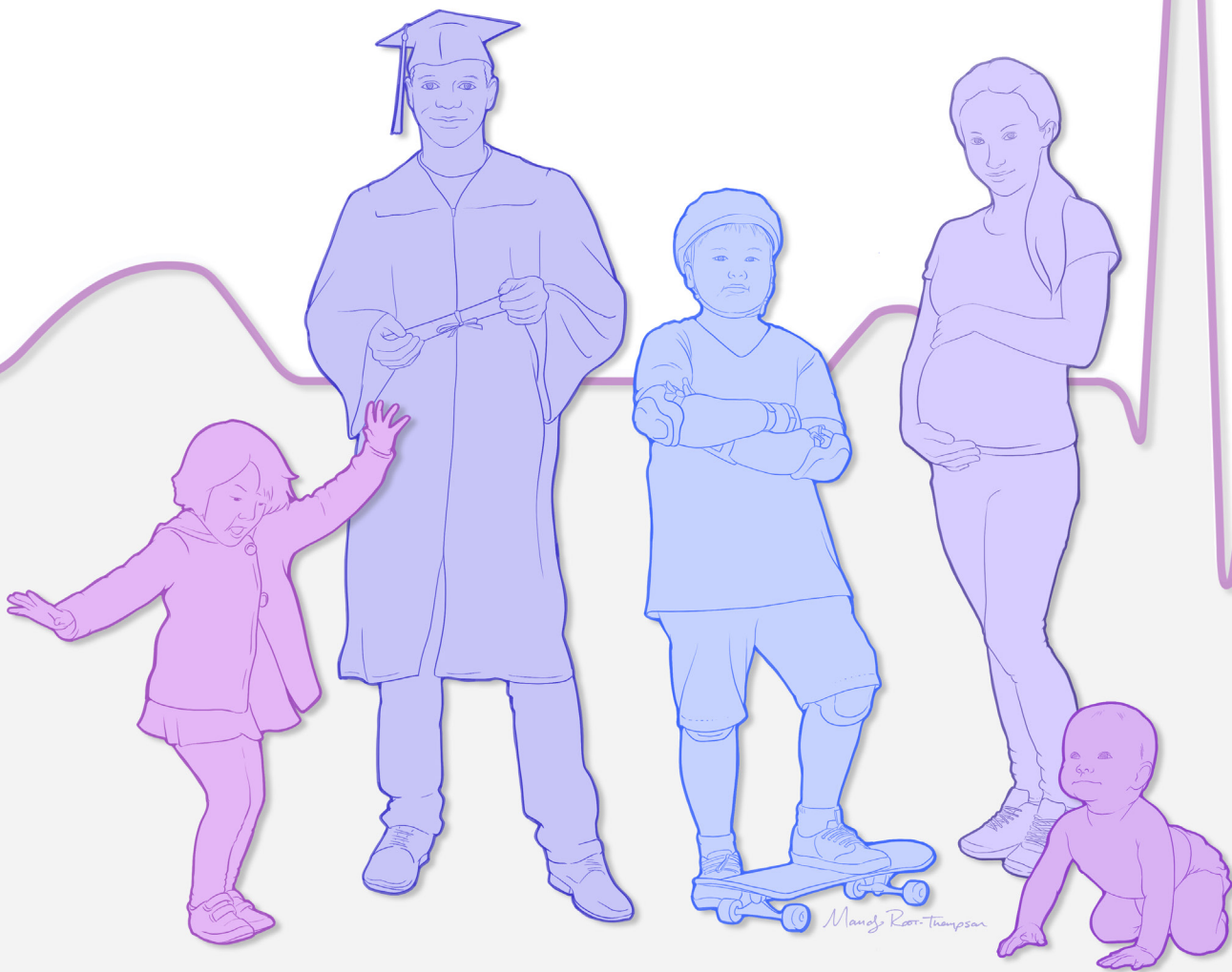


Fall/Winter 2020

Pediatrics

NATIONWIDE

Advancing the Conversation
on Child Health



PEDIATRIC VITAL SIGNS: MEASURING AND IMPROVING THE HEALTH OF A POPULATION

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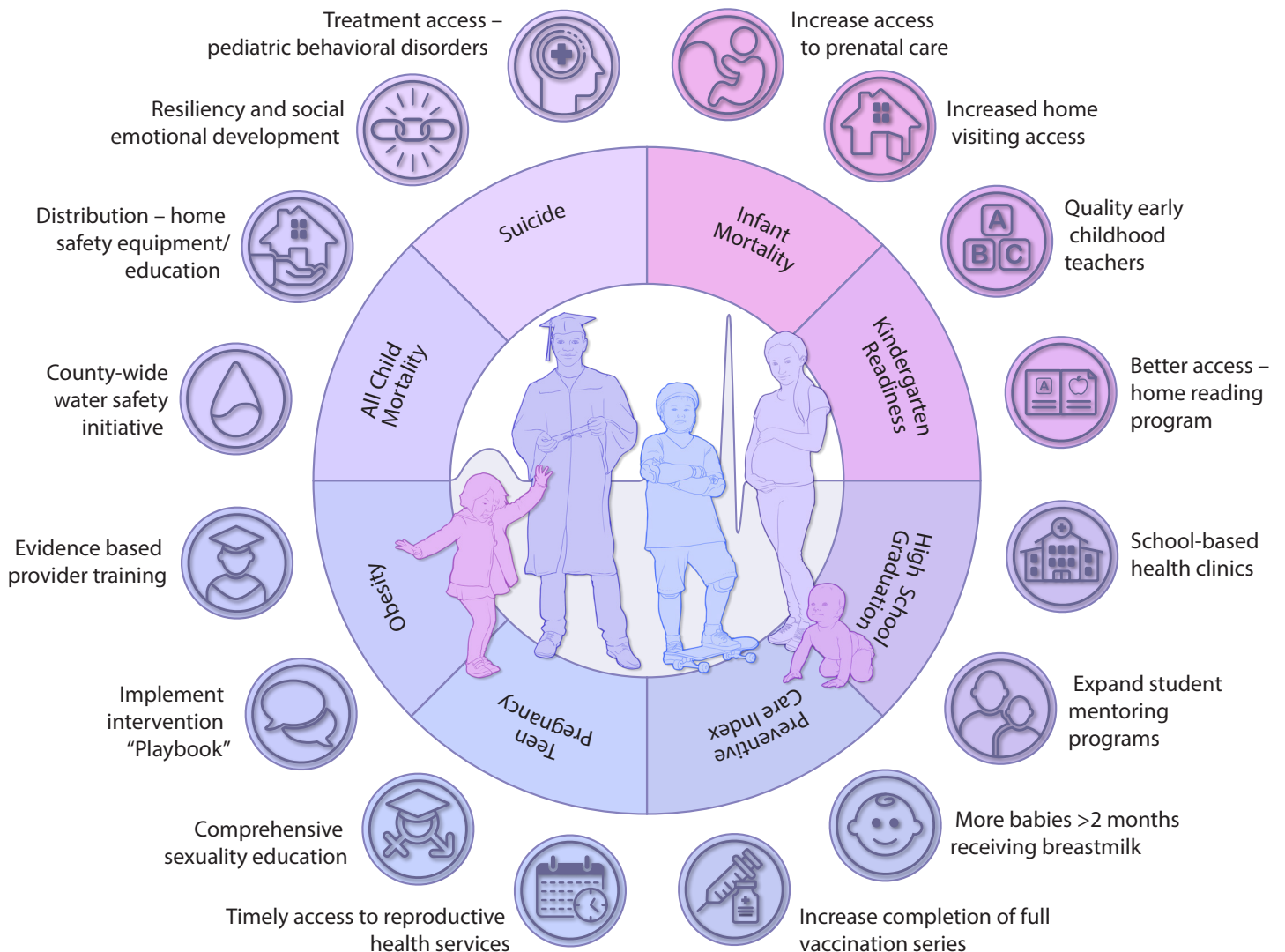
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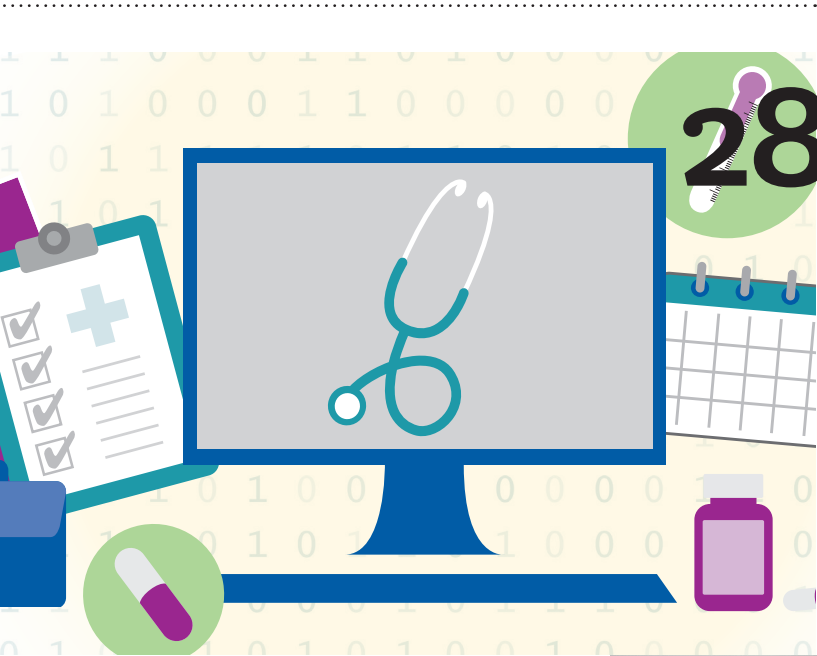
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Eight childhood-spanning metrics — or “Pediatric Vital Signs” — are helping Nationwide Children’s Hospital meaningfully measure the wellbeing of children across a population. The hospital and its community partners have also developed interventions as part of each sign to improve child health.





