

Pediatrics

NATIONWIDE

Advancing the Conversation on Child Health | Fall/Winter 2026

A portrait of a young girl with dark skin and curly hair, wearing a pink shirt and a necklace with a cross. She is smiling slightly and looking towards the camera. The background is a soft-focus green and white.

Turning Evidence Into Advocacy

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for Sickle Cell Disease

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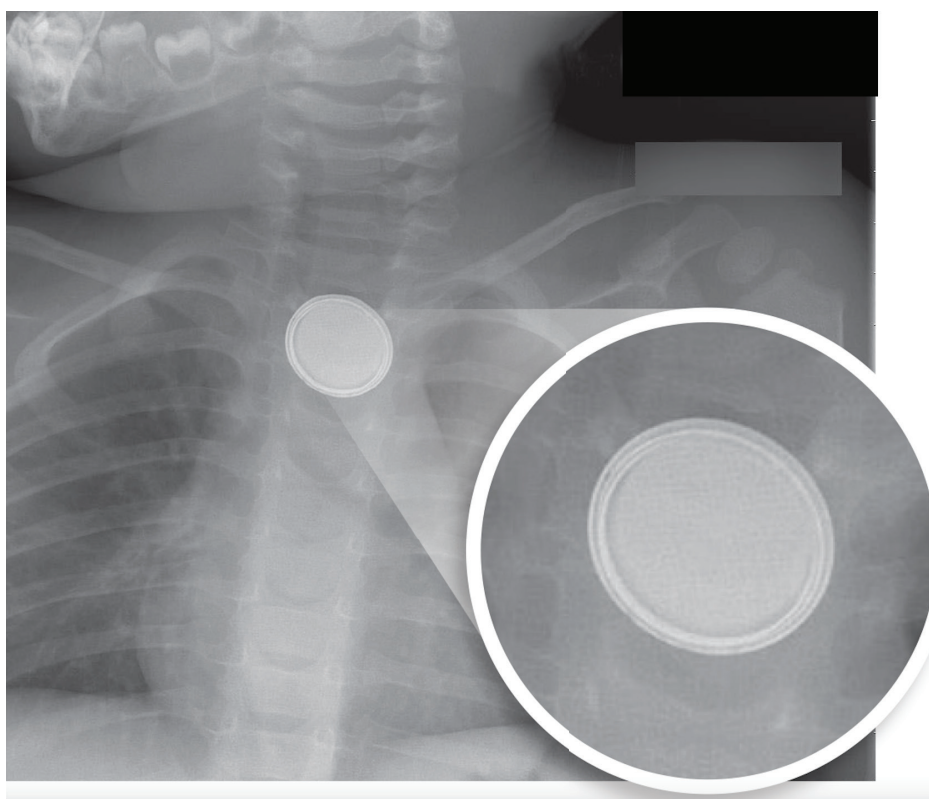
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Turning Evidence Into Advocacy

Every patient has a story, and some stories inspire change far beyond the hospital. Avery, pictured on the cover, helped drive new legislation following a devastating dog attack. Years of treating children with button battery injuries led one otolaryngology surgeon to bring together industry, policymakers, families and fellow physicians to make everyday products safer. Together, these stories show how advocacy has become an extension of patient care, helping protect children long before they ever need a doctor.



Button battery lodged in a child's throat.



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“Having my ferritin treated allowed me to compete at the level I knew I was capable of. Most importantly, I finally felt like myself again.”

— *Miriam Rule, Nationwide Children's patient*



“We learn from every trial and every patient. The future is very bright – there truly is a light at the end of the tunnel for people living with sickle cell disease.”

— *Hemalatha Rangarajan, MD, hematologist at Nationwide Children's*

Delays and Disparities in Uptake of Effective Antiseizure Medications

National prescribing trends suggest many children may receive suboptimal epilepsy therapy.



In the wake of landmark trials (SANAD II) firmly supporting the use of lamotrigine for focal and valproate for generalized epilepsy, neurologists at Nationwide Children's expected these drugs would be increasingly prescribed. Instead, their analysis of nearly 150,000 children receiving their first antiseizure monotherapy revealed that prescription of lamotrigine and valproate actually declined over time. This divide between what practice should be and what is done is known as a knowledge-practice gap, and it was more severe in socially vulnerable, Black and Hispanic patients. The study was published in *Epilepsia Open*.

"Lamotrigine is cheaper, well tolerated and more effective — it's better, but we [pediatric neurologists] don't prescribe it equitably or as much as we should," says the study's lead author Adam Ostendorf, MD, associate division chief of research and co-medical director of the epilepsy surgery program at Nationwide Children's. "It wasn't just a one-off, it was a consistent pattern that seems to be worsening."

The team examined first antiseizure medication prescriptions from 2015 to 2024 in children aged 4 to 18 years. Over this time period, lamotrigine declined from 10% to 5.5% of prescriptions and valproate from 12% to 7.5%. The decline in lamotrigine prescriptions was most profound among socially vulnerable (measured by the social vulnerability index), Black and Hispanic patients.

Levetiracetam, a less effective alternative, increased from 47% to 66% of prescriptions over the course of the study.

"We don't know the reasons behind this prescribing pattern — that's the challenge," says Christopher Beatty, MD, MAS, co-medical director of the epilepsy surgery program at Nationwide Children's and senior author on the study. "We can hypothesize that there is a bias in prescribing, or that certain communities don't want to risk certain side effects. This study opens the door for more exploration."

Lamotrigine's slower initial titration (2-3 months vs 1-2 weeks with other drugs) may also play a role in its poor uptake. However, Drs. Ostendorf and Beatty caution against assuming families cannot manage the prolonged titration.

"When we identify inequity in the care we provide, it's important to take that extra 5-second mental check and ask ourselves, 'What's the reason I'm not using lamotrigine in this patient?'" says Dr. Beatty.

The Nationwide Children's neurology team has already disseminated the information internally, created a simplified prescription order set and begun measuring their prescription trends. They are also studying other aspects of knowledge-practice gaps in epilepsy care, such as the prescription of ethosuximide for absence seizures, use of implementation science to improve outcomes in status epilepticus (NCT06194747) and the qualitative reasons behind disparities in the uptake of surgery for drug-resistant epilepsy.

"We're learning more and more that knowledge alone doesn't change practice," says Dr. Ostendorf. "We need to marry it with deliberate implementation strategies."

Ostendorf AP, Eisner M, Abdel-Rasoul M, Ahrens SM, Twanow JD, Goodkin HP, Beatty CW. Trends in antiseizure medication monotherapy for pediatric epilepsy in the United States. *Epilepsia Open*. 2026 Jun;11(3):1028-1035.

Ostendorf AP, Loddenkemper T, Morgan LA, Appavu B, Farias-Moeller R, Harrar D, Press C, Abend NS, Gaillard WD, Bai S, Eisner M, McHenry L, Kroshus E, Vannatta K, Goodkin HP. Treating seizures faster: The Quality Improvement in Time to Treat Status Epilepticus (QuITT-SE) multicenter randomized stepped wedge clinical trial protocol. *Contemporary Clinical Trials*. 2025;151:107831.

— Katie Brind'Amour, PhD, MS, CHES



Evaluating Adherence and Safety Outcomes for Neonatal UTI Diagnosis and Treatment

Neonates are at increased risk for developing urinary tract infections, yet a knowledge gap exists regarding defining, diagnosing and treating them in the NICU.

A study across seven Nationwide Children's neonatal intensive care units (NICUs) reported 77% adherence to diagnostic criteria for urinary tract infection (UTI) and no safety concerns, with 90% of infants receiving a short course of antibiotics.

A total of 77 NICU infants with non-bacteremic UTI were included in the study, conducted from November 2020 to December 2022. Results were published in the *Journal of Perinatology*.

According to study authors, several factors increase the risk of neonatal UTIs, including immunologic immaturity, urinary catheterization, urinary tract anomalies and lack of circumcision in males.

"The main issue is the lack of a uniform definition of UTI in the NICU," says Pablo Sánchez, MD, author, neonatologist and principal investigator in the Center for Perinatal Research at the Abigail Wexner Research Institute at Nationwide Children's.

"Many NICU patients will have >100,000 colony-forming units/ml of a single organism and yet have no white blood cells in the urine," he notes.

The American Academy of Pediatrics has diagnostic and therapeutic guidelines for UTIs in febrile patients aged 2 to 24 months, but research on neonatal UTI diagnosis and treatment is sparse.

Jacqueline Magers, PharmD, NICU advanced patient care pharmacist at Nationwide Children's, led a prospective surveillance study that assessed adherence and safety outcomes using the diagnostic and therapeutic guideline developed by the Nationwide Children's Neonatal Antimicrobial Stewardship Program (NEO-ASP) in August 2019.

The research team monitored adherence to the guideline's recommendation for a 5-day antibiotic treatment course for non-bacteremic UTI, as well as adherence to its diagnostic criteria.

Safety was evaluated according to whether antibiotic treatment needed to be restarted within 7 days after treatment discontinuation because of a recurrent UTI caused by the same organism. Only one patient had a recurrent UTI with the same organism within 7 days in the study results.

"The study's main takeaway was that 90% of neonatologists adhered to a short course of antibiotics for uncomplicated UTIs," says Dr. Sánchez. "This is important because reducing antibiotic use in the NICU is a constant challenge."

The 77% adherence rate to diagnostic criteria was lower than expected, raising the question about the true diagnosis of neonatal UTI and indicating a significant knowledge gap in defining UTIs in the NICU, the researchers noted.

To follow up, Dr. Sánchez intends to conduct a randomized study comparing short- versus long-term antibiotic treatment duration for NICU UTIs.

Dr. Magers remarked that the NEO-ASP has had significant buy-in from NICU specialists, with a noticeable reduction in antibiotic use. However, she and Dr. Sánchez agree that better diagnosis of UTIs in the NICU is still needed.

"Better diagnostic acumen for UTI in the NICU is necessary so that antibiotic therapy can be used judiciously," explains Dr. Sánchez.

