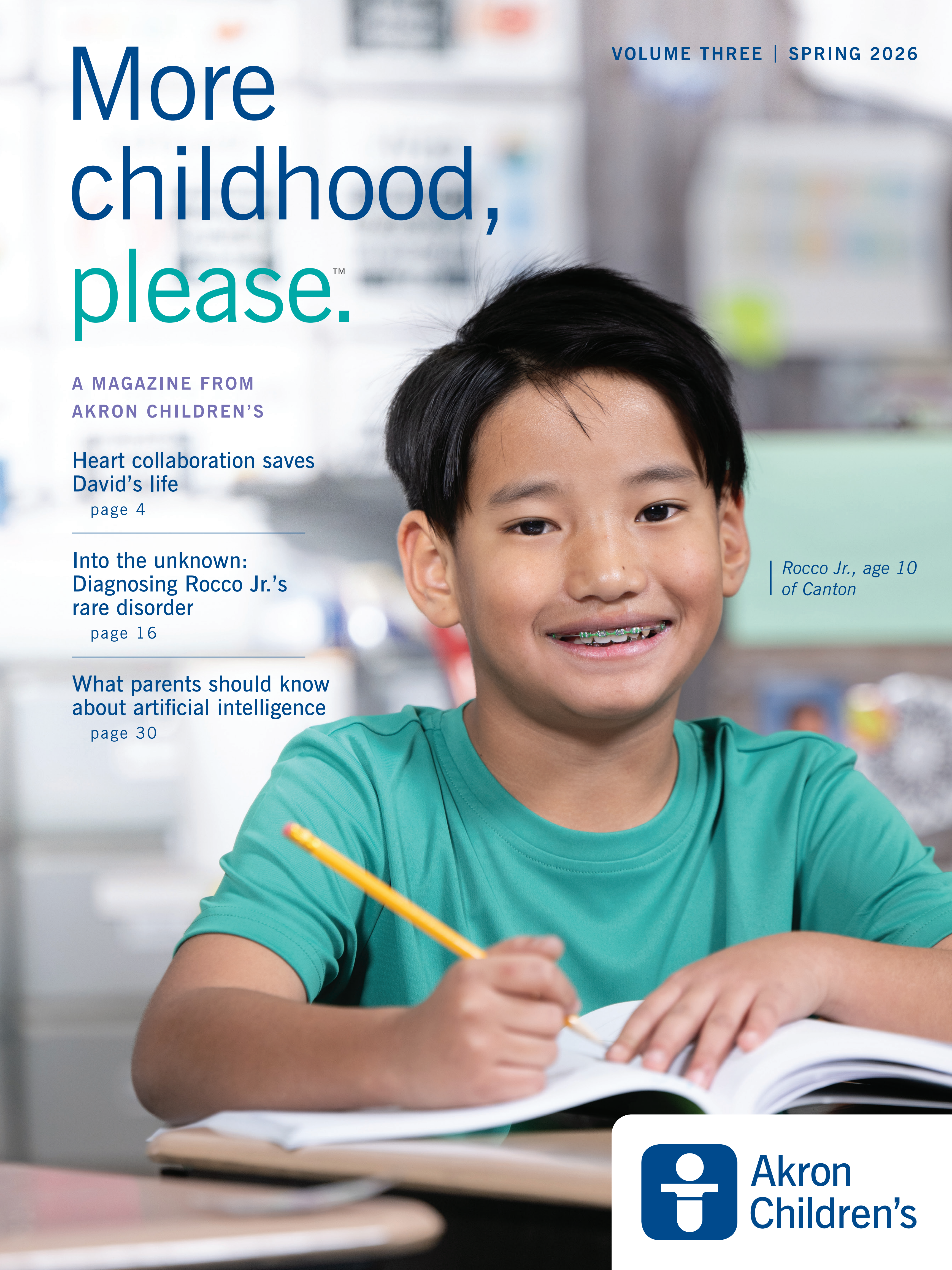
VOLUME THREE | SPRING 2026

More childhood, please.™

A MAGAZINE FROM AKRON CHILDREN'S



*Rocco Jr., age 10
of Canton*

Akron Children's

A letter from Chris Gessner

Dear friends,

Last year, we launched More childhood, please.™ We hope the magazine left a lasting impression. In this new issue, we're proud to share more powerful stories from the patients, families and caregivers who inspire us every day.

You'll meet Rocco Jr., a 10-year-old born with a rare genetic condition that causes hundreds to thousands of precancerous polyps. He underwent a series of operations, and as a result of Rocco's determination, his parents and medical team, he is on a path to an active and healthy life.

You'll also read about David, whose parents learned of his serious heart defect at the 20-week ultrasound. They wondered if their baby would be too sick for treatment, and thanks to the cardiology and cardiothoracic surgery collaboration between Akron Children's and Cincinnati Children's, doctors had a surgical plan in place before David was even born. With multiple heart interventions complete — and one more on the way — David is a curious and happy baby.

In addition to these patient stories, you'll enjoy a special photo essay that captures many ways the Akron Children's team motivates patients during treatment and celebrates their milestones. Whether patients are battling cancer, healing from a burn injury or working to improve their mental health, our caregivers cheer for them every step of the way.

Thank you for your continued confidence in Akron Children's.

Warm regards,

Christopher A. Gessner

Chris Gessner
President and CEO

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Heart collaboration saves David's life

For Bethany and Jimmy Campbell of Brimfield, Ohio, 2025 is a year they will always remember. They celebrated five years of marriage and eagerly awaited their first baby, David. They also faced fear after doctors found a serious heart problem before David was born, one he might not survive. But thanks to teamwork between Akron Children's Heart Center and Cincinnati Children's Heart Institute specialists, David beat the odds.

by Heather Bauders

Diagnosis, planning and immediate intervention

"At the 20-week anatomy ultrasound, they found an issue with David's heart," Bethany recalled. "They sent us to Dr. Chandrakant Patel, cardiologist in the Akron Children's Heart Center, and the Maternal-Fetal Medicine department because my pregnancy became a high-risk one. We faced so many unknowns before David came into the world. We knew that he would have a serious heart defect and may be too sick for treatment."

Tara Karamlou, MD, MSc, a cardiovascular surgeon, who serves as the joint program surgeon for Akron Children's and Cincinnati Children's heart collaboration, met with Bethany and Jimmy before David arrived. "Dr. Ari Gartenberg, interventional cardiologist, and I saw David prenatally," she said. "We discussed David's complex case with our Cincinnati Children's colleagues and came up with a surgical game plan."

His diagnosis of "hypoplastic left heart syndrome (HLHS)" means the left side of the heart is underdeveloped and does not pump blood to the rest of the body. He had an additional complication — a "restrictive atrial septum" — which would require a heart catheterization immediately after birth. Then, he'd need a series of surgeries to give him a chance to live.

Bethany planned to be induced in August 2025, but David had other ideas. Her water broke Aug. 1 — and he arrived at 9 a.m. the next day at Summa Health in Akron. Three hours later, an ambulance transported David and Jimmy to Akron Children's.