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“ Prior to opening the Behavioral Crisis Center, the volume of patients coming for strict behavioral health intervention and crisis in the ED was so strong that it was hard to keep up with the staffing and resources we had. ”

– Mindy Schultz, MSW, LISW-S, director for Social Care Services at Dayton Children’s Hospital

“ As we move forward, we will need innovation to use modalities beyond videoconferencing to get true advantage of virtual care that includes other digital health tools to connect families, emergency departments and schools with the ‘hub’ for timely care. ”

– Ujjwal Ramtekkar, MD, medical director for Tele/Virtual Health for Behavioral Health at Nationwide Children’s Hospital

Improving Diagnostic Accuracy for Pediatric Hypertension

A recent pilot study highlights additional diagnostic criteria for clinicians to consider.



Pediatric hypertension, or high blood pressure (BP), has become increasingly common and now affects more than 3% of children and adolescents. Untreated, hypertension is one of the strongest risk factors for cardiovascular disease and mortality in adults, and substantial evidence links childhood hypertension to long-term renal, cardiovascular and neurodevelopment risks.

To avoid underdiagnosis, evaluation of BP percentiles should be a routine part of pediatric practice, but hypertension is more challenging to diagnose in children because of age-, sex- and height-related variability in BP norms. Over the last decade, ambulatory BP monitoring (ABPM) has become the standard for diagnosing hypertension in children.

“Without using ABPM, the chance of making an error in your diagnosis is close to 40%, so the guidelines strongly recommend using ABPM,” says Mahmoud Kallash, MD, a physician in the Division of Pediatric Nephrology and Hypertension at Nationwide Children’s Hospital.

ABPM uses oscillometric machines to measure mean arterial pressure (MAP) by automatically collecting a series of readings over 24 hours while patients are at home. From there, systolic and diastolic BP values are extrapolated based on manufacturer-specific formulas.

Despite the availability of normative MAP values, current pediatric guidelines recommend using these calculated systolic and diastolic BP values rather than the measured MAP for hypertension diagnosis.

A recent pilot study challenged those guidelines. Published in *Pediatric Nephrology* and led by Dr. Kallash, the retrospective study of 263 patients found that considering the measured MAP values significantly improved diagnostic accuracy.

Additionally, this study was the first to investigate using adult criteria for diagnosing hypertension in male children who are greater than 165 cm tall. For this group, the 95th percentile (hypertensive threshold) for average systolic and diastolic BP calculated using ABPM is higher than the hypertensive threshold used to define hypertension in adults. As a result, tall male children could have an ABPM study that would not result in a diagnosis of hypertension using pediatric criteria but would be interpreted as hypertension using adult criteria.

When adult thresholds for diagnosis of ambulatory hypertension were applied, 10 subjects were hypertensive who were not categorized this way under pediatric criteria. As a result, using the higher pediatric thresholds for this subgroup may allow patients who are at risk for cardiovascular complications to go undiagnosed.

Both under- and over-diagnosis of pediatric hypertension can have negative effects on children.

“Patients with chronic kidney disease or heart disease may already take many medications and adding an unnecessary medication can have a major effect on their physical and mental health,” says Dr. Kallash. “Also, if left untreated, hypertension can result in a faster progression of patients’ renal or cardiac disease.”

Thomas J, Stonebrook E, Klammer B, Patel HP, Kallash M. Challenges of diagnosing pediatric hypertension using ambulatory blood pressure monitoring. *Pediatric Nephrology*. 2020 Aug 6 [Epub ahead of print].

— Natalie Wilson

Updated Guidance on Oral Food Challenges

New report offers guidelines and examples for safely performing oral food challenges in clinical practice.

Oral food challenges are integral for allergists to diagnose food allergies. In 2009, the Adverse Reactions to Foods Committee within the American Academy of Allergy, Asthma & Immunology published a report providing guidance for safely conducting an oral food challenge. Now, an update to this report has been published that expands on previously established guidance and provides more practical information for clinicians and patients.

Irene Mikhail, MD, a physician in the Section of Allergy and Immunology at Nationwide Children's Hospital and one of the updated report's authors, says that even after the previous report came out, ambiguity remained about choosing patients to undergo an oral food challenge and the best way to perform them.

"The previous guidelines left much open to interpretation and to the discretion of the provider," says Dr. Mikhail, who is also an assistant professor of Pediatrics at The Ohio State University College of Medicine.

"This new set of guidelines clarifies and lays out more objective data to guide some of those decisions."

The updated report supplements the previous publication with additional focus on safety; treatment of IgE-mediated allergic reactions; specific guidance for baked milk and baked egg challenges; psychosocial considerations for children and families participating in an oral food challenge; and special aspects of oral food challenges for infants, adults and research participants.

The new guidelines also offer specific examples of when to begin an oral food challenge as well as when a challenge should be stopped. There are tables and figures within the report, plus an extensive online appendix, that provide useful information for both patients and clinicians, including age-specific portion sizes, appropriate timing for antihistamine discontinuation, serum and skin test result interpretation, written consents and instructional handouts.

"Oral food challenges are extremely important for allergy medicine," says Dr. Mikhail. "In a study last



year, we found that even patients who failed their food challenge or had an allergic reaction during it still felt positively about the experience and felt they benefitted from the food challenge."

Although patients may be eager to undergo an oral food challenge, Dr. Mikhail says that many providers remain nervous about them — for good reason.

"You are potentially exposing the patient to something that could cause anaphylaxis," she says. "I think because of that, providers are sometimes reluctant to offer food challenges."

However, with food allergies on the rise, allergists can expect an increased need for oral food challenges.

"I'm hoping these guidelines will help providers feel comfortable with oral food challenges and allow them to use this tool more effectively," says Dr. Mikhail. "If providers have more information, they can understand how they can safely implement oral food challenges in their practice."