Magers J, Burton A, Prusakov P, White NO, Miller RR, Moraille R, Theile AR, Sánchez PJ. Nationwide Children's Hospital Neonatal Antimicrobial Stewardship Program (NEO-ASP). Urinary tract infection in the neonatal intensive care unit. *Journal of Perinatology*. 2026;46(5):754-760.

— JoAnna Pendergrass, DVM

Depression Medication Adherence Varies Among Medicaid Youth

Poor medication adherence increases risk of persistent depression, suicide and self-harm.

A national study of nearly 200,000 Medicaid-enrolled youth ages 9 to 24 found major gaps in the quality of antidepressant treatment and adherence for a new major depressive episode.

Researchers analyzed Medicaid claims from 2016 to 2019 to assess consistency with Healthcare Effectiveness Data and Information Set (HEDIS) measures and guidelines from American Academy of Pediatrics and American Academy of Child and Adolescent Psychiatry.

Researchers evaluated whether participants remained on antidepressants for at least 84 days, completed three follow-up visits in the acute phase and continued medication for at least 180 days in the continuation phase.

Cynthia A. Fontanella, PhD, principal investigator in the Center for Suicide Prevention and Research at Nationwide Children's, led the work, published in *Journal of the American Academy of Child & Adolescent Psychiatry*.

About 49.6% of youth adhered to medication management and 55.2% had at least three follow-up visits during the acute phase of treatment. Only 26.5% met measures for the continuation phase.

Poor adherence increases the risk of persistent depression, relapse, self-harm and suicide. Older teens, young adults, racial and ethnic minority youth and those with substance use disorders (SUDs) were least likely to meet quality measures.

"Several factors may contribute, including shifts in Medicaid eligibility, health plan changes and less parental involvement as youth gain independence. Medicaid and minority patients often face limited access to care and transportation. Concerns about medication side effects, limited trust in providers,

communication challenges and structural barriers can further hinder engagement. Youth with SUDs may also struggle with low motivation, forgetfulness and higher dropout rates," says Dr. Fontanella.

Youth with chronic medical conditions, experience taking medications or involvement with foster care systems were more likely to adhere to treatment. Researchers suggest these patients may be more familiar with navigating healthcare systems, communicating with providers and attending regular follow-ups.

For pediatric providers, the study highlights clear opportunities for improvement. Dr. Fontanella emphasizes educating families about antidepressant benefits, addressing concerns about side effects and reinforcing the need for ongoing medication and follow-up. Regular monitoring, patient-centered communication and culturally sensitive approaches may help improve engagement, particularly among underserved populations.

Primary care visits are key to assessing depression, substance use and social determinants of health. Because these clinicians often initiate treatment, pediatric practices are well positioned to identify barriers, support adherence and ensure consistent follow up.

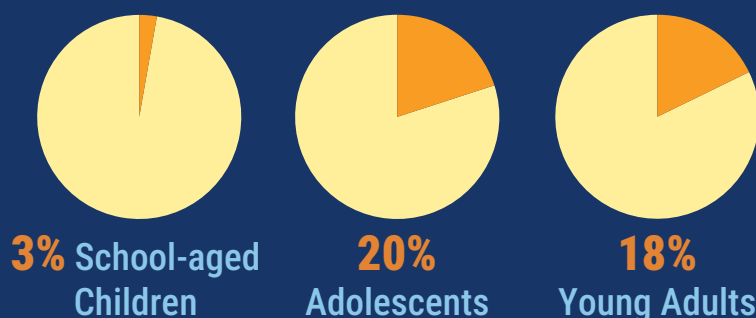
Despite well-established treatment guidelines, a gap remains between recommended depression care and what many people receive in the community. Closing that gap will require greater attention to education, follow-up and targeted support for the youth most at risk of falling out of care.

Fontanella CA, Hyer JM, Steelesmith DL, Campo JV, Fristad MA, Bridge JA, dos Reis S, Brock GN, Olfson M. Antidepressant Treatment Quality of Depressed Youth: A National Evaluation of Medicaid Patients. *Journal of the American Academy of Child and Adolescent Psychiatry*. 2026;65(5):685-696.

— Lynn Dosky

Prevalence of Depression in Youth

Source:
www.nimh.nih.gov/health/statistics/major-depression



Better Transitions From NG Tube to Oral Feeding

An intensive program helped 76% of children with nasogastric tubes transition to oral feeding, avoiding gastrostomy tube placement.

Some children with pediatric feeding disorder who require prolonged nasogastric tube (NG tube) feeding may be able to avoid gastrostomy tube (G-tube) placement through intensive multidisciplinary intervention, according to new research from Nationwide Children's.

Nationwide Children's operates one of only 16 intensive multidisciplinary feeding programs currently available in the United States, serving children with complex feeding challenges who have not responded adequately to outpatient treatment.

In a retrospective study published in *Nutrition in Clinical Practice*, investigators found that 76% of children who entered Nationwide Children's intensive feeding program with an NG tube in place successfully had the tube removed within 1 year while maintaining adequate nutrition status.

The findings challenge a longstanding belief at some centers that children with NG tubes may be poor candidates for intensive feeding therapy because the presence of the tube could worsen oral aversion or interfere with treatment.

"We had seen children come through the program with NG tubes who made enough progress that they were able to have the tube removed and never needed a G-tube placed," says Rob Dempster, PhD, program director of the Comprehensive Pediatric Feeding and Swallowing Program at Nationwide Children's and lead author of the study. "When we started talking with colleagues at other programs, many believed that wasn't possible, and there was very little published evidence in this area. So, we decided to formally evaluate this approach in children with NG tubes."

"These children have always existed," says Praveen Goday, MD, medical director of the Comprehensive Pediatric Feeding and Swallowing Program at Nationwide Children's and senior author of the study. "There just wasn't a specific diagnosis. The consensus definition provided formal criteria for how we identify and define pediatric feeding disorder."



The study included 30 children with NG tubes who completed a 6- to 8-week intensive multidisciplinary intervention program between 2017 and 2022. Children attended three treatment sessions per day, five days per week, for 8 weeks with support from physicians, psychologists, dietitians, feeding therapists and other specialists.

The study team found that children who successfully transitioned off tube feeding tended to be more than 1 year old and were consuming a greater proportion of their nutritional needs orally by the time they completed the program.

Importantly, many children continued progressing after leaving the program.

"About half of the children who ultimately weaned successfully didn't fully come off the NG tube while they were here," says Dr. Dempster. "The families left with a plan and the skills to continue building oral intake at home, and many children achieved full weaning during follow-up."

The findings may help inform referral decisions for children with NG tubes who may be candidates for intensive multidisciplinary intervention before proceeding to G-tube placement.

Dempster R, Evenson E, Gentile M, Arand B, Ahmed R, Garbacz L, Peters B, Neary M, Stefan B, Schellhaas S, Goday PS. Intensive multidisciplinary intervention while on nasogastric tube feeding prevents the need for gastrostomy tube placement: A retrospective study. *Nutrition in Clinical Practice*. 2026;41:1246-1252.

— Lauren Dembeck, PhD



A Blueprint For Better Care: The Constant Drive for Quality Improvement in Primary Care

How a culture of quality improvement has become the model of care for children across the country.

Written by Alaina London

Every day, thousands of children walk through the doors of Nationwide Children's Primary Care Centers for well visits, follow-up care, acute illness and so much more.

Across 14 primary care sites where more than 150,000 patients are seen, teams of physicians, advance practice providers, nurses, behavioral health providers, registration staff, data analysts, quality specialists, and many others, work together to develop and implement quality improvement (QI) projects. Some focus on chronic conditions such as asthma and ADHD while others improve developmental screening, adolescent mental health, vaccination rates or access to care. Together, they create a system where better outcomes aren't left to chance — they're designed.

"In primary care, we emphasize quality improvement as a key component of providing excellent patient

care," says Skyler Kalady, MD, section chief of Primary Care Pediatrics at Nationwide Children's. "We always strive to maintain and grow our culture of continuous improvement."

That culture has become not only a defining feature of Nationwide Children's Primary Care but a model for other institutions across the country.

A Model for Quality Improvement

According to Dane Snyder, MD, former section chief of Primary Care Pediatrics and current associate chief medical officer for Ambulatory Services at Nationwide Children's, one project became the blueprint for everything.

More than a decade ago, the Primary Care Network launched a comprehensive asthma QI initiative. Rather than relying on individual physicians to make isolated changes, the organization invested physician time and leadership into a coordinated effort that standardized goals, measured outcomes and provided regular feedback



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“We really take a team approach. The asthma quality improvement project served as the model because it involved feedback to individual offices, standardized goals and input from every office and all members of the teams. That was really the inflection point.”

– Dane Snyder, MD, former section chief of Primary Care Pediatrics and current associate chief medical officer for Ambulatory Services at Nationwide Children’s

to every practice. The project became the blueprint for everything that followed.

“We really take a team approach,” Dr. Snyder says. “The asthma quality improvement project served as the model because it involved feedback to individual offices, standardized goals and input from every office and all members of the teams. That was really the inflection point.”

Today, projects are intentionally selected to improve care for the largest patient populations and address priorities across preventive care, chronic disease management and patient experience.

QI at Nationwide Children’s relies on collaboration among many individuals and partnerships with Partners For Kids and the Center for Clinical Excellence. Each perspective helps identify problems or solutions that others might miss.

Maintaining Excitement for Quality Improvement

Continuous improvement requires continuous participation, but maintaining enthusiasm for dozens of simultaneous projects isn’t always easy. In 2023, Dr. Snyder introduced an idea that transformed quality improvement into something unexpected: a competition.

Inspired by the NCAA basketball tournament, March Metric Madness pits primary care offices against one another in a four-week bracket competition. Each week features a different quality metric, and clinics compete to improve performance. The winning office earns a trophy, recognition and a celebratory afternoon complete with lunch and wellness activities.

The biggest surprise wasn’t that metrics improved during the competition, it was that they stayed improved.

“What surprised us was that by just focusing on it for one week, the improvements stuck,” Dr. Snyder says. “They’ve been maintained since we first held the competition three years ago.”