That afternoon, David needed an emergency catheter procedure called an "atrial septostomy" to improve blood flow between the two upper chambers of his heart. He needed it to save his life and stabilize him for open-heart surgery. "Bethany got a day pass from Summa and came to Akron Children's to see David," Jimmy said. "I baptized him in the pediatric intensive care unit (PICU) before the procedure, which was very special."

The next morning, David flew to Cincinnati Children's in the Akron Children's medical helicopter.

Specialized surgery

Akron Children's collaborates with Cincinnati Children's to provide complex care in medical specialties including congenital heart disease. The partnership, which began more than a decade ago with kidney transplant care, is expanding to bring world-class congenital heart surgery and cardiac services closer to home for patients and families in the Akron area.

At 5 days old, David had open-heart surgery in Cincinnati. "David's left ventricle couldn't do the job of pumping oxygenated blood to the body because it was too small," said Dr. David Morales, MD, executive co-director of the Cincinnati Children's Heart Institute. "As a result, we performed the Norwood procedure on him. We put the aorta, which usually takes blood rich in oxygen to the rest of the body, with the lung artery. This newer, larger neo-aorta now goes from the right ventricle to the body. We also used a shunt, a tube that connects the right ventricle to the lung arteries, to take blood to David's lungs."

After months of uncertainty and multiple surgeries, Bethany and Jimmy treasure each day with David.

The Akron Children's and Cincinnati Children's heart specialists had a surgical plan in place before David was born.

The Cincinnati Children's specialists perform more than 20 of the rare Norwood procedures a year, along with other complex heart surgeries on the sickest babies. "The day a baby gets heart surgery is one the family will never forget," Dr. Morales said. "It's a very intimate time — talking to them, having them sign the surgery consent form and knowing they're entrusting their baby to you. We can't guarantee them a result, but we can guarantee that everyone on the team is going to do their best."

A second surgery

David spent two weeks at Cincinnati Children's, recovering from surgery. He came off the ventilator days faster than most babies, and his family was relieved he responded so well.

He returned to the Akron Children's PICU to continue his recovery — and he finally went home in late August. "We were happy but terrified," Bethany said. "We were first-time parents, and we'd never been more than 20 feet from a medical professional since David was born. We had a laundry list of medications and had to do tube feedings. We tracked his food intake, time spent feeding, weight, heart rate and blood oxygen saturation each day — and sent that information to the doctors via MyChart. But the Heart Center team provided great guidance, giving us red flags to look for that would require a call to the cardiologist."

> "Every single person on his care team has been encouraging and kind. We're so blessed."
>
> *- Bethany, David's mother*

David is the first grandchild on either side of the family, and everyone wanted to meet him. "We needed to keep our high-risk baby safe, but we didn't want his entire life to be spent in a doctor's office," Jimmy said. "Our immediate family and friends got to meet him. We did fall activities including taking David to the zoo, the apple orchard and on walks — so he could be outside and away from crowds."

David's heart is functioning well, and he loves airplane rides from his dad.

The Norwood procedure kept him alive until he grew enough to have a second surgery — the Glenn procedure — at Akron Children's in early December. "Glenn is an intermediate surgery for babies with HLHS and other single-ventricle heart defects," Dr. Karamlou explained. "We removed the shunt from the Norwood procedure, creating a direct connection to the lungs to improve oxygen levels and reduce the workload of David's single ventricle."

David did well after the Glenn procedure, and the cardiology team is pleased with the function of his heart. "He's been a rock star," Bethany said. "Our checkups and follow-ups aren't as frequent. Jimmy and I are back to work. We're doing 'normal' things like planning play dates, so David can finally start meeting some of his friends."

Looking ahead

David's next surgery will take place as a toddler. "He'll need a Fontan procedure around 3-5 years of age, which we'll do at Akron Children's," Dr. Karamlou said. "We'll bypass his heart and redirect oxygen-low blood directly to the lung arteries. This will boost his oxygen levels and reduce the strain on his heart. Until we perform the Fontan, his oxygen will be lower than other kids. This will eventually lead to some limitations in his exercise capacity."

Looking back

For Dr. Karamlou, a patient like David highlights the strength of the Akron Children's and Cincinnati Children's partnership. "It provides opportunities for collaborative learning, as we share expertise and innovative ideas," she said. "We make both programs better, and our patients receive world-class care."

For Bethany and Jimmy, they look at their son with sheer amazement. "It's been quite a journey, but we rely on our faith in God and our faith in David's doctors," she said. "Every single person on his care team has been encouraging and kind. We're so blessed."

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A perfect match: Elliott's brother becomes her donor

Though rare, the "hemoglobin SD" type of sickle cell disease has touched the Varner family of Akron. Twice. The oldest sibling, 12-year-old Carson, does not have the inherited condition. But his younger siblings — 9-year-old Benny and 6-year-old Elliott — are affected.

by Heather Bauders

Dr. Bodas cuddles baby Elliott at one of her first sickle cell appointments.

Hemoglobin SD

Sickle cell disease affects red blood cells, which are normally round and flexible. People with sickle cell disease have red blood cells that are hard, sticky and shaped like a farm tool called a sickle. Those with hemoglobin SD inherit both hemoglobin proteins S and D. The abnormally shaped cells can clump together, blocking blood flow and oxygen to the body. Symptoms include pain, anemia, organ damage — and complications can lead to fatigue, infections and strokes.

Sickle cell care for Benny and Elliott

Benny was the first Akron Children's patient to receive care for the hemoglobin SD type of sickle cell disease. "After Benny, we only had a 25% chance of our next child being born with sickle cell disease," the kids' mom, Brittany, said. "I guess we got the bad odds because Elliott was born with it. We found it at her newborn screening."

Prasad Bodas, MD, hematologist-oncologist and director of the Akron Children's Sickle Cell Program, had already been treating Benny. Elliott became his patient when she was just 2 months old. "I care for quite a few siblings who are impacted by sickle cell disease," Dr. Bodas shared. "Working with Benny and Elliott — and getting to see them together during appointments — is doubly rewarding."

As Benny's symptoms worsened, Dr. Bodas recommended a special blood test that looks at proteins found on cells in the body. Finding a match for a bone marrow transplant can potentially cure someone with sickle cell disease. Even though Benny had more severe symptoms, Dr. Bodas also wanted to test Elliott. She didn't have pain episodes like her brother, but she battled lung complications and had her spleen removed at age 3.

Carson, Benny and Elliott got tested. Carson, the unaffected sibling, matched Elliott but not Benny. Brittany and her husband, Vicktor, discussed what to do about getting Carson's bone marrow harvested for Elliott.

"A bone marrow transplant has risks and can be fatal for the recipient. It wasn't like Elliott was in a life-or-death situation and needed the transplant to survive," Brittany shared. "We talked about waiting to see if her symptoms worsened, but we didn't want to wait too long and miss the window of opportunity. We discussed options with Dr. Bodas and his team. He gave us the confidence to proceed with the transplant."

Preparing for the transplant

Elliott underwent extensive testing to reduce her risk of transplant complications. Blood work, echocardiograms, electrocardiograms, a chest X-ray and urine tests gave the transplant team a baseline of how Elliott's organs functioned.