Bird JA, Leonard S, Groetch M, Assa'ad A, Cianferoni A, Clark A, Crain M, Fausnight T, Fleischer D, Green T, Greenhawt M, Herbert L, Lanser BJ, Mikhail I, Mustafa S, Noone S, Parrish C, Varshney P, Vlieg-Boerstra B, Young MC, Sicherer S, Nowak-Węgrzyn A. Conducting an oral food challenge: An update to the 2009 Adverse Reactions to Foods Committee Work Group report. *The Journal of Allergy and Clinical Immunology: In Practice*. 2020;8(1):75-90.

— Mary Bates, PhD

Findings Show TEVG Stenosis Spontaneously Resolves

The complication that halted a clinical trial for tissue-engineered vascular grafts for children with congenital heart disease may reverse spontaneously without clinical complications.

Based on promising laboratory and animal modeling of a biodegradable scaffold seeded with a patient's own cells, a clinician-scientist research team now based at Nationwide Children's Hospital initiated a pediatric tissue engineered vascular graft (TEVG) trial in Japan for children requiring the Fontan procedure for univentricular hearts. After its high success rate — with only 1 in 25 patients developing serious stenosis, which was successfully treated — the group launched a similar study in the United States.

Unfortunately, when 3 of the first 4 patients developed postoperative stenosis requiring balloon angioplasty, the study was terminated. All patients were safely treated and remain well several years after the trial.

To find out why the U.S. trial's results differed so drastically from Japan's, the investigators initiated robust computer modeling and found a surprising suggested explanation: early stenosis — a result of the body's inflammatory response and the scaffold's mechanical properties — may reverse on its own. Tests on sheep confirmed the computer model's findings. Stenosis reversed spontaneously in time, without clinical complications.

According to the research, when the TEVG is implanted, stenosis develops due to inflammation, as the body recruits cells and builds new tissue on the scaffold. When the immune reaction calms, stenosis resolves, and the graft is replaced with a new, natural blood vessel that is virtually indistinguishable from native tissue.

"It's possible that this exact phenomenon occurred in the Japanese trial, but was largely missed due to post-surgical imaging timing and different criteria for angioplasty," says Christopher Breuer, MD, director of the Center for Regenerative Medicine and Endowed Chair in Surgical Research at Nationwide Children's and director of Tissue Engineering at The Ohio State University Wexner Medical Center.

Dr. Breuer and Toshiharu Shinoka, MD, PhD, co-director of the Tissue Engineering Program at Nationwide Children's jointly lead the team that designed the TEVG used, ran the trials and published the latest results from the computer and animal modeling. When the team reexamined available imaging from the Japanese trial, they found a few cases where narrowing was observed but monitored via imaging only. Most resolved without intervention.

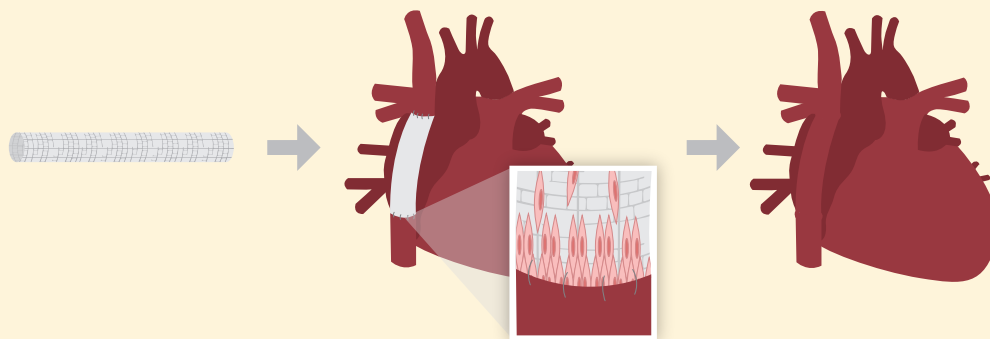
The team is launching a new TEVG trial at Nationwide Children's in 2020, with different stenosis monitoring and intervention criteria designed to accommodate the likely scenario of temporary, asymptomatic narrowing with spontaneous resolution. It is the team's hope that TEVG will successfully, permanently treat single-ventricle congenital heart disease.

Drews JD, Pepper VK, Best CA, Szafron JM, Cheatham JP, Yates AR, Hor KN, Zbinden JC, Chang YC, Mirhaidari GJM, Ramachandra AB, Miyamoto S, Blum KM, Onwuka EA, Zakko J, Kelly J, Cheatham SL, King N, Reinhardt JW, Sugiura T, Miyachi H, Matsuzaki Y, Breuer J, Heuer ED, West TA, Shoji T, Berman D, Boe BA, Asnes J, Galantowicz M, Matsumura G, Hibino N, Marsden AL, Pober JS, Humphrey JD, Shinoka T, Breuer CK. Spontaneous reversal of stenosis in tissue-engineered vascular grafts. *Science Translational Medicine*. 2020 Apr 1;12(537):eaax6919.

Hibino N, McGillicuddy E, Matsumura G, Ichihara Y, Naito Y, Breuer C, Shinoka T. Late-term results of tissue-engineered vascular grafts in humans. *Journal of Thoracic and Cardiovascular Surgery*. 139, 431–436.e2 (2010).

— Katie Brind'Amour, PhD

Tissue engineered vascular grafts use cells seeded on a three-dimensional biodegradable scaffold. The seeded scaffold is placed as a conduit during the Fontan surgery. Over time, the scaffold disappears, leaving a natural vessel composed of the child's own cells.



Diagnosing Adolescent Polycystic Ovary Syndrome

New adolescent-specific guidelines provide more precise guidance on diagnosing polycystic ovary syndrome in adolescent females.



Polycystic ovary syndrome (PCOS), the most common female reproductive endocrine disorder, presents diagnostic challenges in adolescents, highlighting the need for adolescent-specific diagnostic guidelines for PCOS.

“We can’t use the adult criteria for diagnosing adolescent PCOS,” says Andrea Bonny, MD, section chief of Adolescent Medicine at Nationwide Children’s Hospital. The adult and adolescent diagnostic criteria for PCOS were outlined in a recent *Clinical Obstetrics and Gynecology* publication.

Pediatric endocrinology experts disagree on when PCOS should be diagnosed in adolescents and how much menstrual irregularity is normal during puberty.

“The PCOS phenotype begins during pubertal development. However, the phenotypic attributes in the adult diagnostic criteria can be normal phenomena in adolescents,” Dr. Bonny says. These attributes are hyperandrogenism, ovulatory dysfunction and polycystic ovarian morphology.

In recent years, the Endocrine Society, Pediatric Endocrine Society (PES), and the Amsterdam PCOS Consensus Workshop Group have developed adolescent PCOS diagnostic guidelines.

Each of these guidelines require the presence of clinical hyperandrogenism (e.g., acne) and ovulatory dysfunction, yet there are differences between the guidelines on these requirements. For example, the Amsterdam guidelines require that ovulatory dysfunction be present for at least two years. In the PES guidelines, though, ovulatory dysfunction is diagnostic for PCOS

if menstruation has not started by 15 years of age or 2-3 years after thelarche.

Polycystic ovarian morphology is generally not included in the guidelines because this morphology is difficult to assess in adolescents.

“Treating adolescent PCOS can begin before a definitive diagnosis,” Dr. Bonny says, “especially if a patient’s symptoms are distressing. Treatment reduces these symptoms and the risk of comorbidities, such as obesity and psychiatric disorders.”

Obesity is a common comorbidity of PCOS. Weight loss has many benefits, including regulating menstruation, normalizing androgen levels and lessening insulin resistance. Unfortunately, insulin resistance can make weight loss difficult.

Medical therapies for adolescent PCOS are combined hormonal contraceptives (CHCs), spironolactone and metformin. These medications provide similar benefits as those associated with weight loss and also reduce acne. CHCs are often used as a first-line treatment.

“Clinicians should be mindful of treating the symptoms that could contribute to mental health comorbidities,” Dr. Bonny says. Untreated obesity and severe acne could contribute to anxiety, depression and eating disorders.