The initiative has since been presented nationally and replicated by other pediatric organizations, becoming another example of how Nationwide Children’s continues to influence QI beyond its own walls.

Success Beyond the Numbers

Behind every QI metric is a child and family whose experience is better because of the work happening behind the scenes.

“Our hope is that our patients get high-quality care regardless of what site they enter or what provider they’re seeing,” Dr. Kalady says. “We’re following best practice guidelines, and that’s usually the road to best outcomes.”

Patients with ADHD or asthma are coming to more follow-up appointments. There is an increase in safe sleep practices, and vaccination rates, specifically for HPV, continue to improve. Patients are completing visits more consistently and developmental screenings are helping identify autism earlier, allowing families to begin evaluation and intervention sooner.

But even as demand increases and more patients need to be seen, the commitment to quality remains.

The Continuous Improvement of Quality Improvement

Unlike many projects with a clear finish line, QI is intentionally ongoing. The blueprints are iterative and need to be refined. New national guidelines emerge. Community needs evolve. Patient populations change. The work continues.

“I think one thing that’s great about quality improvement is that you see successes but there are always more opportunities,” Dr. Kalady says. “By definition, it’s continuous improvement.”

For Dr. Snyder, that’s part of what makes the work so rewarding.

“What I love about QI is that it’s really about small steps,” he says. “You can make one small improvement, then build upon that with another. Oftentimes projects can be improved with something really small.”

Those small steps, multiplied across thousands of patient encounters every day, have become something much larger: a culture where every improvement, no matter how incremental, helps children receive safer, more consistent and more effective care. ■

A New Therapeutic Era for Sickle Cell Disease

Transformative therapies, coupled with novel approaches to supportive care, provide increasing hope for a normal life.

written by Katie Brind'Amour, PhD, MS, CHES

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or more than 100 years, progress in sickle cell disease (SCD) treatment has been slow.

Its mainstay treatment, hydroxyurea, approved about 30 years ago, is a repurposed cancer drug.

Its first curative therapy, allogeneic hematopoietic stem cell transplant (HSCT), was discovered by accident in 1984, when a little girl with SCD developed leukemia and was treated with a bone marrow transplant that cured both conditions.

Even the approval of other therapies has had limited impact on disease trajectory for patients with SCD; crizanlizumab was removed from the market in Europe for lack of efficacy, and voxelotor was withdrawn from markets worldwide in 2024.

SCD experts lament the longstanding lack of funding and therapies in this field. But with the approval of two gene therapies in 2023 — and numerous others in various stages of development — sentiments are shifting. For the first time ever, there's a reason to believe most patients will soon have ample options to help them live a long, full life.

Understanding the Science of Sickle Cell Gene Therapy

SCD is hereditary and monogenic, caused by a point mutation in the β -globin gene. Since 2006, all U.S. states have been screening newborns for sickle cell trait — where a child has inherited one faulty copy of the gene but has one normal copy — and SCD. Early and even prenatal diagnosis are possible, and treatments such as prophylactic penicillin can be initiated soon after birth.

Conditions like this, with straightforward heredity and established screening pathways, make the perfect candidates for gene therapy.

Despite the theoretical suitability, research takes time. Multiple approaches have emerged, with two commercially available treatments approved to date:

- The first, employed by CASGEVY®, uses CRISPR/Cas9 gene editing technology to modify cells *ex vivo*. The therapy disables a gene called BCL11A that normally stops the production of fetal hemoglobin. As the body begins producing its own healthy fetal hemoglobin, the proportion of sickle cell hemoglobin is reduced dramatically, relieving SCD symptoms and allowing patients to maintain healthy hemoglobin levels without relying on blood transfusions.
- Another approach is taken by LYFGENIA®, which uses a lentiviral vector to deliver an engineered gene into patients' cells, also via *ex vivo* therapy, so they can start to produce a modified β -globin gene. The modified gene helps prevent sickling, allowing the patient's new red blood cells to function like healthy adult hemoglobin.

Other methods are now in clinical trials:

- The RESTORE trial uses a CRISPR/Cas9 gene editing technology to directly correct the sickle cell mutation, converting cells from sickle type to healthy adult hemoglobin. It varies from other methods in that it uses homology-directed repair to precisely swap out the abnormal gene for a normal one.

- The recently concluded BEACON trial evaluated BEAM-101, a first-in-class base-editing therapy for sickle cell disease. By modifying a patient's own stem cells to increase fetal hemoglobin production, the therapy aims to prevent red blood cell sickling and provide a durable, potentially curative treatment option. Early results have been encouraging, demonstrating robust fetal hemoglobin induction and improvement in disease-related complications.

Additional pharmaceutical strategies are in the preclinical or clinical phase as well, including fetal hemoglobin inducers, pyruvate kinase activators, hemoglobin polymerization inhibitors, anti-inflammatory agents and targeted adhesion inhibitors.

Investigators have also been improving the state of sickle cell care through studies on fertility preservation, vitamin supplementation, vaccination strategies and transition care planning. ClinicalTrials.gov shows more than 200 trials in SCD currently recruiting or planning to enroll.

From Clinical Trials to Clinical Therapy

The effort and innovation required to bring a gene therapy to patients does not stop once the treatment is developed and commercialized.

“Delivering approved gene therapies requires careful consideration of all of the safety and efficacy data from clinical trials as well as any post-marketing data available. We carefully review the health status for each patient and discuss the potential risks, benefits and treatment alternatives, and details of what the pre- and post-gene transfer care will look like to aid families when they are considering whether gene therapy is right for them,” says Diana Bharucha-Goebel, MD, medical director of the Gene Therapy Center of Excellence at Nationwide Children’s, which was funded by the Germain Family Accelerator Program as a collaboration between the clinical and research arms of the hospital.

“Being operationally ready involves developing clinical protocols and consents, educating staff, preparing patients and families, navigating reimbursement and ensuring every service involved is ready to manage both expected and unexpected responses,” she says. “Our team uses this systematic approach for each

King Robinson receives gene therapy for his sickle cell disease. Read more of his story on page 14.



existing and newly approved gene therapy that we provide, and we make sure we are always up to date on any emerging data in the field that may impact care or monitoring for our patients.”

Oversight by an experienced team with resources and education standards for participating staff helps ensure the full clinical picture is considered before a patient undergoes a single procedure.

“You cannot pull this off without an excellent team,” Hemalatha Rangarajan, MD, hematologist on the Blood and Marrow Transplant clinical team and the Sickle Cell Clinic at Nationwide Children’s, says of both the clinical and research efforts related to gene therapy. Dr. Rangarajan spearheaded the hospital’s participation in trials for Casgevy as well as the RUBY trial (which used gene editing to promote production of fetal hemoglobin) and the RESTORE trial, while her colleague Anthony Villella, MD, led several recent non-gene therapy drug studies. “Everybody has to do their part. We have pharmacy support, insurance specialists, a gene therapy coordinator, transplant experts, cell therapy experts — the list goes on. We are very collaborative and we have the infrastructure and expertise. That’s why it works so well here.”

Nationwide Children’s is one of only a handful of children’s hospitals in the country approved to offer both commercially approved SCD gene therapies. The in-house capabilities were honed with great effort during the full trajectory of the development and commercialization of two other approved gene therapies: ZOLGENSMA® and ELEVIDYS®.

The Gene Therapy Center of Excellence now helps clinical teams throughout the hospital establish processes and care protocols whenever a new clinical gene therapy becomes an option for Nationwide Children’s

patients. The clinical research arm (Gene Therapy Operations team), housed in the Jerry R. Mendell Center for Gene Therapy in the Abigail Wexner Research Institute at Nationwide Children’s, shepherds investigators and clinicians through research ranging from in-house n-of-1 trials to investigator-initiated clinical trials and industry-sponsored late-phase trials.

“We’re at the level where not all gene therapies are viewed as the same,” says Dr. Villella, who is a hematologist and medical director of the Sickle Cell Clinic at Nationwide Children’s. “We understand the subtle advantages and disadvantages of different approaches, and we can thoughtfully match therapies or clinical trials to individual patients. It’s definitely not a one-size-fits-all process when we think about how best to treat our patients.”

The sickle cell team expects to dose their 20th patient by the end of 2026.

“We used to visit other institutions to learn from their experience,” says Dr. Rangarajan. “But we’ve evolved into an efficient, experienced, high-performing team — and now we’re teaching others what we’ve learned.”

Working Toward a Wealth of Options for All Patients

At present, approved gene therapies are only available to patients with classic SCD, which is caused by inheritance of two hemoglobin S (both producing sickled cells; HbSS). A secondary type, caused by inheritance of one HbS gene and one hemoglobin C gene (HbSC), has been entirely omitted from gene therapy trials to date.

Furthermore, not even every HbSS patient is a candidate for transformative therapies, due in part to their physically demanding preparation and follow-up. And even if patients are qualified, of the three current



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– Hemalatha Rangarajan, MD, hematologist on the Blood and Marrow Transplant clinical team and the Sickle Cell Clinic at Nationwide Children’s



“For a long time, many of us felt sickle cell disease was neglected. Now we’re finally starting to rectify that. It’s really exciting to see this explosion of options.”

– Anthony Vilella, MD, hematologist and medical director of the Sickle Cell Clinic at Nationwide Children’s

options — HSCT, Casgevy and Lyfgenia — none are 100% successful.

“That’s exactly why we need to keep studying and developing more therapies,” says Dr. Rangarajan. “If you look at the data, effectiveness is typically in the 92% to 95% range, which means there will always be patients who don’t respond as expected. Some continue to struggle with chronic pain. We still don’t know all the long-term answers. We are working toward a cafeteria of treatment options so we can choose the right therapy for the right patient.”

At about \$3 million per treatment, gene therapies also remain out of reach for anyone without insurance approval and, realistically, for the vast majority of SCD patients globally.

Dr. Rangarajan is optimistic on that front, too.