Afterward, Elliott was admitted to the hospital for chemotherapy. "We had to destroy her immune system to get her body ready to accept Carson's bone marrow," said Courtney Culbertson, MSN, APRN-CPNP-AC, CPHON, BMT-CN, hematology and oncology nurse practitioner on the bone marrow transplant team. "By eliminating her cells, that reduces the probability of the sickle cell disease returning."

Dr. Bodas, Courtney and the transplant team harvested Carson's bone marrow on May 6, 2025. The next day, Elliott received Carson's bone marrow via infusion. But she wasn't out of the woods just yet.

The road to recovery

Because Elliott's body had to rebuild its immune system, she spent more than a month in the hospital. Brittany, Vicktor and any clinicians entering the room wore masks — and Elliott couldn't leave her hospital room. "She wanted to go outside and play like a regular kid," Brittany said. "It was a hard time for the whole family. Vicktor still had to work, and we have Carson and Benny to take care of. My brother, Dewey, lives with us — and he was a big help."

To pass the time in her hospital room, Elliott played doctor, makeup artist and stylist. She put a schedule on her door, offering checkups and makeovers for nurses. She "dressed to impress" and had clothing competitions with the nurse practitioners.

"Elliott did awesome with the bone marrow transplant, and she handled the entire situation with grace," Courtney shared. "She brought a smile to our faces each day."

The high risk of infection impacted what Elliott could eat. In addition, some foods didn't taste the same after chemotherapy. She had a nasogastric tube (NG tube) for feeding for three months after the transplant to ensure she received enough calories and fluids. She had to avoid fresh vegetables — especially ones like lettuce that are hard to wash — and restaurant food.

Carson, Benny and Elliott love life — and each other.

Stem cell transplant program recognized

Although Benny couldn't get a bone marrow transplant, there's still hope. Akron Children's Hematology and Oncology earned Foundation for Accreditation of Cellular Therapy (FACT) accreditation in 2025. This accreditation allows Akron Children's to offer additional treatments including gene therapy. Benny will be eligible for gene therapy when he's 12, and successful treatment could greatly improve his quality of life.

Dr. Bodas gets a double reward in caring for Elliott (center) and Benny.

Elliott finally got to go home in June 2025. "It was tough at first with the tube feedings, all the medication and her sense of taste being off from the chemotherapy," Brittany shared. "We had to keep her away from crowds and neighborhood kids, so it was an exhausting and lonely time."

'No signs of the disease'

Although she still struggles with the taste of meat, Elliott enjoys her favorite foods that include blueberries, strawberries, cucumbers and Taco Bell cheese rollups. She went back to school this January.

Before Elliott lost her long hair due to chemotherapy, Dr. Bodas would style it at her medical appointments. "I used to braid her hair, building my skills because I have a daughter," Dr. Bodas said with a smile. "I now tell Elliott that her short and wavy hair looks like her favorite provider — me!"

Elliott gets regular blood tests, and the sickle cell team continues to monitor her. "The biggest risk of bone marrow rejection or the return of hemoglobin SD disease is during the first year after transplant," Brittany said. "We're coming up on the one-year anniversary, and at this point, she has no signs of the disease. Elliott is cured, thanks to Carson being a perfect match. We're so thankful!"

New inpatient behavioral health unit will transform care

by Alison Oyler

As the need for pediatric behavioral health services continues to grow, Akron Children's is opening a new, expanded inpatient behavioral health unit to improve access for children and families.

Eva Szigethy, MD, PhD, the Lois C. Orr Endowed Chair in Pediatric Psychiatry, said the new unit will not only expand the organization's capacity for inpatient care — it will reshape how that care is delivered.

The renderings below reveal a first look at the new inpatient behavioral health unit. This expanded, reimagined space is designed to increase access to care and transform the way patients are supported.

"This new unit is much more than a larger space with more beds. It's really reengineering how we provide behavioral health care and how we train staff to optimize the safety of our patients in a therapeutic environment," said Dr. Szigethy. "We wanted to make sure that we provided a tiered hospitalization experience with different subunits and programming for kids with a diversity of needs."

Opening in spring 2026, the behavioral health unit will move from its current location on the eighth floor of the main hospital building on the Akron campus to a newly renovated space on the fifth floor of the Kay Jewelers Pavilion. With a total of 40 inpatient beds for patients ages 5 to 18, the space will be divided into three units based on the patient's diagnosis and the level of support needed: regular-acute care, high-acute care and crisis stabilization.

Supporting kids and families during a crisis

The new crisis stabilization unit provides brief, intensive crisis management for kids who require a short hospitalization, averaging three to four days. Dr. Szigethy shared that it will provide a new care pathway for patients who are often seen in the emergency room but don't require a long-term stay for treatment.

"The objective of the stay is truly, as the name suggests, to give the child and the family the crisis management skills they need, as well as a few days to prepare at home," she said. "We connect them to resources in the

Participants at the summer behavioral health camp engage in art and journaling activities, using creative projects as tools for reflection and building healthy coping skills.

community, either with our programs or our community partners. The parents can safety-proof their house, get extra support for their child in school and benefit from more intensive parent training."

Donna Koterba, MSN, RN, NE-BC, CRRN, director of the inpatient behavioral health unit, said that allowing parents and caregivers to stay overnight with their child is an important new undertaking for the unit.

"Our new crisis stabilization unit will keep families involved and connected during a difficult time," she said. "Families are considered partners in care, not visitors, and this new unit will help to strengthen the entire family's coping skills."

Creating a safe, therapeutic environment

The new space's thoughtful design uses therapeutic architecture, incorporating color schemes and natural light that have been shown to reduce stress and promote healing.

It features a spacious gym for structured group activities and exercise, a multimedia room, a sensory stimulation room and a large outdoor area. "I'm so excited that our patients will be able to get outside," Donna expressed. "It's going to create a calming, natural environment that encourages physical activity and movement, which is essential to their mental health and well-being."