To date, adolescent patients with PCOS are not routinely screened for psychiatric disorders. Dr. Bonny recommends routine psychiatric screenings and subsequent treatment, if necessary, for these patients.

Ebersole AM, Bonny AE. Diagnosis and treatment of polycystic ovary syndrome in adolescent females. *Clinical Obstetrics and Gynecology*. 2020 Sep;63(3):544-552. [Epub ahead of print]

— JoAnna Pendergrass, DVM

“Redo” Surgery After Anorectal Malformation Repair Can Improve Functional Outcomes

A reoperation can improve continence and quality of life in children still struggling with fecal incontinence following ARM repair.



In a new study, researchers from Nationwide Children’s Hospital show that redo surgeries are safe and may be an effective option for patients with fecal incontinence after an anorectal malformation (ARM) repair. For many patients, a reoperation can correct their anatomy, restore continence and improve quality of life.

ARMs are rare congenital abnormalities in which the lower part of the gastrointestinal tract does not develop properly. The goal of surgeries to repair ARMs is to restore normal anatomy and increase continence. Although outcomes are generally good, some patients with a previously repaired ARM remain fecally incontinent.

In the new study, published in the *Journal of Pediatric Surgery*, researchers assessed the benefit of reoperations in patients suffering from fecal incontinence after a previous ARM repair. The researchers collected objective outcome measures from more than 150 patients with a previously repaired ARM who underwent a redo surgery to further correct their anatomy.

“We were able to show with objective scores that redo procedures not only improved continence for many children but also improved quality of life,” says Richard Wood, MD, chief of the Department of Pediatric Colorectal and Pelvic Reconstructive Surgery at

Nationwide Children’s and the study’s lead author.

Dr. Wood and his colleagues found that at one year post-redo, nearly half of the patients were on laxatives only, and three-quarters of those patients were continent. Overall, 77% of the patients were clean (≤ 1 accident per week) after their redo surgery.

In addition, the complication rate was low. Strictures were the most common complication seen after reoperations, as no dilations were performed, but were easily managed with a minor procedure.

Moreover, the researchers report that 20% of patients with expected poor continence potential became fully continent on a laxative-based regimen after redo surgery. Traditionally, many of these children would not even be offered a redo surgery, given their perceived poor potential for bowel control. These results suggest that such assessments are subjective and potentially limiting, as reoperation can be beneficial to a proportion of these patients.

“If you have a patient with fecal incontinence after ARM surgery, one should ask if the patient’s anatomy is optimal or if it could be improved upon,” he says. “This study showed that there are many children who are incontinent who can achieve continence with a reoperation.”

Dr. Wood, who is also an associate professor of Surgery at The Ohio State University College of Medicine, emphasizes the importance of involving the patients and their families in decision-making.

“A major goal is optimizing a child’s continence,” says Dr. Wood. “But I think the most important factor that we deal with is improving quality of life.”

Wood RJ, Halleran DR, Ahmad H, Vilanova-Sanchez A, Rentea RM, Stallings P, Ganesh N, Gasior A, Levitt MA. Assessing the benefit of reoperations in patients who suffer from fecal incontinence after repair of their anorectal malformation. *Journal of Pediatric Surgery*. 2020;S0022-3468(20)30423-1.

— Mary Bates, PhD



Choking Prevention is Vital Element of Care for Families Living With Prader-Willi Syndrome

Education intervention offers a simple way to address this common cause of death among patients with PWS.

Individuals with Prader-Willi Syndrome (PWS) suffer from poor oral muscle control, generalized low muscle tone that can make it hard to swallow properly, a poor gag reflex and an insatiable desire to eat. Together with a low production of saliva and a tendency to rush food consumption (not chewing properly, consuming large quantities or sneaking food quickly), patients can be uniquely predisposed to suffer from a choking incident — and to die from one.

Choking is common in this population, affecting at least 1 in 3 patients at some point, and leading to death in about 8% of the PWS population, according a 2007 study in the *American Journal of Medical Genetics*. Furthermore, the risk is not restricted to young children. The average age of death due to choking is about 24.

When Amy Moffett, CPNP-PC, a nurse practitioner in the Prader-Willi Syndrome Clinic at Nationwide Children's Hospital, learned of the prevalence of this problem, she saw an opportunity to change the quality—and perhaps even the duration — of life for the clinic's patients.

“It was clear that we needed to offer our families choking-related education and some first aid training,” says Moffett. “Obviously, our goal is that nobody chokes, but if something does happen, we want families to know what to do.”

Moffett and her colleague Kathryn Anglin, RN, MSN, a long-time nurse in the PWS Clinic at Nationwide Children's, worked with clinic endocrinologists, nursing

staff and community programming teams at the hospital to develop a basic choking education and prevention training for families. Families were given a pre- and post-test to assess their knowledge about choking risks and their comfort level with choking interventions.

All of the education was delivered during waiting periods between visits with different clinicians in the multidisciplinary clinic. Families watched an age-specific choking prevention and intervention video developed by the American Heart Association. They also had the chance to practice the Heimlich maneuver on mannequins.

“It is something we don't think about as endocrinologists very often because it's not part of the endocrine system, but an increased risk of choking is something we need to think about within our patients' full spectrum of disease,” says Kathryn Obrynba, MD, director of the PWS Clinic at Nationwide Children's. “I can't say enough how simple it was for us to integrate this education into our clinical workflow.”

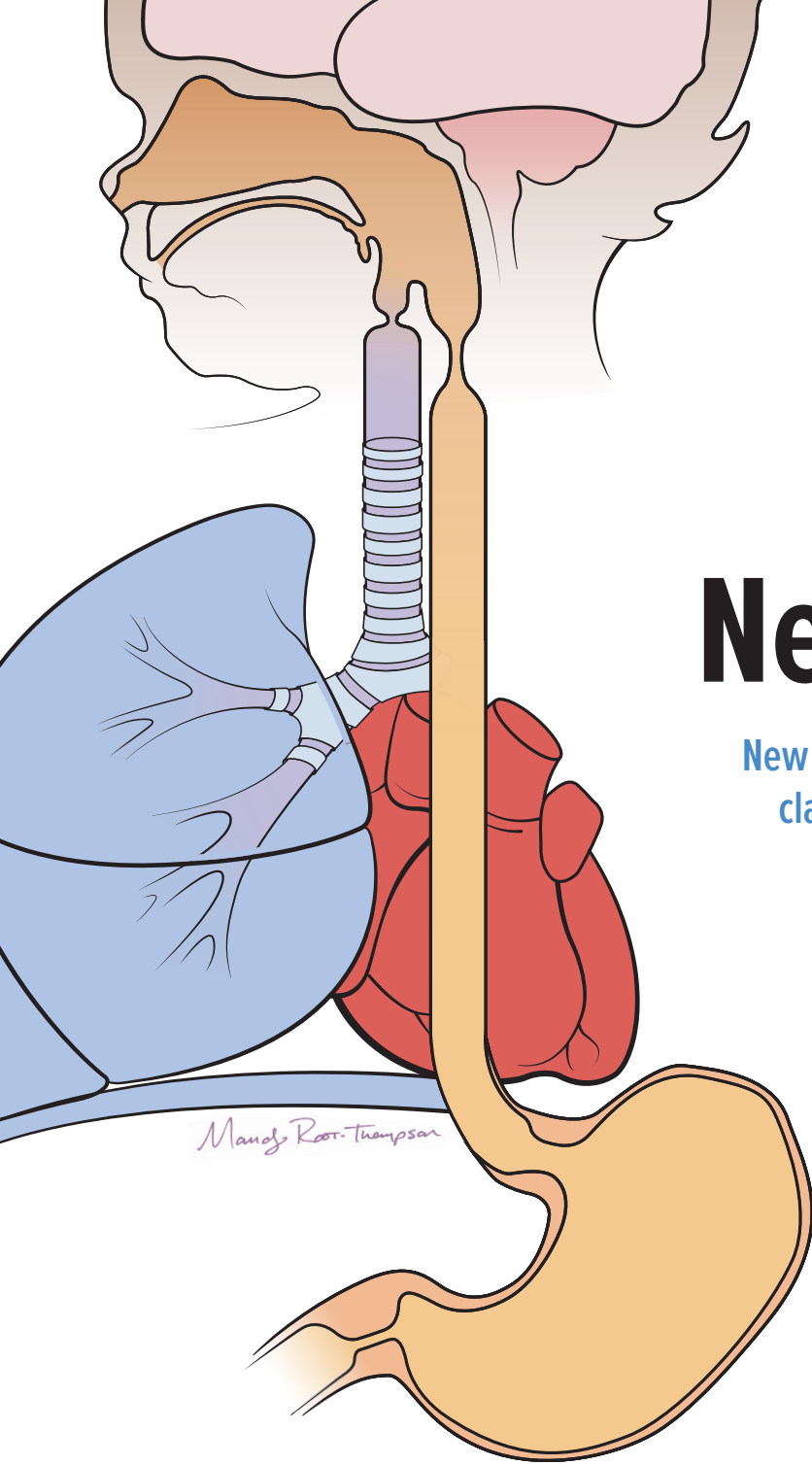
Within 12 months of initiating the QI project, the team surpassed their goal of educating 80% of the clinic's PWS families. The project has also demonstrated clear post-test improvements in family knowledge of choking risks and comfort with interventions.