“The field is moving incredibly fast,” she says. “Researchers around the world are already working toward non-chemotherapy approaches to gene therapy, *in vivo* gene therapies that could be delivered by infusion and other strategies that may ultimately make treatment more accessible and less toxic. We learn from every trial and every patient. The future is very bright. There truly is a light at the end of the tunnel for people living with sickle cell disease.”

As genetic and cellular therapies advance, Drs. Rangarajan and Vilella’s goal is to make everything available to Nationwide Children’s patients, from the most basic drugs to the most advanced gene therapies and emerging clinical trials. The team proactively seeks out industry-sponsored studies and collaborates with other Ohio hospitals to enable patients based

outside of the Columbus area to obtain gene therapy. They also engage in diverse research on everything from fertility preservation to pain crisis management strategies and procedural improvements in therapy administration.

“For a long time, many of us felt sickle cell disease was neglected,” says Dr. Vilella. “Now we’re finally starting to rectify that. It’s really exciting to see this explosion of options.”

Dr. Rangarajan agrees.

“Our goal is that many of the patients we see today will grow to be survivors — people living normal lives because of these transformative therapies,” says Dr. Rangarajan. “We hope to reach a future where children born with sickle cell disease never have to know what it is truly like to live with its complications.”

“That day is coming,” she says. “And we’re very proud to be a part of it.” ■

Hanna R, Frangoul H, Pineiro L, McKinney C, Mapara M, Dalal J, Rangarajan HG, Atkins H, Sharma A, Chang KH, Jaskolka MC, Kim K, Yu Q, Mei B, Afonja O, Walters MC, for the RUBY Investigators. CRISPR-Cas12a gene editing of HBG1 and HBG2 promoters to treat sickle cell disease. *New England Journal of Medicine*. 2026;394:1281-1291.



Therapy fit for a King

Marsha Marshall decided to raise King Robinson when he was just a baby at the request of his mother, Tameka Robinson, who was suffering from complications of sickle cell disease. It wasn't long before King was diagnosed as well.

For a woman in her late 50s, it was a lot to manage, especially after her husband passed away. It was a challenge, she says, for someone who had no children of her own, but a welcome one, even as frequent hospital stays due to pain crises took their toll on the family's time and finances — and on King's ability to make friends, take part in activities and attend school. The disease also took its toll on King's mother, who passed away when King was 9.

"When I came across a program people were offering to try and cure sickle cell, I took it to the doctors [at Nationwide Children's] and asked about it," says Marsha.

She wanted the cure for King that his mother never had, and a chance at a normal future for him.

Unfortunately, the trial she was interested in (RUBY) was discontinued before King could receive the therapy.

Determined to find a curative option that would meet his needs, the hematologists and cell therapy experts at Nationwide Children's Sickle Cell Clinic went through numerous consultations with Marsha and King. Then they proposed Casgevy, which had just become FDA approved for children 12 and older. King was 11 at the time, but the clinical team worked to get him ready to receive the therapy as soon as he was eligible.

That's when the hard work really began.

"There is a lot to do to prepare, including multiple drawn-out stem cell collections for some patients, each of which requires them to be in the hospital on apheresis," explains Dr. Villella. Patients are also offered fertility preservation during this time. "When the gene therapy is finally ready, they have to undergo chemotherapy, much like with bone marrow transplant [BMT]. But once they get their stem cells back and they engraft, and blood counts come back to normal, gene therapy patients are pretty much done — there's no immunosuppression follow-up like there is with BMT."

After several week-long stays in the hospital to collect stem cells, King's cells were shipped off for editing. Months later, a 1-ounce bag of cells returned.

"Each drop is worth about \$3,000," says Dr. Rangarajan. "It takes just 10 minutes to infuse."

In December, 2025, at age 12, King became one of the youngest SCD patients in the country to receive gene therapy.

“We are still in shock, I think. It had been just King and me and sickle cell for so long, we have to figure out a new way of living. He’s learning to make friends, and he’s excited to start high school.”

– Marsha Marshall

“That first week after the infusion patients feel fine, but by about 10 days in, it’s pure hell, because of the chemo,” explains Dr. Rangarajan. “Then, they start to recover and kids are back to school in about two months. With BMT, it can take much longer. We say the two treatments are kind of flip-flopped: with gene therapy, the hard part is upfront, and with BMT, it’s the follow-up that’s most demanding.”

After spending a month recovering in the hospital following the infusion, King rang the bell and returned home. Shortly after, he was back to piano lessons, taekwondo and schoolwork. He even earned a “Learner of the Week” award at school — an unprecedented achievement for King due to a lifetime of frequent absences. Despite some residual pain, his hemoglobin levels have been excellent and he’s been free of complications since receiving the therapy.

Now King and Marsha still come to the Sickle Cell Clinic, but not for transfusions and infusions — just checkups (gene therapy patients must be followed for 15 years) and psychology visits to help transition out of a life without chronic illness.

“We are still in shock, I think,” says Marsha. “It had been just King and me and sickle cell for so long, we have to figure out a new way of living. He’s learning to make friends, and he’s excited to start high school.”

The two are now simply trying to appreciate life as it unfolds. A major Harry Potter fan, King recently enjoyed his first plane ride for a trip to Universal Studios, courtesy of his godsister, Lanita Cooper. Marsha also insists that he go to college when the time comes.

“I want him to be good at something. I want to see him thrive in this life, rather than what we’ve been doing: surviving with pain and sickle cell,” says Marsha. “Things are looking up.” ■



Turning Evidence Into Advocacy

The healthcare community is increasingly recognizing their role in shaping policy, leveraging front-line experience, injury data and research.

written by Abbie Miller, MS

In June 2024, 11-year-old Avery Russell was playing at a friend's house when she was viciously attacked by two dogs. What happened that day changed her life — and it ultimately led to a change in Ohio's laws.

That change didn't happen overnight. It took enormous bravery from a young girl and her family. It also took harnessing the perspective and advocacy power of Avery's care team and hospital, who knew she wasn't alone. Nationwide Children's treats 400 patients per year with dog bite injuries.

Physicians have unique connections to problems that affect the health of children and families — not only because they treat patients, but because they see first-hand where systems, policies and products fall short. Increasingly, pediatricians are extending their impact beyond the clinic by partnering with researchers, families, policymakers and industry to advocate for evidence-based solutions. Their goal is not simply to improve individual outcomes, but to create lasting changes that help entire communities thrive.

Advocacy as Problem Solving

For trauma experts and others involved in injury prevention advocacy, their work usually starts as the search for an answer to a problem that they can't solve with care alone.

"Once an injury happens, we can do everything we can to treat the child, but we can't always undo the impact of that injury. For some children, a serious injury can change the course of their lives," says Rajan Thakkar, MD, FACS, section chief of Pediatric Surgery, trauma medical director and co-director of the Burn Center at Nationwide Children's and professor of Surgery at The Ohio State University College of Medicine. "Trauma is one of the biggest reasons for hospitalization among children, and many people don't realize the volume and severity of injuries that impact children."

Take, for example, Avery's case. Her injuries from the June 2024 attack were life altering — severely damaging her ears, nose, forehead and shoulder.

She spent 9 hours in her first surgery at Nationwide Children's, where she would stay for the next month.



During her stay, she had two more surgeries and began physical, occupational, speech and music therapies in addition to receiving psychological support to begin healing from the mental and emotional trauma. Her injuries were so severe that she needed to relearn how to walk and feed herself.

Avery, her family and her care team, armed with data that injuries like Avery's were increasing and affecting more children in Ohio each year, decided it was time to act. They began an advocacy campaign that ultimately led to Avery's Law, a bipartisan Ohio bill that imposes stronger penalties for owners of dangerous dogs. The law was signed in December 2025 and went into effect March 20, 2026.

"Avery's willingness to share her story, combined with data showing a general increase in dog bite injuries, provided powerful support for the bill," says Dana Schwartz, MD, pediatric surgeon at Nationwide Children's and assistant professor of Pediatric Surgery at Ohio State. "We were passionate about preventing dog bites before, but the evidence showing increases and Avery's family being willing to advocate really catalyzed everything."

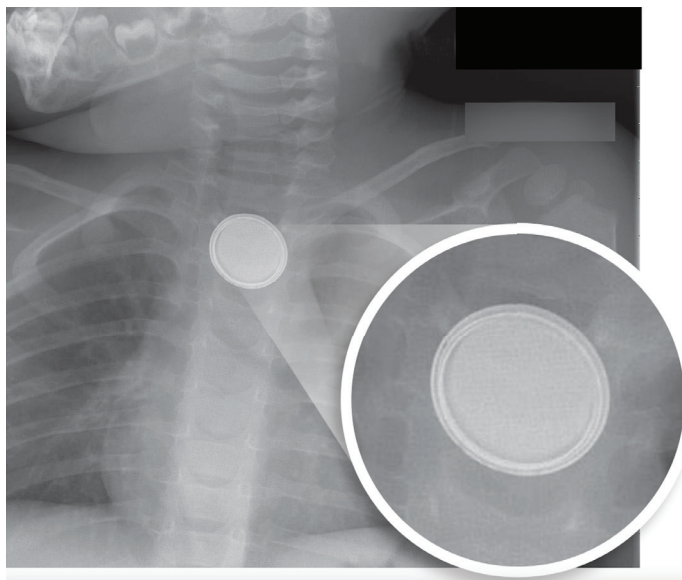
Importance of Coalition Building and Collaboration

For Kris Jatana, MD, FAAP, FACS, otolaryngology-head and neck surgeon, surgical director of clinical outcomes and medical director of quality at Nationwide Children's, coin-cell (button) battery injuries are a life-altering and life-threatening problem affecting children around the world.



"Once an injury happens, we can do everything we can to treat the child, but we can't always undo the impact of that injury. For some children, a serious injury can change the course of their lives. Trauma is one of the biggest reasons for hospitalization among children, and many people don't realize the volume and severity of injuries that impact children."

– *Rajan Thakkar, MD, FACS, section chief of Pediatric Surgery, trauma medical director and co-director of the Burn Center at Nationwide Children's and professor of Surgery at The Ohio State University College of Medicine*



X-ray image of a lithium ion coin cell (button) battery lodged in a child's throat: when ingested, button batteries rapidly cause chemical burns that can do irreversible damage.