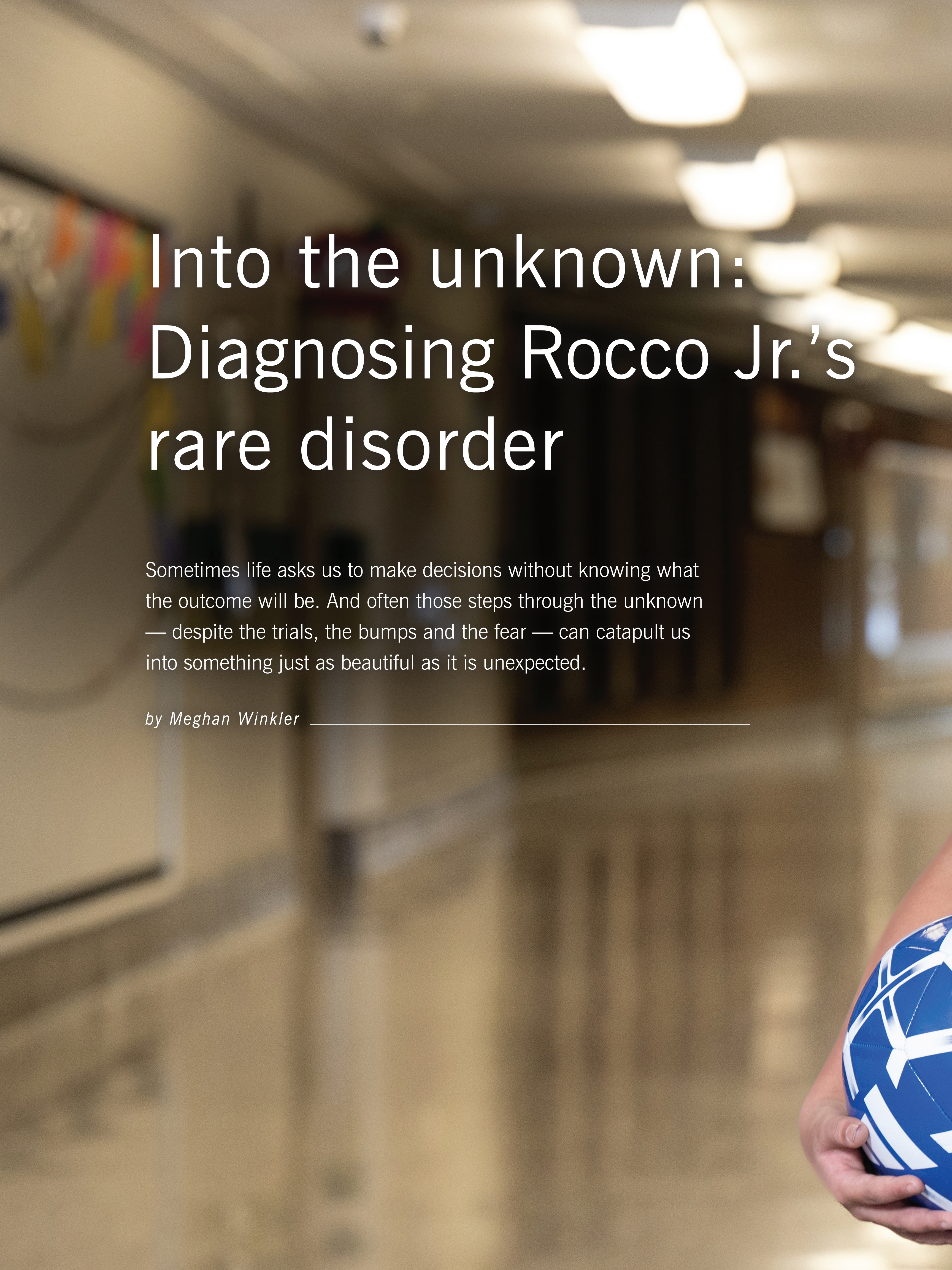
New programming to support healing

Dr. Szigethy described how the new space will support improvements to behavioral health programming. "We're implementing a program that encourages behavior change through positive reinforcement by staff using a token economy system," she said. "Families are trained in these positive reinforcement techniques so they can maintain them once the child goes home."

Donna said as more children and teens in our region struggle with anxiety, depression and other mental health disorders, this new unit will help to provide essential behavioral health care services closer to home.

"There are so many kids who are in crisis and need help," she said. "Having this expanded space is going to open the door for more kids, especially through the crisis stabilization unit. Not every child who comes to the hospital in crisis needs to stay here for a long time. Sometimes they're just going through a hard time or trauma, and we'll help them work through it.

"This new unit represents hope for children and families, who may not have otherwise had it," she added. "It will provide an atmosphere that understands mental health and the care that is essential to healing."



Into the unknown: Diagnosing Rocco Jr.'s rare disorder

Sometimes life asks us to make decisions without knowing what the outcome will be. And often those steps through the unknown — despite the trials, the bumps and the fear — can catapult us into something just as beautiful as it is unexpected.

by Meghan Winkler


Mila
Rocco

Rocco Jr. with his care team, Dr. Kevin Watson, gastroenterologist (left); Morgan Houser, nurse clinician; and Dr. Justin Huntington, division director of pediatric surgery.

Crystal Brodzenski and Rocco Ross Sr. began fostering in 2018, but most of their placements had been short term. So, when they got the call about a 4-year-old boy in need of a place to stay in early 2020, they knew opening their home to him meant embracing the unknown.

"We knew nothing about him other than he was given to us by Summit County Children's Services," said Rocco Sr.

The pandemic hit just weeks later, and it was clear the boy would be with them for the foreseeable future. But their love for him was only growing stronger, and he had quickly become a natural and essential part of their family. Two years later, they officially adopted him and named him Rocco Jr. after his adoptive father.

Rocco is a Nepalese immigrant. Despite Crystal and Rocco Sr.'s certainty that he was meant to be a part of their family, there were many unknowns around his adoption — including his family health history. So, when he started having health complications, they had no additional context to explain them.

The search for answers

Rocco always had low energy and a pale complexion, so it wasn't until an Akron Children's nurse practitioner noticed a heart murmur that anything seemed out of the ordinary. He was referred to a cardiologist who ordered some routine blood work.

Later that night, Crystal received a terrifying phone call.

Rocco's hemoglobin levels were so low he was at risk of going into cardiac arrest at any moment. They had to get him to the hospital immediately — without causing him to panic. "It was hard to navigate telling him what was going on without scaring him," said Crystal.

Rocco spent the weekend at the hospital receiving blood transfusions. While there, it was discovered that he was not only severely anemic, but he also had a significant amount of blood in his stool. The family met Kevin Watson, MD, FAAP, gastroenterologist, who worked with Rocco's hematologist to manage his symptoms. After he was stabilized, Dr. Watson then performed a colonoscopy.

"It wasn't until we did his colonoscopy that we discovered the underlying cause of his issue," said Dr. Watson.

He and his team found thousands of polyps in Rocco's colon. The extreme volume of them made biopsies impossible, which led Dr. Watson to diagnose Rocco with "familial adenomatous polyposis," or FAP for short. It is a rare genetic condition that causes hundreds to thousands of precancerous polyps to form in the colon and rectum. If untreated, it leads to a nearly 100% risk of colorectal cancer.

According to Dr. Watson, this diagnosis is very rare, especially in kids. And without his family health history, FAP was not even a consideration until the results of Rocco's colonoscopy proved otherwise.

A plan is made

Alongside Dr. Watson and his team, Rocco and his family immediately began creating a plan. He would need to have his colon and rectum removed, receive a temporary ileostomy bag to collect digestive waste and undergo reconstructive surgery.

They met with Justin Huntington, MD, division director of pediatric surgery, who told Crystal and Rocco Sr. that the best thing to do for Rocco's young body was to divide the procedure into three separate surgeries over several months. They began in February 2024, when Dr. Huntington removed his colon and created an ileostomy.

"Learning the ileostomy bag was difficult," said Crystal. But their nurse, Morgan Houser, helped them through every step of the way. "After that first surgery, we worked with her a lot. She must be the most patient person in the hospital. We felt so supported."

Rocco's second surgery was that spring when Dr. Huntington and his team removed Rocco's rectum and created a J-pouch out of small intestine to act as a reservoir for stool. And his third and final surgery was to reverse the ileostomy bag.

FAP is a lifelong condition, so he will undergo scopes at least once a year for the rest of his life. Rocco still works with the gastroenterology team, as well as neurology and genetics to prevent any future polyps growing anywhere else in his body.