Manzardo AM, Loker J, Heinemann J, Loker C, Butler MG. Survival trends from the Prader-Willi Syndrome Association (USA) 40-year mortality survey. *Genetic Medicine*. 2018;20(1):24-30.

Moffett A, Anglin K. Prader-Willi Syndrome choking prevention and education: A practice change. Presentation at the Pediatric Endocrinology Nursing Society: Long Beach, CA. April 27, 2019.

Stevenson DA, Heinemann J, Angulo M, Butler MG, Loker J, Rupe N, Kendall P, Clericuzio CL, Scheimann AO. Deaths due to choking in Prader-Willi syndrome. *American Journal of Medical Genetics Part A*. 2007;143A(5):484-487.

— Katie Brind'Amour, PhD



ADVANCES IN Neonatal GERD

New studies provide insights into diagnosing, classifying, and treating GERD in infants.

by Mary Bates, PhD

and Nationwide Foundation Endowed Chair in Neonatology at Nationwide Children's Hospital, says that feeding and airway-digestive problems are common in infants but may not always indicate GERD. Ambiguity lies with the definition of troublesome symptoms in newborns or nonverbal patients in general, making it difficult to demonstrate objectively if and when symptoms are truly due to GERD.

As a result, infants are frequently subjected to a battery of empiric therapies, such as prolonged use of acid suppression medications, feeding modifications and positional changes.

Now, two new papers from Dr. Jadcherla's lab provide new evidence-based insights into diagnosing, classifying and treating GERD in infants.

In the first study, Dr. Jadcherla and his colleagues used pH-impedance monitoring to differentiate esophageal sensitivity phenotypes in NICU infants referred for GERD symptoms. Symptoms may occur due to esophageal sensitivity to acid, non-acid reflux or other non-GER causes. The researchers documented many symptoms, including vomiting, arching, irritability and

Differentiating gastroesophageal reflux (GER), which is defined as the passage of gastric contents into the esophagus, from GER disease (GERD), when reflux is associated with troubling symptoms, remains a challenge in infants. Symptom-based diagnosis and treatment of GERD has been in practice widely, and practicing this way is a fundamental problem.

Sudarshan Jadcherla, MD, principal investigator, director of the Neonatal and Infant Feeding Disorders Program

cough, and related the frequency of these symptoms to acid reflux.

They found that the majority of symptoms exhibited by babies were not actually related to acid reflux. Only vomiting and cough were found to be caused by acid alone. Other common symptoms, such as irritability and arching, could be related to non-acid reflux.

Dr. Jadcherla and his colleagues differentiated four esophageal sensitivity phenotypes based on pH-impedance monitoring. They hope that by identifying these phenotypes in patients, targeted therapeutic strategies can be developed and unnecessary therapies can be avoided.

“The results highlight that many of the symptoms that doctors and nurses report are not always acid-related and so could be treated without using acid suppression medications,” says Zakia Sultana, a research assistant at Nationwide Children’s and an author of the study.

“You can’t prescribe acid suppressing medication just by looking at a baby,” she says. “You have to do some diagnostic testing, such as pH-impedance with some symptom correlation. Then you can see if this baby’s symptoms might be related to other factors, not necessarily acid in their esophagus or stomach.”

Dr. Jadcherla, who is also a professor of pediatrics at The Ohio State University College of Medicine, says there are risks to prolonged use of acid-suppressing medications in infants.

“These medications can alter the bowel flora, modify bone density, increase the risk of infections to the gut and airway, and cause other long-term consequences,” he says. “I recommend that clinicians investigate before they medicate.”

Sultana emphasizes the need for innovative treatment strategies to address non-acid-related symptoms.

“What is coming up from the stomach to the esophagus? If it’s not acid, what is it and how do we treat it? These are the questions that remain for future studies,” she says.

In the second study, Dr. Jadcherla and his team tested the effectiveness of behavioral modifications for treating GERD in infants in a randomized clinical trial. For decades, nonevidence-based approaches, including restricting feeding volume and changing the baby’s body position, have been thought to modify GERD and its symptoms.

The researchers identified the infants who needed acid suppressant therapy based on objective testing, that is, based on their pH impedance metrics, and then randomized them into two groups. One group received acid-suppressive therapy only, with no restrictions on feeding volume or body positions. In the other group, feeding volume was restricted and body position was regulated, in addition to the acid-suppressive therapy.

“There was no difference between these approaches in short-term or long-term outcomes,” says Dr. Jadcherla. “We found that by the end of four weeks, the infants in both groups were okay and did not need any more interventions.”

The improvement in symptoms and feeding outcomes over time, irrespective of feeding modifications, may suggest that maturation plays a role in resolving symptoms.

In any case, Dr. Jadcherla says this study shows that feeding restrictions and altering body positions have no major influence on GERD or its treatment – and therefore, these factors should no longer be confounding variables in future trials of GERD therapies.

“From this we learned infants can be fed what they can eat without imposing volume restrictions. Variabilities in feeding positions are common and have no effect on GERD,” he says. “And acid-suppressing medication should only be used in those that have evidence of acid-GERD and for only a limited period of time.”

Overall, Dr. Jadcherla says further studies are needed to define true GERD and identify effective therapies to treat its symptoms or complications.

“Reflux often goes away with time and maturation, but when pathological, it requires careful evaluation and therapy,” he says. “One has to be cautious in distinguishing normal from abnormal. That’s where the need for testing comes in, and translation of evidence-based strategies will then be possible.”

Dr. Jadcherla’s research work is supported by R01 awards from the National Institutes of Health (NIH).

Jadcherla SR, Hasenstab KA, Wei L, Osborn EK, Viswanathan S, Gulati IK, Slaughter JL, Di Lorenzo C. Role of feeding strategy bundle with acid-suppressive therapy in infants with esophageal reflux exposure: a randomized controlled trial. *Pediatric Research*. 2020 May 7. [Epub ahead of print]

Jadcherla SR, Sultana Z, Hasenstab-Kenney KA, Prabhakar V, Gulati IK, Di Lorenzo C. Differentiating esophageal sensitivity phenotypes using pH-impedance in intensive care unit infants referred for gastroesophageal reflux symptoms. *Pediatric Research*. 2020 May 6. [Epub ahead of print]



THE NEW EMERGENCY DEPARTMENT FOR BEHAVIORAL HEALTH

How pediatric hospitals are creatively tackling the unique care needs of a growing population of youths in crisis.



by Katie Brind'Amour, PhD

From attention deficit disorder to anxiety or depression, mental health conditions affect about 1 in every 5 children. While some of these cases resolve, many children go on to adulthood with mental or behavioral health disorders, and continue to suffer problems at home, school, work and in their social lives.