A new titanium battery aims to offer a safer alternative. Read what the research shows.

PediatricsNationwide.org/Titanium-Battery

Throughout his residency and fellowship training, Dr. Jatana saw a growing number of cases involving button battery ingestions and insertions into the nasal cavity or ear canal. These incidents often resulted in devastating injuries that could not be surgically repaired and, in some cases, led to the deaths of otherwise healthy children.

A turning point for Dr. Jatana was the case of an otherwise healthy toddler who developed bilateral vocal cord paralysis and experienced significant respiratory distress, ultimately requiring a tracheostomy tube.

"I quickly realized that prevention needed to be the primary focus," says Dr. Jatana, who is also a professor of Otolaryngology-Head and Neck Surgery at Ohio State.

That case, along with many others, motivated Dr. Jatana to pursue solutions beyond the operating room. In June 2010, he began building a national task force through the American Academy of Pediatrics (AAP) and the American Broncho-Esophagological Association (ABEA). Over time, that effort evolved into today's Global Button Battery Task Force, which he continues to help lead.

"We needed to bring together all relevant stakeholders and collaborate to find solutions to this preventable problem," says Dr. Jatana.

The task force eventually brought together battery manufacturers, electronics companies, product safety organizations, members of the U.S. Consumer Product Safety Commission and medical experts representing multiple specialties.

"We focused on a central question: 'What can we do to prevent these injuries?'" Dr. Jatana explains. "Through productive discussions, we worked toward our shared goal of injury prevention."

Those advocacy efforts initially led to the introduction of the Button Cell Battery Safety Act. Although the legislation was introduced in 2011, it failed to gain traction in the U.S. Senate. The proposed legislation sought to mandate safer packaging, stronger warning labels and more secure battery compartments.

"When we first started our efforts, you could buy a pack of button batteries and pop them out of the package like candy," says Dr. Jatana.

When the legislation stalled, the task force did not give up. Instead, members engaged more deeply with industry leaders to pursue voluntary safety standards.

Between 2014 and 2015, voluntary safety standards for lithium coin cell batteries were implemented. These standards established child-resistant battery compartments, clearer warning labels and safer battery packaging across the industry.

At the same time, Dr. Jatana sought to better understand the mechanism of injury caused by button batteries. His landmark research demonstrated methods to reduce tissue damage before battery removal and slow injury progression after removal through neutralization treatments. These interventions were incorporated into the National Capital Poison Center's Triage and



“While delivering exceptional care remains our responsibility, the greatest impact comes when we can prevent these devastating injuries from occurring in the first place. That’s how we can truly make a difference beyond the walls of the hospital.”

– Kris Jatana, MD, FAAP, FACS, otolaryngology-head and neck surgeon, surgical director of clinical outcomes and medical director of quality at Nationwide Children’s and professor of Otolaryngology-Head and Neck Surgery at Ohio State

Treatment Guideline for button battery ingestions and helped shape the medical management of this condition world-wide.

“What I’ve learned along this journey is the importance of persistence despite challenges and setbacks,” says Dr. Jatana. “Nothing in medical training prepares you for building stakeholder buy-in around problems that affect patients. I quickly learned the importance of collecting and sharing meaningful data to drive change.”

To collect that data, Dr. Jatana worked with product safety engineers to develop a novel mechanism to collect data using a smartphone app for medical professionals through a new nonprofit organization, the Global Injury Research Collaborative.

In 2022, federal legislation was finally signed into law in the United States, transforming previously voluntary safety standards into mandatory requirements. Reese’s Law took effect for industry in March 2024.

Most recently, these injury prevention efforts have contributed to the development of the first commercially available button battery with esophageal-protective features. This titanium-based coin-cell battery represents the beginning of what Dr. Jatana hopes will become a new industry standard in battery manufacturing. In June 2026, Dr. Jatana led the first peer-reviewed study published in medical literature

evaluating this battery within the context of current medical management protocols.

“This initiative demonstrates that there is no limit to what we can do to improve the lives of children,” says Dr. Jatana, who has received two AAP Advocacy Awards and the Chevalier Jackson Award from the ABEA. “While delivering exceptional care remains our responsibility, the greatest impact comes when we can prevent these devastating injuries from occurring in the first place. That’s how we can truly make a difference beyond the walls of the hospital.”

Data-Driven Advocacy

Trends in trauma data can drive advocacy efforts. Communication across clinical teams and government relations helps to identify opportunities for engagement and provide evidence to support new policies.

“When we notice trends, such as increasing injuries from e-bikes, we look at our registry data, then our first call is to Government Relations,” says LeeAnn Wurster, MS, RN, TCRN, CPNP, trauma and burn program manager at Nationwide Children’s. “We let them know that we have data and experience in this area and that we want to help talk to legislators to prevent these injuries. We also work with Media Relations to help get the word out and make sure the information that is going out is evidence-based.”



“Most of my research leads to advocacy for policy change, because policy is the most effective tool we have for saving lives. Education is important, but at the end of the day, it’s rarely enough. You have to combine it with other interventions, and policy is the most important.”

– Gary Smith, MD, DrPH, director of the Center for Injury Research and Policy at the Abigail Wexner Research Institute at Nationwide Children’s and professor of Pediatrics, Emergency Medicine and Epidemiology at Ohio State



"The first thing we want people to do when they are considering advocacy is talk with their organization's Government Relations team. We have a lot of tools and resources that can help them be more successful, and we can help people think strategically about how they approach legislators."

– Charlie Solley, MPA, vice president of Government Relations at Nationwide Children's

It's not just coincidental data trends that drive advocacy. The Center for Injury Research and Policy (CIRP) was established to conduct research that would ultimately make the world safer for children.

"Most of my research leads to advocacy for policy change, because policy is the most effective tool we have for saving lives," says Gary Smith, MD, DrPH, director of CIRP at the Abigail Wexner Research Institute at Nationwide Children's and professor of Pediatrics, Emergency Medicine and Epidemiology at Ohio State. "Education is important, but at the end of the day, it's rarely enough. You have to combine it with other interventions, and policy is the most important." Dr. Smith and others in CIRP have a long and successful track record of moving from publication to policy that spans local ordinances, state, regional and federal legislation, and industry partnerships.

"One of my first projects when I came to [Nationwide] Children's in the 1990s was investigating injuries to children associated with shopping carts," he says. "We worked with legislators to encourage a national product safety standard organization to adopt strengthened product safety standard for shopping carts."

Another case where carefully designed research helped support a new safety policy came from a collaboration between CIRP and Sleep Medicine. They tested the effectiveness of voice notification in residential smoke alarms to awaken children from deep sleep and prompt their escape. They showed that these voice alarms were more effective than the typical high-frequency tone alarm in most homes.

This work contributed to the National Fire Protection Association approving the use of voice notification in residential smoke alarms in the U.S. Fire Alarm Code.

CIRP also works closely with the Central Ohio Poison Center to conduct and publish research that can be

used by advocates, clinicians and policy makers to understand risks and trends and take action to prevent pediatric poisoning.

"After we publish a study, our work is only half done. We need to make sure our findings are used to make changes that lead to healthier, safer lives for children," says Dr. Smith.

Learning to Be an Advocate

While Kristen Fox, PhD, principal investigator in the Center for Biobehavioral Health at Nationwide Children's and assistant professor of Pediatrics at Ohio State, trained for her career as a psychologist and researcher, she didn't expect advocacy to be one of her favorite parts of her job.

"When I was a fellow, I had the opportunity to get involved with advocacy through one of the professional organizations I'm involved in, the Society of Behavioral Medicine," she says. "It was a new program in 2020 designed to create health policy ambassadors across the country. I wasn't sure if I could make a difference, but now I'm glad I said yes."

Dr. Fox has covered a variety of different priority areas related to the mission of the Society of Behavioral Medicine, participating in Hill Days advocating for congenital heart disease research and supporting funding research in general.

While Dr. Fox mostly performs her advocacy work through her professional organization, she works collaboratively with Nationwide Children's Government Relations team.

"The first thing we want people to do when they are considering advocacy is talk with their organization's Government Relations team," says Charlie Solley, MPA, vice president of Government Relations at Nationwide Children's. "We have a lot of tools and

resources that can help them be more successful, and we can help people think strategically about how they approach legislators.”

For trauma team clinician-advocates, their partnership with government relations enables them to maximize their impact.

“I think when you see these things clinically, you feel compelled to try to act towards prevention. I think what I didn’t realize is that with the help of our Government Relations team, they make it very easy,” says Dr. Schwartz. “Also, as a physician, I don’t have any formal training in advocacy. I don’t know a lot about how the government, particularly here in Ohio, works. And so, when the opportunities arise, I feel grateful that we have a great Government Relations team to reach out to us with specific opportunities.”

Becoming a Trusted Source of Information for Legislators

While advocacy takes on many forms, the ultimate goal for Dr. Fox and her collaborators is to become the trusted resource for legislators.

“We do informal emails about once a month to keep the lines of communication open — we flag important topics in specific districts, offer information about how scientific publications or news impact a population, and so on. We’re making ourselves available and helpful,” she says. “When we hear that there’s a new staffer in the office we’re assigned to work with through the ambassador program, we take the initiative to reach out.”

As a result of her focus on building positive, collaborative relationships with legislative offices, she and her ambassador group have been asked to help draft letters and questions for hearings.



“I think when you see these things clinically, you feel compelled to try to act towards prevention. I think what I didn’t realize is that with the help of our Government Relations team, they make it very easy. Also, as a physician, I don’t have any formal training in advocacy. I don’t know a lot about how the government, particularly here in Ohio, works. And so, when the opportunities arise, I feel grateful that we have a great Government Relations team to reach out to us with specific opportunities.”