A new normal

"Our biggest question after all of this was, 'Will he have a good quality of life?'" Crystal reflected. But after seeing his high-energy personality return, as well as his complexion, she is confident he will. "He has to drink a lot more water and be mindful of what he can and can't eat, but he can have a normal life. He gets to play soccer, which he loves, and go to school."

But more than anything, Rocco's parents are sure he will have a great life because of his resilience and ability to handle his condition. "He's been a champ," said Rocco Sr. He went on to describe how Rocco Jr. uses his experience to help educate kids at his school about the digestive system, and he even hopes to become a doctor or surgeon one day.

"He always says, 'If we meet someone else with FAP, I can help them,'" said Rocco Sr.

The power of positive thinking

Now Rocco is 10, and he doesn't shy away from the realities of his condition. "One of the difficult things we've had to talk to him about is that if he has kids someday, there is a big chance they could have FAP, too," Crystal said.

But Rocco isn't afraid. He knows firsthand that it's possible to not only live with FAP, but to thrive.

And that is key to his growth, said Dr. Watson. "Rocco and his family have been so positive throughout this entire process. The power of positive thinking and having gratitude really does make a big difference. That mentality has served Rocco and knowing that his parents have been so supportive carries on with him, empowering him to handle almost anything thrown at him."

Crystal and Rocco Sr. couldn't have known what was in store for them when they first met him six years ago. And through all the trials of navigating a mysterious and severe health condition, they couldn't be more grateful to raise the bright, funny and energetic boy that Rocco is today.

Rocco Jr. with his parents, Rocco Sr. and Crystal.

How a kidney transplant shaped a future nurse

by Brooke Uehlein

When you meet her today, she's a steady, confident presence in the Akron Children's Pediatric Intensive Care Unit (PICU). Aliyah Torgler, BSN, RN, speaks with warmth, provides care with a focused purpose and carries a quiet understanding from her own personal experience. What most of her patients and their families do not know is that she once lay in an Akron Children's PICU bed herself, exhausted and frightened.

Aliyah grew up in Jackson Township after being adopted from China as an infant. She arrived in Ohio at 10 months old with no medical records or known family history.

Aliyah grew up in Jackson Township after being adopted from China as an infant. She arrived in Ohio at just 10 months old with no medical records and no family history to guide her parents or pediatrician.

Her childhood was full of the usual joys such as school, having fun with friends and playing "nurse."

"I remember using shoelaces as makeshift IVs or as bandages on my stuffed animals," shared Aliyah.

During track season in eighth grade, Aliyah noticed she could not keep up at practice. She started sleeping more and had no stamina as the day progressed. Strange bruises appeared in places that didn't make sense. Her mother noticed these changes first, sensing the excessive napping was deeper than teenage fatigue.

Aliyah's pediatrician suspected hormones and suggested a visit to an allergy and immunology doctor. Her first round of tests and blood work was so alarming that the provider ordered a redraw. After the same results a second time, the provider concluded Akron Children's would be better suited to help Aliyah.

"It was a Saturday morning when the phone rang," said Aliyah, describing the prompt instructions given to her mother to drive north to Akron Children's Hospital Emergency Room. By the time they reached Akron, Aliyah was in acute kidney failure.

Aliyah remembers the blur of that day with the rush to the PICU and the fear she might die. She learned the unfamiliar word "nephrologist," which is a doctor who specializes in diagnosing and treating kidney conditions. Little did she know that her nephrologist, Shefali Mahesh, MD, would become a defining figure for her and her family.

"I remember thinking, 'I don't understand what's happening,'" Aliyah said. "But I know it's serious."

Within hours she began "hemodialysis," a medical treatment that supports filtering waste, toxins and fluid from a person's blood when kidneys fail.

"Aliyah had shrunken and scarred kidneys; it was clear that she would not recover any function," explained

Dr. Mahesh. "Although she was scared, she was decisive and had a 'let's tackle this problem' attitude. In hindsight, she had the makings of a PICU nurse back then too: staying calm in a crisis and a desire to find a solution."

Dr. Mahesh explained dialysis and how it would be a bridge to a transplant. "This is important to convey, especially with children, so they know from day one that we are working toward the goal of getting them off dialysis and to a transplant," she said.

Aliyah remembers the protocols during dialysis and transplant time being firm with rules such as no new pets for the family, undergoing psychological evaluations, home inspections and endless amounts of blood draws and lab appointments. "At age 13, I learned a whole new vocabulary that included dialysis, transplant, phosphorus and potassium," she shared.

She endured a year of machines, tubing, sterile routines and responsibility. Her parents helped with logistics, but Aliyah eagerly learned how to set up her dialysis herself. She recalls meticulously washing her hands and learning each step.

> "It is impossible to put into words what that gift meant. It gave me my life back. I will never be able to thank this person enough."
>
> *- Aliyah, PICU nurse*

Once a PICU patient herself to now a PICU nurse, Aliyah Torgler, BSN, RN, cares for the next generation at Akron Children's.

"Always being intrigued by the medical field, I would research and look things up on my own," she said. "Looking back, I learned a lot at a very vulnerable stage of life."

As time passed, Aliyah missed being a freshman high school student and felt her world narrow into a series of medical appointments, dietary restrictions and the long wait for a transplant. A bright memory was when her closest friend, McKenna, and her mother stopped by for a surprise visit. Teachers expressed their care and encouragement via a school tutor who came to the house. Aliyah said her care team became an extension of her family.

Once her nephrologist, now her colleague, Dr. Shefali Mahesh and Aliyah share a meaningful bond on the same care team.

In November 2015, after a very active donor search, the call came that there was a living donor match. It was an acquaintance; someone connected to her family stepped forward.

After receiving the news, Aliyah and her mother prepared to travel to Cincinnati Children's. Through a collaboration between Akron Children's and Cincinnati Children's, the Cincinnati specialists performed the transplant Nov. 17, 2015. She returned to Akron Children's just eight days later.

"It is impossible to put into words what that gift meant," Aliyah said. "It gave me my life back. I will never be able to thank this person enough. Because of this donor, I graduated high school and attended college 'on time.'"

Recovery was slow and steady. By the start of her sophomore year, Aliyah began to feel like a teenager again. She returned to school and started to imagine what the future may hold. Her experience affirmed her decision for a future profession in health care.

"I spent years watching nurses do more than care for a patient," said Aliyah. "They care for a whole family."

Aliyah remembers the providers and nurses who were gentle when she was scared, patient when she was overwhelmed and present in ways that mattered. Aliyah knew she wanted to be that for someone else.

While attending nursing school at The University of Akron, she also participated in the Akron Children's Assuring Success with a Commitment to Enhance Nurse Diversity (ASCEND) clinical internship program as a nurse tech. She eventually found her way back to the PICU, serving in a unit she once spent many days in as a patient.

Today, Aliyah brings a perspective few clinicians have. She knows what it's like to be the child in the bed. She knows what if feels like to have a worried parent at the bedside. And she knows what it means to have a team that refuses to give up on you.

"Our relationship has evolved from doctor and patient to now being on the same care team," said Dr. Mahesh, who has worked with Aliyah to care for one kidney patient in the PICU so far. "She is my only patient who is now a caregiver at Akron Children's. This is so unique."