To make matters worse, numerous conditions — and their sequelae — are on the rise. According to the Centers for Disease Control and Prevention, the incidence of depression and anxiety is growing among children ages 6-17. After accidents, suicide is the leading cause of death among kids 10 and older.

And of course, as in any health-related emergency, many families turn to the emergency department for care. From 2011 to 2015, more than 13 million youth (ages 6-24) presented to the ED with a psychiatric concern, according to a 2019 publication in *Pediatrics*. Unfortunately, more than half remained at the ED for 3 hours or more, and the vast majority (84%) were discharged without seeing any mental health professional.

A 2020 study in *Pediatrics* from Rachel Stanley, MD,

division chief for Emergency Medicine at Nationwide Children's Hospital, showed that in the period from 2007 to 2016, pediatric ED visits for deliberate self harm rose 329% and visits for all mental health disorders rose 60%.

THE PROBLEM WITH A STANDARD ED

While emergency departments should always be an option to treat young people in crisis (especially those in true medical emergency situations), they're not often the best care solution. The vast majority of young people coming into EDs in a behavioral health crisis do not need medical care—they haven't physically injured themselves and do not require clinical care for coexisting health conditions. Furthermore, more than 80% do not require hospital admission or transfer to an inpatient psychiatric facility.

Regardless, patients and their families sit in hectic rooms that are often ill-equipped for people in a mental health crisis. Surrounded by equipment with wires and cords, medication closets, and furniture with sterile design and purely medical purposes, problems such as anxiety, disorientation, suicidal ideation and violent behavior can easily amplify.

“What we learned from being in a traditional ED is that the environment just isn’t conducive to positive outcomes — we were assessing kids in gowns on hospital beds, and it didn’t feel good for our population,” says Ericka Bruns, LPCC-S, director of Acute Services at Nationwide Children’s Hospital. Prior to the opening of a range of new programs and facilities, her therapist team felt there was a better model of care they could achieve. “We wanted our new psychiatric crisis department consultation rooms to look very much like the outpatient setting — chairs and desks, warm colors and wide hallways, motor skill and comfort rooms, and spaces for kids with behavioral dysregulation to avoid restraint whenever possible. Through triage, we are able to find the right space in our environment that best suits their needs.”

As psychiatric visits to the ED grow (national visits for suicide-related incidents alone jumped 2.5-fold from 2011 to 2015), hospitals are struggling to accommodate the patient load from a staffing and a facility perspective. Patients with potential for suicide must be constantly supervised. Staff are frequently injured due to lack of training in psychiatric crisis management and the fact that the care environment is often oriented for medical rather than mental health care.

When mental health professionals are available, they are often not affiliated strictly with the ED and must be called in for consultation, resulting in lengthy waits. In the meantime, medical evaluations and lab tests further increase agitation, time and costs for families. And unfortunately, these tests are often uninfluential in clinical decision-making for these kids except in a small subset of cases — identifiable by history or an exam — according to the Health Resources and Services Administration’s toolkit for improving pediatric mental health care in the ED.

UNIQUE CARE SOLUTIONS

Recognizing the unsuitable and resource-draining

nature of standard ED environments for children experiencing behavioral health concerns, many hospitals have sought out alternative ways to meet the needs of patients in crisis both through their facility and the type of care they provide.

These tactics are not quick, easy or (when they require new or renovated facilities) cheap. However, they can improve the quality and environment of care, reduce ED staff burden, improve parental satisfaction, reduce time to discharge, lower the cost of care, and decrease risks to patients and staff. Psychologically, they can also be much more calming for patients in fragile mental states.

Approaches include specialized ED rooms, integrated ED care teams, psychiatric EDs, telehealth crisis consultations, inpatient and partial hospitalization, bridge programs, hotlines and outpatient services.

Special ED Rooms

Perhaps the most straightforward facility accommodation hospitals can make is to triage visitors with a psychiatric concern to a separate waiting area — a room or hallway set up to be less stimulating and more like a living room. These provide calm, comfortable places to wait before or between services.

One step beyond separate waiting areas are special ED rooms designed to meet the needs of psychiatric patients while also fulfilling legal requirements for medical equipment and supplies. Ligatures and physical hazards can be locked away inconspicuously and accessed only as needed (for example, in hidden panels or behind cabinets or doors). The rooms can be painted or decorated to reduce the emphasis on medical treatment and instead promote more conversational care approaches.

Prior to the construction of its Psychiatric Crisis Department, Nationwide Children’s used this type of set-up, with five specialty behavioral health rooms set



“What we learned from being in a traditional ED is that the environment just isn’t conducive to positive outcomes—we were assessing kids in gowns on hospital beds, and it didn’t feel good for our population.”

— Ericka Bruns, LPCC-S, director of Acute Services at Nationwide Children’s Hospital



Patient comfort and safety at the Big Lots Behavioral Health Pavilion is in every detail. Beds are in an L shape because trauma-informed care suggests that patients like to occupy the corner of the room because it provides them a safe “nest.” Eight different bathroom door designs for the inpatient unit were tested — until one was found one that provides the right combination of privacy and safety. The door is made of foam and attaches with a strong magnet so it can be removed. Each room also has customizable color-changing lighting.

For a virtual tour of the Big Lots Behavioral Health Pavilion at Nationwide Children’s, visit PediatricsNationwide.org/BH-Crisis-Care

aside in the ED, a special bathroom safe for suicidal patients, and an integrated staffing model.

Integrated ED Care Teams

When feasible, hospitals can also address the behavioral health needs of ED patients through staffing. By committing a counselor, behavioral health social worker, nurse or pediatric psychiatrist to be on call or onsite, some of the burden can be removed from medical staff and transitioned to more appropriate providers.

On-call mental health professionals or staffers permanently based in the ED can provide suitable assessments and referrals and ensure patients receive adequate follow up after their visit.

While this collaboration is ideal for patients, it demands flexibility for co-locating staff, calling in providers from elsewhere in the hospital in short order, booting up telehealth services for remote consultations, or a solid

understanding of demand — both throughout the day and seasonally — to adequately address patient needs without overstaffing the ED with mental health professionals.

If integrated staffing is not an option, ED staff can benefit from crisis stabilization and de-escalation training such as the Marcus Crisis Prevention Program offered by the Children’s Hospital of Atlanta, which helps reduce ED staff injuries and the need to use patient restraints. Their team has already trained more than 5,000 medical professionals around the world to offer more patient-friendly, risk-reducing care to psychiatric patients presenting at a standard ED, as well as to patients in other hospital departments.

Type B EDs or Psychiatric EDs

One unique approach, as taken by Dayton Children’s Hospital, involves reclassifying the type of center used for behavioral health emergencies. Rather than having

patients in an emotional or psychiatric crisis treated in the standard (Type A) ED, patients can be triaged over the phone, through local care sites, or upon presentation (via self-selection if they follow signage) and sent directly to their Behavioral Crisis Center.

Their facility is able to avoid many of the staffing and equipment requirements for standard EDs by falling under the category of Type B emergency centers, per the Emergency Medical Treatment and Active Labor Act (EMTALA). This puts it more on par with labor and delivery departments, allowing it to customize the equipment, look and feel of the rooms — as well as the staffing — to the primary needs of its patients.

“Prior to opening the Behavioral Crisis Center, the volume of patients coming for strict behavioral health intervention and crisis in the ED was so strong that it was hard to keep up with the staffing and resources we had,” says Mindy Schultz, MSW, LISW-S, director for Social Care Services at Dayton Children’s. “We knew we needed to do more and have a dedicated service for kids in crisis, to expand our holistic continuum of care and fill those gaps in the system.”

The new set-up saves families about \$1,000 per visit and more than an hour of ED visit time, compared to what patients averaged in the standard ED for less targeted treatment in the past.