– Dana Schwartz, MD, pediatric surgeon at Nationwide Children’s and assistant professor of Pediatric Surgery at Ohio State

“I worked with another policy ambassador to draft a letter, and we brought in another legislator’s office. The result was a bipartisan letter that our teams helped the healthcare staffers develop. It was especially exciting because they sent the final letter to us, and it had four Congress people’s signatures on it with a congressional seal, and we could see the words that we had written were still in there,” says Dr. Fox. “It was a powerful moment to feel like we had really helped those offices advance something that was important to them and not only aligned with their priorities in their districts and in their states but also aligned with our priorities.”

Training the Next Generation of Advocates

“People are understanding more and more how powerful their voice is,” says Aileen Collins, Government Relations manager at Nationwide Children’s. “They want to be part of making a difference.”

However, as important as advocacy is to child health, most pediatricians and pediatrics-focused scientists receive little, if any, training and support. This is beginning to shift as formalized training becomes integrated into residency and fellowship offerings.

The Advanced Competency in Pediatric Advocacy Program for pediatric residents at Nationwide Children’s aims to close the gap in training described by many physicians. The program, which is an elective, aims to help those interested in child advocacy and community partnership by creating opportunities for early involvement. Through seminars, mentoring and completion of an individual project, early career physicians have a unique opportunity to gain skills that will help them to be better advocates in the future.

In addition to residency electives, national programs are helping to fill the training gap and build networks of advocates.

Spring 2026 TC4iP Day of Action

A Conversation About E-Bikes
Understanding the Rising Risk to Youth
Webinar hosted by Trainees for Child Injury Prevention
Wednesday, May 20, 2026 | 2 - 3 p.m. ET
Register: bit.ly/T4CiP-EBikeWebinar



Moderator
Dr. Phyllis Agran
UCI School of Medicine



Panelist
Dr. Justin Assioun
Rady Children's Hospital



Panelist
Ofc. Jason Schaefer
City of Irvine, CA



Panelist
Dr. John Mao
American College of Surgeons Governor Marin General Hospital



T4CiP #EBikeParentCheck Day of Action
May 20, 2026

ACTIVITIES INCLUDED:

Educational events with peer groups	Bike rodeo	Create and distribute educational materials
Local advocacy & legislative support	Morning Report	Collaboration with local AAP chapters, city, kids, coalitions, and community organizations
Media Interviews	Noon Conference	
Podcasts	Helmet distribution events	Shared info at well-child visits
Social Media Takeovers	Facebook Posts	Blog Post/Newsletter Features
Instagram Posts	Webinars	Selfie Signs

More motor than bike.

Older kids average **10 mph** or slower on a regular bike.

Some e-bikes can get up to **28 mph** That's almost 3x faster!

Higher speeds can lead to more serious injuries!

If your child isn't ready for a motorcycle or moped, they're not ready for an e-bike.

T4CiP #EBikeParentCheck

E-BIKE Helmet Check



Faster speeds mean you need more protection.

If you ride any class of e-bike, wear a high-quality helmet made for higher speeds. Look for one with an ASTM F1952, NTA 8776, or DOT label.

No helmet, no ride. Even if it is "just in the driveway" or the neighborhood.

Be aware of local and state policies and other applicable laws before riding.

T4CiP #EBikeParentCheck

The spring 2026 TC4iP Day of Action focused on awareness and advocacy concerning e-bike safety. Participants used a comprehensive social media toolkit with content available in English and Spanish, supported a webinar, and shared a guide to help parents.

Trainees for Child Injury Prevention (T4CiP) is a year-long training program for medical students, residents and fellows that also aims to fill gaps in traditional medical education to support physicians in advocacy.

T4CiP is a partnership between the Center for Injury Research and Policy, the American Academy of Pediatrics' Section on Pediatric Trainees and the Council on Injury, Violence, and Poison Prevention. It's a national program that also includes media relations staff from the AAP as part of the education team," says Laura Dattner, MA, research writer and T4CiP coordinator in CIRP at Nationwide Children's.

The first cohort of trainees was in 2021, and the program has grown from around 50 people per cohort to 80.

"It's become a very competitive program. We have 150 to 200 people apply each year," says Dattner.

Child injury experts from across the country serve as the 10 faculty who provide mentorship during virtual sessions each month. Program participants apply their learnings in two "days of action" each year that focus on different injury prevention topics — most recently, e-bikes, and in October 2026, youth suicide prevention.

Once T4CiP participants complete their year-long training, they aren't left on their own.

"We recognize that a one-year session isn't necessarily enough for a trainee," says Dr. Smith. "We give them the option to continue as part of the T4CiP Alumni Committee."

These alumni spearhead additional child injury prevention advocacy projects. They also join in the monthly T4CiP meetings, serving as junior facilitators to support the training of those who entered the program after them, while still strengthening their own skills.

After a career of research and advocacy that spans almost five decades, Dr. Smith says, "Advocacy often falls victim to 'tyranny of the urgent,' which means that it too often gets pushed aside to make room for all our daily demands such as responding to emails, phone calls, and clinical duties. Successful advocates learn to make the time to translate knowledge into effective action." ■

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Stronger Together: The Unique Power of the Ohio Children's Hospital Association



Ohio Children's Hospital Association

Saving, protecting and enhancing children's lives

The Ohio Children's Hospital Association (OCHA) was formed 40 years ago when the CEOs of Ohio's six children's hospitals got together to address a new methodology for reimbursement that did not take into consideration pediatric conditions and acuity.

"Ohio's children's hospitals are safety net hospitals for kids and the largest Medicaid providers in the state; 54% of the patients who seek care at our six member children's hospitals rely on Medicaid for insurance coverage," explains Nick Lashutka, president of OCHA. "Compared to adult hospitals who see a significantly lower average Medicaid payor mix, even small changes in Medicaid reimbursement can be disastrous for children's hospitals in Ohio."

By working together with legislative leaders, they ultimately created a Medicaid outlier program that established a methodology that appropriately accounts for the unique needs of children with high acuity conditions such as cystic fibrosis or those who needed Level IV NICU care.

That coming together was just the beginning. Since then, OCHA has worked with the Ohio General Assembly to protect child health, primarily through advocacy for Medicaid. They've also joined forces with the national Children's Hospital Association and other state-specific groups to advocate on the federal level.

"Ohio's children's hospitals compete in the marketplace, but when it comes to advocacy, we are 100% unified," says Lashutka. "And we don't just flag problems. They collaborate to present solutions to complex policy problems affecting children."

This solution-oriented mindset may not be common among state advocacy groups, but it is one of the secrets to the successes OCHA has achieved.

"We feel strongly that we are the experts," Lashutka says. "Legislators need solutions, so it's our job to help them achieve solutions that not only meet their goals but also protect child healthcare. This happens through education, education and some more education."

When it comes to negatively impacting child health through legislation, Lashutka and others say that it is generally the unintended negative impact of a change that was made with adults in mind.

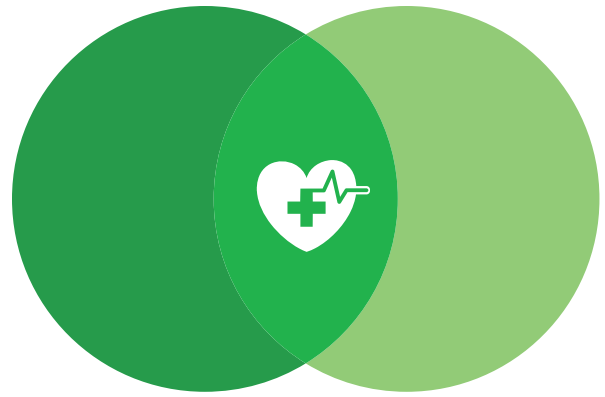
"People sometimes forget the unique care that children's hospitals provide. Adult care and adult systems can take more of the focus," says Aileen Collins, Government Relations manager at Nationwide Children's. "It's our job to make sure that the unique needs of children are not overlooked and we consistently bring child health to the table."

“ People sometimes forget the unique care that children's hospitals provide. Adult care and adult systems can take more of the focus. It's our job to make sure that the unique needs of children are not overlooked and we consistently bring child health to the table.”

— Aileen Collins, Government Relations manager at Nationwide Children's

Beyond the Clinic: Bipolar Disorder Care Where Kids Live, Learn and Grow

written by Madison Storm



For many children and adolescents with bipolar disorder, care begins in a crisis: severe mood symptoms, suicidality or hospitalization. They are evaluated in an emergency department or admitted for inpatient care. Stabilization is an immediate priority. But what happens next?

A new state-of-the-field review from Eric Youngstrom, PhD, director of the Institute for Mental and Behavioral Health Research at Nationwide Children's argues that bipolar disorder care must move beyond crisis response and specialty clinics to support children where they live and learn, with an emphasis on earlier identification, prevention and individualized treatment.

"The future of bipolar disorder management must move beyond the walls of specialty clinics and hospitals and into the community," Dr. Youngstrom says.

This shift reflects a broader rethinking of bipolar disorder in youth, one that emphasizes predicting risk earlier, continuous monitoring to prevent escalation and tailored care for long-term developmental outcomes.

From Crisis Response to Lifelong Management

Crisis management will always be an essential component of bipolar disorder treatment, but it no longer defines success. Instead, the field is moving toward a proactive, longitudinal framework grounded in three priorities:

- **Prediction:** Identifying which youth are most at risk — often before a clear diagnosis, using family history, symptom patterns and screening tools
- **Prevention:** Intervening early to reduce symptom severity, delay onset or prevent progression
- **Personalization:** Adapting care over time based on developmental stage and functional needs

"The burden and challenges associated with pediatric bipolar disorder are not limited to those acute, episodic moments," says Ian McKay, PhD, clinical psychologist in the Department of Psychiatry and Behavioral Health at Nationwide Children's. "Families often describe months or years of disrupted sleep, mood instability and social or academic impairment before anyone names what's happening."