Aliyah's life now is full of work in the PICU, exploring new restaurants, being active with her dogs, Benny and Stetson, and planning her upcoming wedding with her fiancé, Derek. Her dear friend from middle school who knocked on her door during a challenging time, McKenna, will serve as her matron of honor during one of the happiest days of Aliyah's life.

As Aliyah reflects on her journey, she is overwhelmed with gratitude and all those who shaped her childhood and future: her donor, parents, friends, nephrology team and Dr. Mahesh.

To those children and their families waiting for transplants, she offers a message only someone who lived it can give:

"I see you, and I know how hard it is. Life will look very different one day, and it is worth the wait."

Give more "CHEESE!"

Marty Joe, age 2
cleft lip & palate
bilateral clubfoot

Marty Joe might not know he was born with cleft lip and palate or bilateral clubfoot. But he does know some important things: like how to howl like a wolf, melt hearts with a smile and stomp in puddles like a pro. Your donation helps us give more kids like Marty Joe the childhood they deserve.

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Banners, beads and bells mark treatment milestones

From cancer to mental health issues to severe burns, treatment can be a long and sometimes painful process. Akron Children's caregivers love to encourage patients along the way — and celebrate when they finish treatment. Here are some special ways Akron Children's departments show support for their patients.

by Holly Pupino


CAROLIN

Spreading cheer together, Beads of Courage CEO Beth Moneck (left) shows off beads with Child Life Specialist Renee Redenshek.

Beads of Courage

Patients battling cancer receive a keepsake — a colorful, artist-made glass bead — to mark each blood draw, hospital admission, chemo round, test or procedure. Ask any patient with cancer or a blood disorder about a bead on their strand, and they will know the story behind it. They might have even designed one or two beads themselves, thanks to the national nonprofit Beads of Courage, Inc. and local donors who make it all possible.

"Patients are so proud to display their beads," said Child Life Specialist Renee Redenshek. "It's flipped the script from, 'I went through all of these terrible, scary things' to 'Look at how brave I was this whole time during treatment.' It's been a really helpful tool."

Caroline Martin proudly shows beads she collected throughout her cancer treatment.

Levi Buxman, with his parents Branden and Lauren, rings the end-of-treatment bell after battling leukemia since being diagnosed in November 2023.

Project Outrun and the Finish Line Festivals

In addition to Beads of Courage, patients can create a pair of custom-designed sneakers at the start of cancer treatment. The shoes — donated by the nonprofit organization Project Outrun — remind patients of the importance of staying active and continuing to pursue their dreams.

Project Outrun also coordinates end-of-treatment ceremonies that have taken on the vibe of a marathon finish line party. There's a giant inflatable finish line arch, a medal, a gift card to the patient's favorite restaurant and a bell to ring. But first, the patient pass through a tunnel of friends, family and providers holding signs, tossing streamers and clapping.

"We call them Finish Line Festivals because what these kids are enduring is so physical," said Project Outrun founder Andy Shepperd. "Providing the Finish Line Festivals — and celebrating end of treatment with our Project Outrun families — means so much to us. We love being a part of their fight and their finish, as they ring cancer's bell."

Project Outrun founder Andy Shepperd provides Finish Line Festivals for patients like Levi to celebrate the end of cancer treatment.

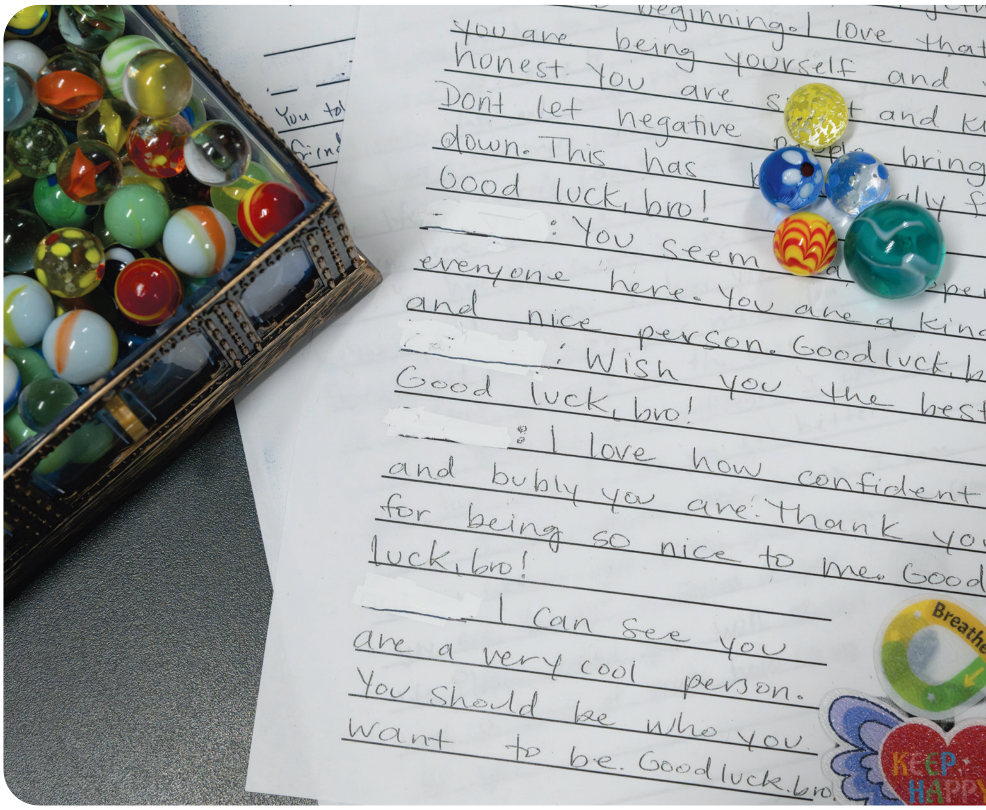
At PHP graduation, each patient chooses a marble to symbolize the skills and support they received during the program.

Partial Hospitalization Program marble ceremony

For young people diagnosed with anxiety, depression or other behavioral health challenges, the Partial Hospitalization Program (PHP) offers 10 days of intensive psychiatric services in an outpatient setting. When it's time to fully reengage with school and home life, the PHP graduate chooses a marble — and fellow participants gather in a circle for a send-off.

"Each patient holds the marble and shares an affirmation," said Catherine Thier, behavioral health clinical operations supervisor. "It might be something like 'I like your style,' 'I like the way you opened up about your trauma' or 'I appreciated the way you validated me.' The therapist writes down all the comments, we decorate and laminate it. I know of PHP graduates who still have that marble 10 years or more later."

PHP graduates receive affirmations from fellow program participants.