In psychiatric-specific EDs, instead of wire-filled, medically oriented rooms, patients find chairs or a couch and desk in their room. Much as they would in an outpatient visit, they speak to staff conversationally, rather than wearing a medical gown and sitting on a hospital bed. Medical personnel are available for assessments as needed but make up the minority of care providers on staff, reversing the typical expertise balance compared to integrated Type A EDs.

Nationwide Children’s and the University of Pittsburgh Medical Center (UPMC) have similarly tailored ED solutions. The Psychiatric Crisis Department in Columbus and UPMC’s Psychiatric ED both have separate buildings focused exclusively on psychiatric care, with medical assistance available as needed and environments set up to be reassuring, safe and calming.

While Nationwide Children’s is obviously focused exclusively on kids, UPMC has built in a pediatric specific section for their ED, which also has adult and acute milieus. Both approaches enable people in crisis or psychiatric emergencies to be evaluated, treated and referred or admitted, if necessary, in more patient-friendly environments than a standard medical ED.

Telehealth Crisis Consultations

In areas where access to pediatric mental health specialists is limited — or when it is infeasible to provide integrated care due to staffing or resource limitations — telehealth can expand the crisis services available in EDs, acute care settings or community centers. Remote consultations offer a novel way to improve access for crisis care when an ED is too remote, small or understaffed to have a psychologist or mental health social worker present at all times.

As virtual ED visits become more widely available and utilized, many mental health professionals are optimistic they will improve the quality of mental health care delivered to children presenting to standard EDs and result in better referrals and fewer readmissions.

To function most effectively, however, telehealth providers must be properly connected to community support services and aware of available care options for follow-up and referrals, to ensure kids end up with the ongoing care they require.

Nathan Call, PhD, clinical director and psychologist at the Marcus Autism Center at Children’s Hospital of



“We’ve started to see real traction, and as more clinicians use telehealth, I believe it will increasingly become an accepted practice. Even after COVID, it will be hard to go back to everything—even emergency care—having to be in a brick and mortar establishment, especially since so many interventions have to involve the home environment anyway.”

— Nathan Call, PhD, clinical director and psychologist at the Marcus Autism Center at Children’s Hospital of Atlanta

“If you’re not in the mental health field, it’s like navigating a foreign country. The PIRC serves as a transitional and triage program to help direct patients to the proper level of initial care. The bridge allows us to walk with the family through that, to navigate the system along with them to get that first appointment and make sure things are okay.”

— Linda Richey, LISW-S, director of the Psychiatric Intake Response Center (PIRC) at Cincinnati Children’s Hospital Medical Center

Atlanta, revealed the effectiveness of telehealth for clinic-to-home parent coaching for patients with autism as part of a National Institutes of Health grant. When COVID-19 hit, the hospital ramped up and expanded their telehealth approach into other behavioral health services to reserve on-site visits for patients with only the most severe concerns. They, like Nationwide Children’s, are at least temporarily conducting virtually all non-urgent care via telehealth services.

“We’ve started to see real traction, and as more clinicians use telehealth, I believe it will increasingly become an accepted practice,” says Dr. Call. “Even after COVID, it will be hard to go back to everything — even emergency care — having to be in a brick and mortar establishment, especially since so many interventions have to involve the home environment anyway.”

Acute Inpatient Care and Partial Hospitalization

Inpatient care, offered through psychiatric departments using specialized inpatient beds and intensive assessments, surrounds patients with the expertise they require to get back on track. Acute care programs offer an alternative to typical inpatient admission, and often accept patients for a few days to a couple of weeks. Both of these program options are designed to offer intensive medical attention (including medication management), constant supervision and an evolving care plan designed to transition them to residential or partial hospitalization services — or, ideally, back home.

However, many hospitals suffer from a consistent shortage of beds for this type of care. To address this problem, some institutions have invested in specialized units and larger facilities to accommodate full-time inpatients, short-term “acute” care and day patients requiring less intensive care or supervision.

Nationwide Children’s, for example, built the new Big Lots Behavioral Health Pavilion, which opened in early

2020 and focuses primarily on acute services. After triage in its Psychiatric Crisis Center (a specialized psychiatric ED), patients who need further assessment or intensive care step up to inpatient, partial hospitalization or a short-term intensive treatment stay in the Youth Crisis Stabilization Unit.

The Youth Crisis Stabilization Unit typically has about a three-day length of stay prior to transitioning patients into their ongoing treatment plan and is a step beyond short-term “non-admission” stays offered at some EDs (called the Extended Observation Suite at Nationwide Children’s), which give staff a day or so to assess patients and develop appropriate safety plans for transition in one direction or another. The three-day program has already demonstrated lasting reductions in suicidal ideation, improved functioning, increased readiness for transition and high levels of patient satisfaction 3 months after care.

Bridge Programs and Hotlines

“If you’re not in the mental health field, it’s like navigating a foreign country,” says Linda Richey, LISW-S, director of the Psychiatric Intake Response Center (PIRC) at Cincinnati Children’s Hospital Medical Center. The PIRC serves as a transitional and triage program to help direct patients to the proper level of initial care. “The bridge allows us to walk with the family through that, to navigate the system along with them to get that first appointment and make sure things are okay.”

Rather than even entering the ED, patients are initially triaged on the phone to determine if they meet criteria to be seen in an alternate location and receive the same psychiatric assessment they would receive if they presented to the ED but in a more appropriate environment. In 2019 alone, the PIRC diverted 500 would-be ED patients to more appropriate venues for care.

Many other hospital systems, including Nationwide Children’s and UPMC, also have bridge programs

(called the Critical Assessment and Treatment Clinic at Nationwide Children's). Oftentimes, the programs function as hyperspecialized resource centers staffed by masters-level counselors, social workers and referral coordinators who are extremely familiar with local providers, programs and the resources available to help families obtain appropriate care after discharge from inpatient services or the ED. When the required services are not available without a waiting period, bridge programs also provide interim services until children can transition.

Crisis response programs, such as the Acute Crisis Response Team at Nationwide Children's, may staff local hotlines and supplement ED triage needs, directing crisis callers to the most appropriate services, providing advice to parents and dispatching mobile response teams when needed.

When patients call into the UPMC PsychCare+ line, for example, the center serves as both a triage service and crisis hotline. Callers can receive some advice over the phone, get a referral or recommendation on where to seek care, or have a mobile response team or clinician sent to the home, school or other location to help with urgent on-location care. These teams often assess for suicide and make immediate safety or stabilization plans and referrals, as well as provide some coping education for patients and their families.

Outpatient Services and Community Embeddedness
Beyond their campus services, many children's hospitals have also begun widespread behavioral health outreach initiatives. By boosting the community's ability to recognize and respond to behavioral health concerns, and by training primary care providers in standardized suicide screening and basic intervention techniques, many local providers can help kids get into the right care at the right time.

Partners For Kids® — an accountable care organization operated in partnership with Nationwide Children's — offers formal Project ECHO training in behavioral health to primary care providers, attempting to increase the chance kids will receive appropriate care without having to travel. The hospital also staffs mental health professionals in schools, satellite Primary Care Centers and Close to HomeSM Centers, and is now researching the best approaches to telehealth consultation for distant EDs in order to offer more accessible psychiatric care regionally.

“Our community work is intentionally designed to support local providers and agencies to address more mental health conditions at less intensive levels, rather than refer to us,” says David Axelson, MD, chief of the Department of Psychiatry and Big Lots Behavioral Health Services at Nationwide Children's. “We're also hoping that our comprehensive community approach will reduce ED use for crisis patients, reduce readmissions and create a better pattern of service utilization, where outpatient and other interventions are successful enough to keep kids out of crisis care.”

STIGMA REDUCTION AND CRISIS PREVENTION

While the rising incidence of suicide-related ED visits and behavioral health conditions is certainly cause for concern, some practitioners choose to consider optimistic explanations as part of the increase, citing a reduction in stigma and improved awareness of mental health as a legitimate, treatable issue.