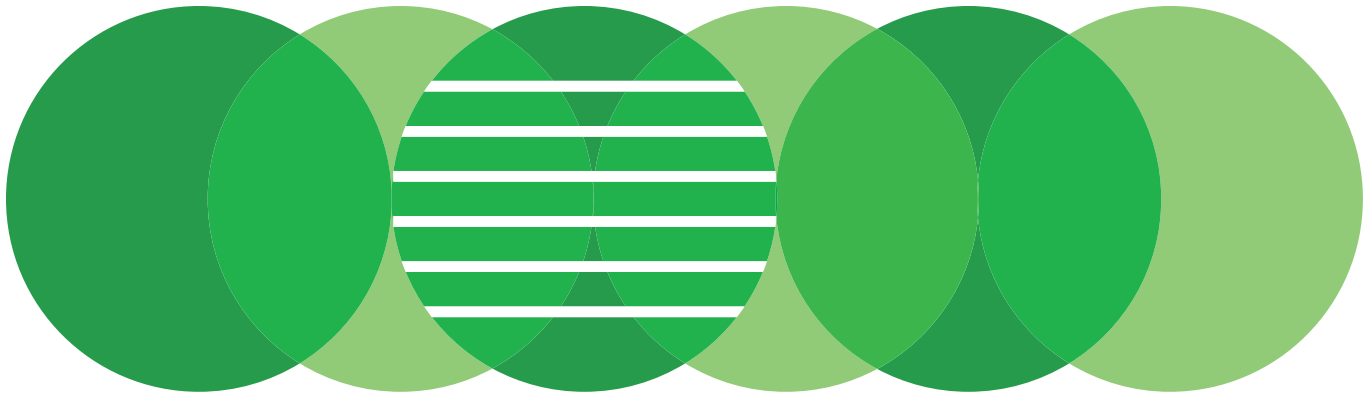
That shift changes how clinicians measure progress. A more comprehensive approach means considering how a young person is functioning across the board.

"In many youth cases, a spectrum of risk is the most clinically useful approach. We shouldn't wait until things become severe, or someone meets full diagnostic criteria, to get involved," Dr. McKay adds. "There is a lot of opportunity during critical developmental periods to intervene earlier, track symptoms over time and help reduce how serious things become."



"The future of bipolar disorder management must move beyond the walls of specialty clinics and hospitals and into the community."

— Eric Youngstrom, PhD, director of the Institute for Mental and Behavioral Health Research at Nationwide Children's



“Crisis management is a big part of the care and it’s important,” says David Axelson, MD, chief of the Department of Psychiatry and Behavioral Health and the Section of Psychiatry at Nationwide Children’s. “We really want to help youth with bipolar spectrum disorders grow and develop and function broadly beyond just the crisis.”

Dr. Youngstrom frames this comprehensive approach as a move from short-term stabilization to sustained management and health promotion, assessing how youth are functioning across all domains, not just during acute episodes.

“The most effective care is embedded in daily life,” he explains. “Treatment success should be measured by thriving; reclaiming school, work and relationships.”

Rethinking Diagnosis: From Binary to Spectrum

In children and adolescents, bipolar disorder rarely presents as a clear-cut diagnosis. Symptoms overlap with more common conditions such as ADHD, anxiety and depression. Developmental state further complicates interpretation.

“In kids and teenagers, sometimes it’s hard to have a definite diagnosis, so you have to think about it more probabilistically,” says Dr. Axelson.

This probabilistic model represents a fundamental change. Rather than asking whether bipolar disorder is present, clinicians consider where they fall along a spectrum of risk. This approach integrates multiple sources of information — family history, symptom patterns and standardized screening tools — to estimate likelihood and guide decision-making over time.

“There’s a lot of gray area,” Dr. Axelson adds. “We’re often seeing presentations very early in the course of illness, and it may not be clear.”

Dr. Youngstrom’s framework of Evidence-Based Assessment reinforces this approach, using iterative data, such as screening scores and historical factors, to refine diagnostic probabilities and inform care decisions.

“Rather than viewing diagnosis as a static, one-time decision, this approach uses iterative information to shift probabilities and improve decision-making,” Dr. Youngstrom explains.

This model allows clinicians to act earlier, even when diagnostic certainty remains incomplete.

Identifying Risk Earlier

If bipolar disorder exists along a spectrum, early identification becomes both more possible and more necessary. Early recognition depends on moving screening into routine care. This makes routine pediatric visits a critical opportunity to detect early warning signs, particularly for children with known risk factors.

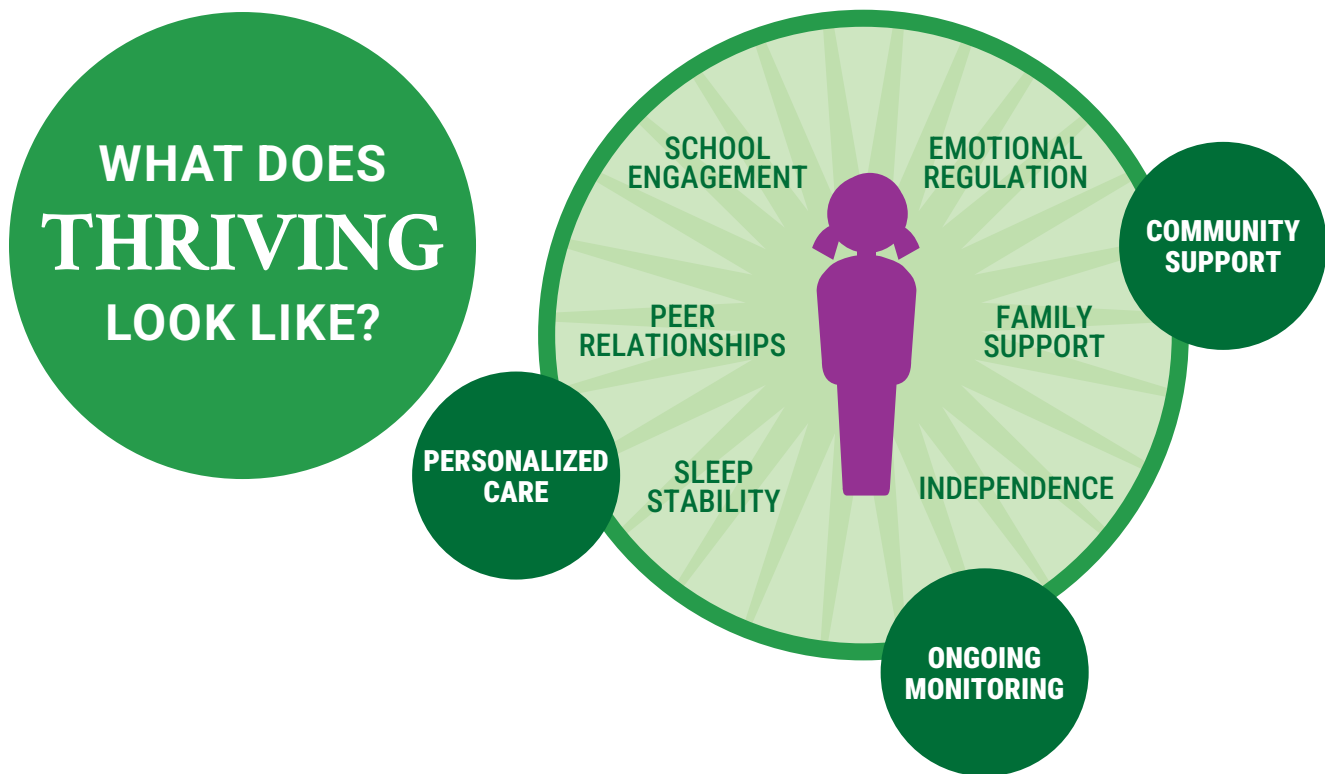
“The role of primary care is identifying kids that may be at risk,” Dr. Axelson says.

“It’s really the front door,” Dr. McKay agrees. “Primary care is where concerns first surface, and ideally it’s part of a team-based system where behavioral health and specialty care help guide next steps.”

Dr. Youngstrom’s review emphasizes tiered screening approaches that start with broad tools and progress to more specific measures when concerns arise. These strategies help detect youth who may not yet meet diagnostic criteria but still warrant monitoring.

“Children of parents with bipolar disorder have a five- to ten-fold increased risk,” Dr. Youngstrom says, noting that this information should anchor assessment decisions.

Early warning signs often appear as patterns rather than isolated symptoms, including episodic changes in



sleep, energy and functioning, especially when paired with family history. Dr. Axelson emphasizes the same point in clinical practice.

“If somebody’s not responding well to usual treatment and there’s a family history of bipolar illness, that should be considered. Although bipolar disorder is not common, it is also not rare. This likely affects about 2% of children eventually, so you have to think about it,” he says.

Beyond Symptom Reduction: Defining Success as Thriving

Another major shift is redefining treatment success. Symptom stabilization remains the foundation of care, but it does not define the endpoint.

“Thriving means more than just fewer symptoms,” Dr. McKay says.

Many youth with bipolar disorder continue to experience subthreshold symptoms even outside of acute episodes. These lingering effects can interfere with development and daily functioning.

As a result, treatment goals must expand beyond symptom control to include developmental progress:

- Regular school attendance
- Participation in extracurricular activities
- Building and maintaining peer relationships
- Building independence

“Trying to think about achieving normal developmental

goals is really important,” Dr. Axelson says.

Community-Based Care: Bringing Treatment Into Everyday Life

Because bipolar disorder affects so many areas of life, effective care must extend beyond clinical settings. Community-based care is not simply an extension of treatment — it is where much of the ongoing work happens.

Schools play a central role in supporting youth with bipolar disorder.

“These kids struggle in school, so having therapists or interventions there can be important,” Dr. Axelson notes.

Supports such as individualized education plans and school-based mental health services can help maintain stability during vulnerable periods and reduce disruptions to learning and social development.

Family involvement is equally important. Much of the day-to-day management of bipolar disorder, including sleep routines, stress management and medication adherence, depends on consistent support at home. Dr. Youngstrom highlights practical interventions that are “sensible, easy, cheap and safe,” including sleep hygiene and behavioral supports.

