and ventricular septal defect. When Vince was 4 months old, Children's specialists performed surgery to repair the holes and Vince returned home. Six years later, Vince became ill with what his parents thought was the flu. Instead, they discovered his heart



was failing and too weak to pump blood to his organs or support his breathing. To keep Vince healthy enough to receive a heart transplant, he became the first person in the Midwest to be hooked up to a Berlin Heart: a pump outside the body which helps send blood to other organs. He regained his strength and, three

weeks later, Vince received a perfect heart match. Now 24 years old, Vince is healthy and enjoys golf, fishing, camping and basketball. He continues to return to Children's for regular testing and checkups.



In 2016, when MJ was 7 years old, he was playing with friends on the playground at school when he suddenly collapsed. MJ was transported to Children's, where it was discovered he had a stroke caused by an arteriovenous malformation (AVM). AVMs are a rare, abnormal tangle of blood vessels in the brain – when they rupture, they cause bleeding in the brain. Neurosurgeons at Children's performed two brain surgeries on MJ to clean the affected area and fix the issues caused by the ruptured AVM. MJ spent two months at Children's recovering from his surgeries and also visited Children's for months of physical and occupational

therapy. Today, MJ is doing great in high school, playing on the soccer team and in the school band.

Milwaukee, Wis.

When Ksenia was 17 years old, she suddenly started to feel chest pain impacting her ability to move, eat and do daily activities. She went to the doctor and they immediately called an ambulance to take her to Children's Wisconsin. Ksenia was admitted to the Intensive Care Unit in respiratory failure with irritated airways that weren't responding to antibiotics. During this time, several other teens were admitted with similar lung injuries – doctors discovered the link between these patients was vaping. Doctors began treating Ksenia with steroids and slowly she began to improve. The specialists at Children's alerted the public and a multidisciplinary team created a care protocol. This enhanced collaboration between specialists helped care for kids here in Wisconsin and beyond. Ksenia credits her eye-opening experience with guiding her to make healthier lifestyle choices and be vape-free. Ksenia, now 21 years old, enjoys singing and listening to music, playing with her pets and being outside with her friends.

### Ksenia Nashotah, Wis.



When Phoenix was born, her parents noticed she was having difficulties eating and sleeping and wasn't meeting developmental milestones. She was referred to the Genetics Clinic at Children's

## Phoenix

#### Sister Bay, Wis.

Wisconsin. The genetics counselor at Children's had seen Phoenix's symptoms in their studies, and when she was 3 months old, she was diagnosed with Marshall-Smith Syndrome. This syndrome is an ultra-rare genetic bone disorder that less than 60 people worldwide are known to have had. Most children with this syndrome don't live past age 3. Phoenix had a trach and G-tube put in to help with breathing and eating and has had several surgeries

and procedures since. Phoenix, now almost 10 years old, makes several visits to Children's Wisconsin each year to see more than a dozen specialists, including our Complex Care team that has helped Phoenix thrive and grow. Phoenix loves all types of art and music and loves to laugh, read books and play with dolls.





Two years ago, now 13-year-old Sammy had scored several touchdowns in his football game the day before – but suddenly he had severe stomach pain and fatigue. Sammy saw doctors in Sheboygan who suspected it was his appendix, but they weren't

comfortable operating on a child Sammy's size so they sent him to Children's. Once at Children's, several tests and scans revealed Sammy's appendix was fine, but he had a mass attached to his colon. Sammy's body began shutting down – fluid was building around his lungs, his organs began swelling and he needed a blood transfusion. After he was moved to the Pediatric Intensive Care Unit, the rheumatology team found that the mass was lymph nodes that had swollen and bonded together. Specializing in the unusual, Children's providers started Sammy on a steroid treatment and his condition began to improve. After three weeks of treatment and physical therapy, Sammy was able to go home and is doing well today.

Almost 2-year-old Amelia is a sweet and funny girl who loves to talk, run, read books and play with animals. When Amelia was 6 months old, she was often sick with fevers, rashes and colds. In February 2022, she was vomiting, breathing at a fast pace and making grunting noises. After local providers discovered Amelia's heart was enlarged, she was transported to a local hospital. She was intubated, had a feeding tube placed and underwent many tests. She was diagnosed with Kawasaki disease and experienced a leak in one of her heart valves, four coronary aneurysms and multiple blood clots. Amelia was transported and admitted to Children's Cardiac Intensive Care Unit to receive more specialized care. After weeks of heart monitoring, medications and other efforts to reduce stress on her heart, she slowly started to heal. Today, Amelia takes medications and continues to see specialists at Children's for lab work, echocardiograms and other cardiac tests.

### Amelia

**Cottage Grove, Wis.** 



### Jackson "Jack"

Manitowoc, Wis.

funny noises. His parents took him to a local emergency department and he was later transported to Children's Wisconsin. Jack was diagnosed with hypoplastic left heart syndrome, one of the most complex congenital heart conditions, which requires a series of three open-heart surgeries. After these surgeries when Jack was 11, he went in for a routine checkup and doctors discovered he was in end-stage heart failure. He deteriorated quickly while in Children's Cardiac Intensive Care Unit and was placed on

When Jack was a few days old, he was cold,

fussy, wasn't nursing and began making







# Gabriel

Juneau, Wis.

Gabriel has seen many specialists at Children's Wisconsin during his 16 years. Gabriel was born with Down syndrome and has autism. It's not always easy for Gabriel to express himself or communicate his needs, and he has sensory issues that make going to appointments challenging for him. Gabriel comes to Children's Dental Clinic for regular cleanings and checkups, where the specialists provide patient, safe and appropriate care for him. Sometimes he receives medication before procedures and

every couple years he receives sedation so he can obtain a deep cleaning and complete X-rays. Children's providers worked together while Gabriel was under sedation to take care of other medical needs, like cleaning his ears, a sedated hearing test and endoscopy when he was having trouble swallowing. In addition to attending home school, he loves listening to music, swinging and watching his dad in his workshop.



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15-year-old Dalton loves hockey, track and football. When Dalton was 11, his mom discovered his torso was shockingly thin. Dalton had been having difficulty swallowing for a few months but had been embarrassed to say anything. Dalton's primary doctor referred him to a local gastroenterologist (GI), who suspected he had achalasia, a rare swallowing disorder where nerve cells in the esophagus deteriorate and disrupt swallowing. They referred him to Children's Wisconsin, which is one of the only pediatric facilities in the Midwest to offer a specific achalasia testing procedure. Following this test, Dalton was diagnosed with type 3 achalasia, an exceedingly rare condition for a child and the most severe type. Dalton was the first patient at Children's to have a relatively new procedure called Peroral Endoscopic Myotomy (POEM), which cuts the muscle fibers to enable swallowing. Dalton had a follow-up procedure to make additional incisions, and now Dalton can eat more normally, has more energy and continues to receive follow-up care.

**Dalton** Wausau, Wis.





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