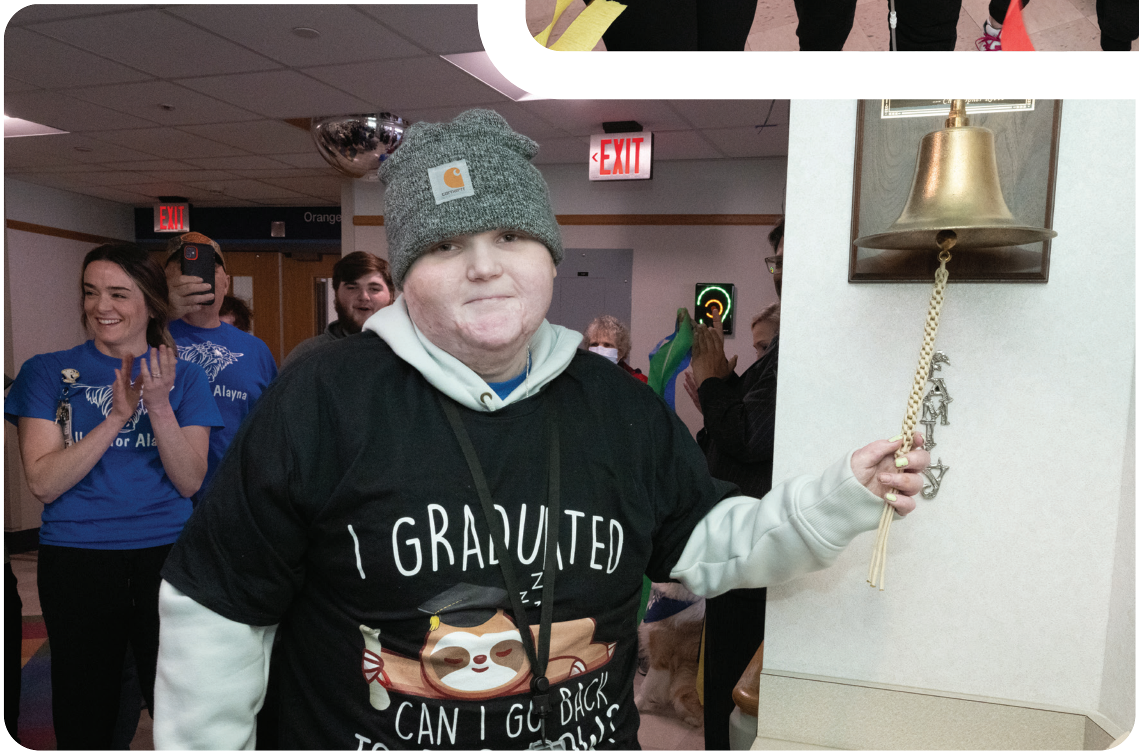
beginning. I love that
you are being yourself and
honest. You are s t and k
Don't let negative p ople bring
down. This has b ally f
Good luck, bro!
[redacted]: You seem a
everyone here. You are a kind
and nice person. Good luck, b
[redacted]: Wish you the best
Good luck, bro!
[redacted]: I love how confident
and bubly you are. Thank you
for being so nice to me. Good
luck, bro!
[redacted] I can see you
are a very cool person.
You should be who you
want to be. Good luck, bro.

Burn Institute bell-ringing celebration

To overcome a severe burn requires strength and perseverance. When patients complete treatment at the Adult and Pediatric Burn Institute, supported by The Paul and Carol David Foundation, they ring a restored fire bell that features a quote from the late actor Christopher Reeve: “A hero is an ordinary individual who finds the strength to persevere and endure in spite of overwhelming obstacles.”

Anjay Khandelwal, MD, FACS, FICS, FABA, medical director of the Burn Institute, said each patient’s bell-ringing ceremony is personalized with music, messages and the people important to their recovery. “We give them a medal — a symbol of the phoenix that indicates rising from the ashes,” he shared. “The medal is inscribed with the words: courage, strength, resilience and hope. I let them know how proud we are of them as a team.”

Alayna Bailey’s care team, family and friends gathered for her clap-out to celebrate the end of inpatient burn treatment.



What parents should know about artificial intelligence

by *Meghan Winkler*

Dr. Sarah Rush, vice president of medical informatics, and Dr. Michael Redovian, child adolescent psychiatrist, respond to questions on AI use by sharing their clinical perspectives.

Artificial intelligence (AI) is a powerful tool, and its effects are far-reaching. Not only does it impact the business and professional world, but it is increasingly prevalent in social, creative and academic spaces as well — where kids are coming face-to-face with this fast-growing technology.

To help parents navigate this topic, Michael Redovian, MD, child adolescent psychiatrist, and Sarah Rush, MD, vice president of medical informatics, sat down to answer some of your questions about AI.

How do you explain AI to kids?

Dr. Redovian: It's important to first assess what your child already knows. Start by addressing any misconceptions they might have, and make sure you're talking about AI in the context of being a tool.

Some kids might be interested in the nitty-gritty of it all (algorithms, predictive modeling, etc.). But if you emphasize AI's role as a tool or a toy that needs to be used appropriately, you're on the right track.

Dr. Rush: AI is math, not magic!

It is basically a super-powered pattern finder. It looks at huge numbers of examples and uses math to make its best guess about what should come next. That's why AI can feel impressive and why it can mess up. It doesn't "understand" like a person does.

Use AI like a learning tool. It can help you brainstorm or explain a topic in a different way. But it is important that you read everything it writes and check it with a trusted source (parent, teacher, textbook, reliable website).

With the use of AI, do kids risk losing the ability to think independently? How can they develop confidence in themselves if they always rely on AI for an answer?

Dr. Redovian: There's always the risk that kids can over-rely on a given tool, especially one as powerful as AI. Our job as parents, educators and responsible adults is to educate the kids on how to use the tool safely and effectively. This means that if they're going to use AI to help them better understand a topic, show them how to make sure the answer is valid.

If they're tempted to use AI to produce an essay, talk to them about how these types of essays typically feel "soulless" because there's no personal connection to the material — and how teachers have tools at their disposal to check whether something is genuine or AI-produced.

Trying to tell kids that they shouldn't use AI is probably not going to help, so we must educate them on proper use.

Can AI bots replace real-life relationships, and can that impact kids' empathy or social skills?

Dr. Redovian: In a study by Common Sense Media, about 48% of kids who tried AI chatbots only used it a couple of times. They looked at the chatbot as a novelty, gave it a shot and found that it wasn't nearly as cool as they thought it would be.

That said, we typically see that kids who tend to be lonely or feel misunderstood by their peers might be more likely to rely more heavily on AI relationships. The key thing to remember is that chatbots are designed to keep people engaged, so they're more likely to tell a kid that their thoughts and ideas are good. Kids might not get that feedback from peers, which could lead to social difficulties down the road. But it's too early to know for sure whether it will.

How do I set boundaries around AI use when the tech is constantly changing?

Dr. Rush: One of the best ways to set boundaries around AI is to anchor your approach in a few rules that don't change: protect your data, keep yourself accountable and use AI to help — not to replace — your judgment.

Start with data security. You don't control what happens to everything you type or upload after you press "enter." So, share the minimum needed to get help, and do not enter sensitive or private information.

Next, be clear about responsible and ethical use. In simple terms, that means using AI in ways that are honest, safe and fair.

"Honest" means you don't use AI to pretend you did work you didn't do, to fake messages or images or to mislead someone about what is true.

"Safe" means you don't rely on AI alone for serious decisions, and you don't use it in ways that could harm someone — like giving medical advice, encouraging risky behavior or helping with bullying.