To make these support more accessible, Nationwide Children’s continues to expand programs that connect specialty expertise with community care. Behavioral

health integration within primary care practices further supports early identification and intervention in familiar settings. Consultation services such as Behavioral Health Treatment Insights and Provider Support (BH-TIPS) allow primary care providers to connect directly with pediatric psychiatrists for diagnostic and treatment guidance.

“That can be a very good resource for someone who’s not sure if bipolar disorder should be in the differential,” says Dr. Axelson. “These clinicians can help identify kids that may be struggling and get them to specialty care.”

For youth transitioning out of crisis care, programs such as the Critical Assessment and Treatment Clinic at Nationwide Children’s provide short-term follow-up and stabilization, helping bridge the gap between inpatient treatment and ongoing community support.

These initiatives reflect a broader goal: bringing evidence-based tools beyond specialty clinics and into everyday care environments.

Community Care Challenges Across the Lifespan

Despite progress, access to care remains a major challenge.

“There is a significant access gap where the most cost-effective community treatments are unavailable in the regions that need them most, often leading to the incarceration of minority youth rather than clinical treatment,” Dr. Youngstrom says. “The most vital challenge is translation — turning new science into something that actually reaches the people who need it.”

Delays of weeks or even months can leave youth vulnerable during critical periods of recovery. Access to intensive community-based services remains limited in many areas, while workforce shortages often make it difficult for families to receive care as frequently as needed.

Care coordination presents another challenge. Managing bipolar disorder often involves multiple systems, including psychiatry, therapy, primary care and schools, all of which must communicate effectively to support a young person’s changing needs.

“You want good coordination between providers, and that communication can be challenging,” Dr. Axelson says.

These coordination challenges often become even more apparent as adolescents transition into adulthood. The move from pediatric to adult services can create disruptions in care, particularly because adult treatment systems may place less emphasis on family involvement and community supports.

“That transition can be tough,” Dr. Axelson says. “Not waiting until the last minute and taking a thoughtful approach as someone reaches 17 or their last year of high school [can help ease the transition].”

Planning early, maintaining continuity whenever possible and establishing clear handoffs between providers can help reduce gaps during this vulnerable period and support long-term stability.

Looking Ahead: A Community-Based Future

This shift outlined by Dr. Youngstrom calls for a shift in perspective as much as in practice. Bipolar disorder is not defined by isolated episodes. This is a condition that develops over time and affects multiple domains of a young person’s life, reshaping the role of pediatric providers and the goal of care.

“Bipolarity is a spectrum. Move away from rigid categorical boxes and toward a dimensional model — ask ‘How bipolar this presentation?’ rather than ‘if’ it is bipolar,” Dr. Youngstrom says.

Clinicians are not only managing symptoms; they are supporting a trajectory, helping young people build the skills and stability needed for long-term success.

“We may not have a definite diagnosis yet,” Dr. Axelson says. “We may need to try different things and reassess over time.”

Expanding care into community settings creates more opportunities to intervene earlier, monitor more effectively and support families over the long term. The result is a model that meets children where they are and helps them move forward. ■

Youngstrom EA. Assessment and Treatment of Bipolar Disorder in the Community. *Annual Review in Clinical Psychology*. 2026;22(1):343-371.



“If somebody’s not responding well to usual treatment and there’s a family history of bipolar illness, that should be considered. Although bipolar disorder is not common, it is also not rare. This likely affects about 2% of children eventually, so you have to think about it.”

– David Axelson, MD, chief of the Department of Psychiatry and Behavioral Health and the Section of Psychiatry at Nationwide Children’s

Iron Deficiency Begins Before Anemia

Why Pediatricians Should Recognize and Treat Iron Deficiency Before Anemia Develops

For generations, pediatricians have been taught to think about iron deficiency in the context of anemia. We routinely screen infants for anemia and, when hemoglobin is low, diagnose and treat iron deficiency. If hemoglobin is normal, we generally assume iron status is adequate.

Today, it is clear that this approach misses many children with clinically significant iron deficiency.

Recent studies show that children experience the effects of iron deficiency before their iron stores reach the traditional laboratory definition of deficiency. This evidence helped shape new recommendations from the American Academy of Pediatrics (AAP) and coming soon from the American Society of Hematology (ASH). Together, they represent an important shift in how we understand, diagnose and manage pediatric iron deficiency.

Recognizing the Signs Earlier

During Miriam Rule's freshman year of high school, her race times suddenly slowed. She struggled to finish workouts, needed daily naps and developed brain fog and muscle soreness. For a normally energetic teenager who loved to run, the change was alarming. Yet routine blood work showed she was not anemic.

A family friend, who is an elite running coach, encouraged her family to request ferritin testing, which revealed significant iron deficiency. Oral iron provided modest improvement, but her symptoms returned the following season. After a referral to Nationwide Children's, she began receiving intravenous iron, which restored her iron stores, energy level and athletic performance. By her senior year, she qualified for the state cross-country championships. She also

made it to the Nike Cross Country Regionals and earned a chance to compete in college.

"Having my ferritin treated allowed me to compete at the level I knew I was capable of," says Miriam, who is now 18 years old. "More importantly, I finally felt like myself again."

Miriam's experience is not unusual. Iron deficiency without anemia may present as restless sleep, chronic headaches, poor concentration, exercise intolerance, declining athletic performance or behavioral changes. Many children simply adapt to these symptoms. Families may not recognize that anything is wrong.

A New Approach to Screening

Rather than waiting for symptoms to prompt testing or for anemia to appear on routine screening, the new guidelines from AAP recommends proactive screening at key developmental stages. Pediatricians should obtain both a complete blood count and serum ferritin in breastfed infants between 9 and 12 months of age, formula-fed infants between 15 and 18 months of age and menstruating adolescents within one year of menarche or by age 14.

The guidelines also redefine iron deficiency using higher ferritin thresholds. These new levels better reflect when the body begins to experience inadequate iron for normal function. Iron deficiency is now defined as a serum ferritin level of 20 ng/mL or less in children up to 10 years old. In children and adolescents aged 11 years and older, the threshold is 30 ng/mL or less.

Using these physiologically based definitions more than doubles the estimated prevalence of iron deficiency among young children, from 16% to 34%. The prevalence of iron deficiency anemia changes very little. This

By **Amanda E. Jacobson-Kelly, MD, MSc**, director of the Iron Disorders Program at Nationwide Children's Hospital and associate professor of Pediatrics at The Ohio State University College of Medicine

reinforces what many pediatric hematologists have observed in practice: iron deficiency is far more common than iron deficiency anemia. We will now identify children previously considered healthy because their hemoglobin was normal as having iron deficiency, and they will receive appropriate evaluation and treatment.

Why More Screening Is Worth the Effort

I recognize what these recommendations mean for busy primary care pediatricians. They expand routine screening, increase laboratory testing and require more conversations with families, as well as additional treatment and follow-up.

That is a significant commitment. But I believe it is one worth making. When iron deficiency goes unrecognized, children may struggle in school, athletes experience unexplained declines in performance and families spend months searching for answers. Earlier screening gives us the opportunity to identify these children before those problems become more significant.

Treatment Must Evolve

Most children with iron deficiency require therapeutic-dose oral iron. Dietary changes or a standard multivitamin are generally insufficient to replenish depleted iron stores.

For children who cannot tolerate oral iron, have malabsorption, follow highly restricted diets or require more rapid iron repletion, intravenous iron should be considered. Modern formulations have an excellent safety profile. At Nationwide Children's, my colleagues and I administer thousands of pediatric intravenous iron infusions each year with an outstanding safety record.

Blood transfusion is rarely recommended for iron deficiency. Unless a child is hemodynamically unstable



or actively bleeding, transfusion exposes them to unnecessary risks and will not adequately correct the underlying iron deficit.

A New Definition of Iron Deficiency

Most importantly, a normal hemoglobin level should no longer reassure us that iron status is normal. We have learned that iron deficiency can exist long before anemia develops. Our screening and treatment strategies should reflect what we now know about iron deficiency so we can recognize it earlier and treat it sooner. ■

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Post-concussion Screen Time: Amount and Type Matter for Recovery

A new study, published in *British Journal of Sports Medicine*, found that moderate screen time may speed recovery in youth with concussion. The study, led by Jingzen (Ginger) Yang, PhD, MPH, showed that a median 141 minutes of screen time each day as associated with a 35% faster recovery.

[PediatricsNationwide.org/Concussion-Screen-Time](https://pediatricsnationwide.org/concussion-screen-time)



A Novel Tool Opens New Door to Personalized Genetic Risk Assessment

A recent study led by investigators from the Steve and Cindy Rasmussen Institute for Genomic Medicine at Nationwide Children's is helping make genetic information more accessible through a public platform that could advance disease risk prediction and precision medicine. Published in *Nature Communications*, the study introduces the PGS Browser, an online resource designed to help researchers interpret and apply polygenic scores (PGSs).

[PediatricsNationwide.org/PGS-Browser](https://pediatricsnationwide.org/pgs-browser)



Integrated Crisis Care Continuum Expands Access for Youth and Families

As pediatric mental health needs continue to rise, Nationwide Children's has developed an integrated crisis care continuum designed to connect children and families with timely services matched to their clinical needs while reducing unnecessary emergency department visits and inpatient hospitalizations. The model, described in the journal *Child and Adolescent Psychiatric Clinics of North America*, coordinates five core services: Telecrisis, Mobile Response and Stabilization Services (MRSS), the Critical Assessment and Treatment Clinic (CATC), the Psychiatric Crisis Department, and the Youth Crisis Stabilization Unit.

[PediatricsNationwide.org/Crisis-Care-Continuum](https://pediatricsnationwide.org/crisis-care-continuum)

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Catherine Krawczeski, MD

Physician-in-Chief and Chief Medical Officer
at Nationwide Children's Hospital



Dennis Durbin, MD, MSCE

President, Abigail Wexner Research Institute
at Nationwide Children's Hospital

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Jan Arthur
Jennifer English
Alicia Shoemaker

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Abbie Miller, MS, MWC

Staff Writers

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Contributing Writers

Katie Brind'Amour, PhD,
MS, CHES
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Art Director and Designer

Tanya Burgess Bender

Illustrator

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