"Fair" means you remember that AI can reflect bias, so you don't use it to make decisions about people (like who gets an opportunity or who is "at fault") without human review and a clear reason.

Finally, build in verification. AI can sound confident and still be wrong. Treat its output like a first draft, check important facts with reliable sources and slow down when the stakes are high.

Dr. Redovian: The most important thing parents can do for their kids is to foster open communication. Even if you don't know every single nook and cranny of the application, showing interest will show your kids that you care.

Parents can also check websites like Common Sense Media to find tools surrounding setting limits on electronics/social media/etc. It's crucial to be familiar with the parental control settings on your kids' devices and apps.

It's also important to model healthy boundaries with technology. Kids are much more likely to do what you ask them to do if they don't think you're being a hypocrite!

Health system happenings

Akron Children's will provide primary care for Broadway club members and community kids.

Akron Children's partners with Boys & Girls Clubs of Northeast Ohio

Akron Children's has been named the exclusive pediatric partner for health care services and programming for Boys & Girls Clubs of Northeast Ohio (BGCNEO). As part of the collaboration, Akron Children's will have a pediatric primary care office at BGCNEO's Broadway Club, located at 6114 Broadway Ave. in Cleveland. Club members and community children through age 21 will have access to same-day sick visits, wellness checkups, preventive screenings and behavioral health care. The facility is scheduled to open in October 2026.

Primary care network expands

Akron Children's Pediatrics expanded its reach in Stark County by opening a Jackson Township office. Community Health Care joined Akron Children's primary care network, and the practice name is now Akron Children's Pediatrics, Jackson. The brand-new office has convenient parking, 24 primary care exam rooms and access to the hospital's extensive network of pediatric specialists.

Pediatric primary care services are being added to the Akron Children's location in Montrose, which currently houses urgent care and walk-in care for orthopedic and sports injuries. The primary care office is set to open in June 2026. It will offer wellness checkups and vaccines, sick visits, management of chronic diseases such as diabetes and a dedicated behavioral health room.

"Opening these new locations is an exciting step forward in bringing care closer to home for families," said Gia Polichena, Akron Children's Pediatrics operations and strategic planner. "We're making pediatric care more convenient and accessible, so every child has the support they need to grow and thrive right in their own community."

Akron Children's Pediatrics, Jackson

Shawnee Emrich, medical assistant in the Ronald McDonald Care Mobile, vaccinates patient Mathew Robertson.

Ronald McDonald Care Mobile® serves Mahoning Valley kids

Akron Children's launched a primary care clinic on wheels, donated by Ronald McDonald House Charities of Northeast Ohio. Services range from wellness checkups and vaccines to sick visits and referrals to specialists. The Care Mobile reduces barriers to care — such as transportation issues — by visiting schools, neighborhoods and libraries. Kids throughout Mahoning, Trumbull and Columbiana counties get the medical care they need, close to home.

Warren Health Center improvements

Construction is underway at Akron Children's Health Center, Warren. Rehabilitative services moved to a larger suite. Specialty services and urgent care will have separate suites, making room for more specialties to be added. The primary care office is also adding six exam rooms and another provider. The entire project is slated to be completed in the fall of 2026.

Healthy Info, Healthy Kids campaign

Medical misinformation — the spread of false, confusing or misleading information that often goes against what medical experts know to be true — is everywhere. That is why Akron Children's launched the "Healthy Info, Healthy Kids" campaign.

Our goal is to ensure that families have access to dependable, evidence-based resources to help them make good health care decisions. Through ongoing education, clear communication and strategic partnerships, Akron Children's will continue to serve as a trusted source of truth in a rapidly evolving health information landscape.

The Healthy Info, Healthy Kids campaign tackles health care topics including vaccines, child suicide and the behavioral health crisis, gun safety, autism care and the impact of Medicaid cuts on the patients we serve. We are partnering with parents to share easy-to-understand health information with a focus on protecting and improving kids' health. Learn more by visiting akronchildrens.org/healthy-info.

The brightest light

Every family is unique, and so are their health care experiences. In "The parent's perspective," you'll learn about amazing patients from the people who know them best.

by Kailey Riffe

We noticed something was different about Nolan when he was learning to stand. He struggled with simple motor skills, and even physical therapy wasn't enough to get him on track. As a special education teacher, I'm all about early intervention, so we decided to see a neurologist.

And that's when our lives changed forever.

> "Today, Nolan's big personality is one of the brightest lights in our life. He loves to learn, play and build things – and he gifts us with belly laughs almost every day."
>
> *- Kailey, Nolan's mother*

At 2 years old, Nolan was diagnosed with Duchenne muscular dystrophy, a genetic disorder that causes progressive muscular degeneration.

We were devastated. We felt robbed of the life we had dreamed about. Questions like, "Why us?" and "Why our baby?" echoed through my head each day. The grief ran deep. It was a very difficult time in our life, and I struggled to see any light through the darkness.

But, over time, I realized that the true light in my life was my sweet, silly, bright boy. Nolan has never let his disability get in the way of his happiness, so we decided to do the same. Instead of focusing on our grief over losing the life we had expected, we chose to find the joy in the life we were given so that we can be the best parents to Nolan and his baby brother, Reed.

Now Nolan is 6 years old, and while he knows he is different, we emphasize his many strengths rather than his disability. Through building his confidence, teaching him emotional regulation and how to persevere through hard things, I like to think that maybe he teaches us to do the same.

When Nolan was 4, we were informed of a life-changing gene therapy at Akron Children's. His team in the Neuromuscular department advocated for him to the insurance company, and we will forever be grateful that they worked so diligently to get him this treatment. After years of hearing there was no hope for improvement, Nolan received the treatment in 2024. Since then, he has already taken great strides in his functioning.

Today, Nolan's big personality is one of the brightest lights in our life. He loves to learn, play and build things — and he gifts us with belly laughs almost every day. His witty sense of humor and creative spirit only grow with him as he gets older. And he is an amazing big brother to Reed and is always sure to include him in everything.

Nolan gets the laughter going for the Riffe family: Kailey, Reed, Nolan and Michael.

While I still struggle to talk about Nolan's diagnosis, focusing on the joy he brings and leaning on a strong support system of friends and family has helped a lot. I have also been able to connect with other families through Akron Children's. I even helped start the Sharpsville Inclusive Play & Accessibility Fund. As a special education teacher at the school Nolan attends, I know how difficult our playground is for Nolan and other students with disabilities to navigate. Our goal is to build a brand-new, all-inclusive playground on the school grounds — so all students can play together safely and collaboratively.

To any parent who is facing a life-altering diagnosis, these changes may feel extremely dark and devastating. It's OK to grieve and mourn the loss of what you thought would be. But when you take things day by day, you will find light in the things that make you feel positive and hopeful.

Duchenne muscular dystrophy is a part of Nolan's life, but it is not his whole life. As his mom, I know that he wants what every other child wants: to be loved, included and enjoy his life. That's why I teach my boys to have compassion and empathy and to embrace people's differences, even if they're hard to understand. Because my dream is for my sweet boy to live in a world that treats him with the love and respect that he — and everyone — deserves.

Nolan, 6 years old, began a gene therapy treatment for Duchenne muscular dystrophy two years ago at Akron Children's.

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