Concerted efforts at stigma reduction are, in fact, a large part of some hospitals' approach to improving care — by getting kids any care at all.

“A lot of kids experiencing symptoms aren't receiving treatment, and that's what our new building is about,”



“We're hoping that our comprehensive community approach will reduce ED use for crisis patients, reduce readmissions and create a better pattern of service utilization, where outpatient and other interventions are successful enough to keep kids out of crisis care.”

— David Axelson, MD, chief of the Department of Psychiatry and Big Lots Behavioral Health Services at Nationwide Children's

says Bruns. “It’s nine stories, smack downtown and all lit up. We want folks to know we’re not embarrassed to focus on behavioral health. It’s part of the whole child and it’s something to highlight.”

Coupled with the Caring Contacts crisis prevention text message service, Nationwide Children’s is targeting Zero Suicide, which involves universal screening for suicidal ideology — a tactic adopted in the hospital’s extended care network at Cincinnati Children’s and numerous other pediatric institutions. In-hospital crisis response teams and staff training have further enabled progress toward reduced self-harm and improved patient experiences.

“We’ve been working hard to reframe the way we approach psychiatric care, flipping it on its head so that it is painstakingly patient-focused rather than clinician-focused,” says Elizabeth Sysak, MD, director of PsychCare+ and senior administrator over psychiatric emergency services at UPMC. Her program redesigned their psychiatric ED so that staff are fully visible and can see patients in each of their three segmented waiting areas at all times — a tactic that reduced safety incidents by half. Their off-site crisis center also works hard to avoid the typical “hospital vibe.”

Similar approaches to the patient experience at any level of behavioral health care can help maintain stability in the care environment. As hospitals incorporate patient-oriented approaches to design and décor, staff visibility and other resource set-ups (such as peer navigators and iPads), the entire experience shifts from one that induces anxiety to one that suits patient needs and helps prevent crisis escalation.

WHAT’S NEXT FOR PEDIATRIC BEHAVIORAL HEALTH CRISIS CARE?

As stigma falls and growing numbers of hospitals expand or improve their approaches to serving kids in crisis, providers are hopeful for the future of behavioral health care. Locations with significant staff and financial resources aim to expand outreach via telehealth and mobile units, and specialized centers will now have the bandwidth to conduct better research on best practices and outcomes.

“The issue of getting people the care they need, when and how they need it, hasn’t been solved yet,” says Luke Kalb, PhD, assistant professor at the Kennedy Krieger

Institute and lead author of a *Pediatrics* paper that helped draw attention to the nationwide increase in ED use for psychiatric problems. “There are no easy answers to this challenge. It’s going to require a lot of people to come to the table — providers, policymakers, insurers, hospital administrators and more — to really make concerted efforts and come up with effective long-term strategies.”

In the meantime, research emerging from specially designed facilities should help identify best practices and reveal which tactics are most effective in addressing community needs. By sharing the wide range of approaches and future outcomes from such programs, it is the hope of hospitals leading the way in behavioral health crisis care that all pediatric treatment programs will be able to adopt the most effective strategies in time.

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Children’s mental health matters more than ever.

To find free evidence-based resources for families and professionals, visit OnOurSleeves.org.

ON OUR SLEEVES
The Movement to Transform Children’s Mental Health



SPOT THE DIFFERENCES

Type A vs Type B Emergency Departments
for Pediatric Behavioral Health Crisis Care



Figure 1. A standard Type A ED room requires medical beds, equipment, technology and medications to be easily accessible and available so that a minimum level of clinical care can be administered in any room. Staffing must also include 24-hour medical personnel. Although additional waiting rooms and customized care rooms or on-call/on-site psychiatry staff can also be present, the rooms and staff must still meet primary Type A ED requirements.



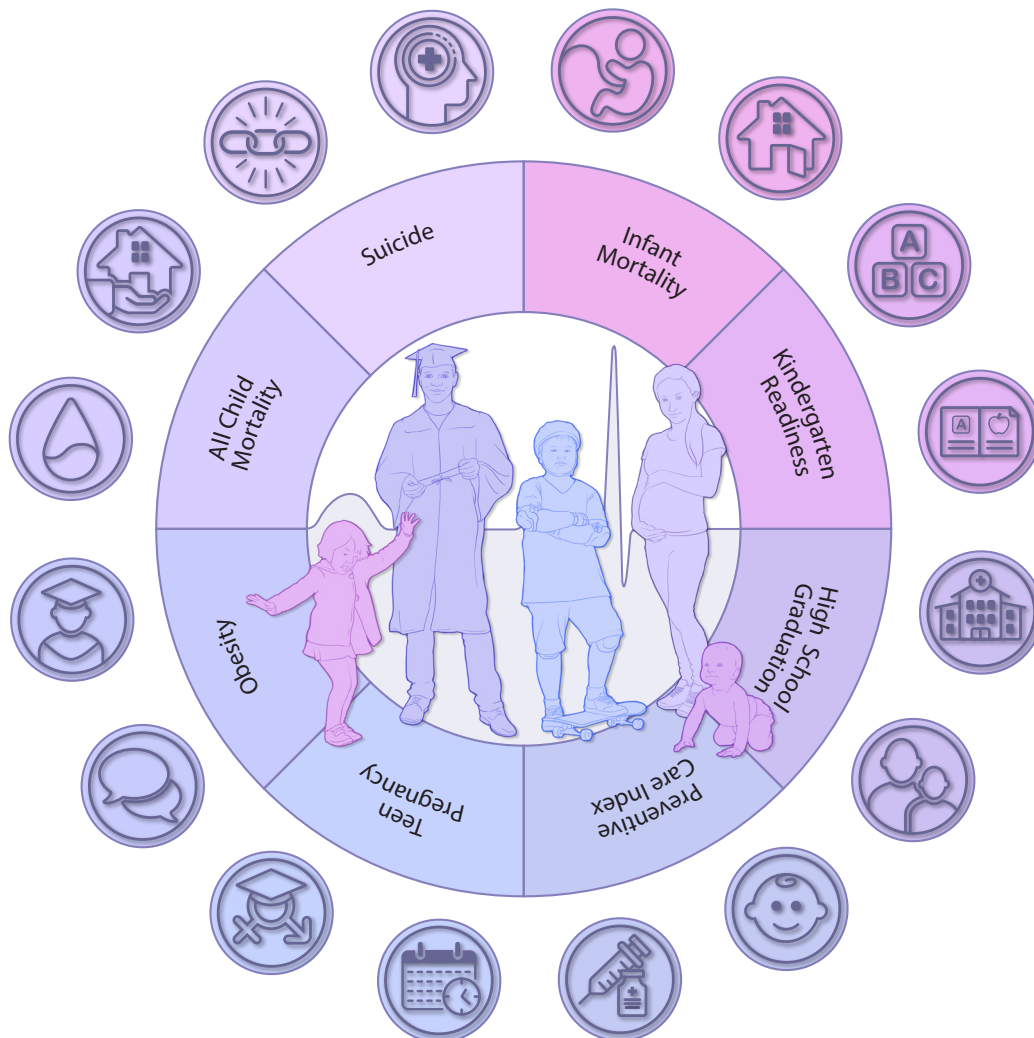
Figure 2. This Type B ED room at Dayton Children's offers an environment like a living room or outpatient care room, set up to relieve anxiety, encourage conversation, avoid self-harm risks and minimize the "hospital" feel of the care spaces. Staffing balance can also emphasize the appropriate type of expertise. Care must still be available and provided to any comer at any time of day, but many set-up and staffing requirements are far more flexible than Type A EDs.

PEDIATRIC VITAL SIGNS:

Measuring and Improving the Health of a Population

Nationwide Children’s Hospital and its community partners have begun an “audacious” project to help every child in their region.

by Jeb Phillips



Despite the best efforts of primary care providers and children's hospitals, some children do not receive the care they need. Patients can only spend a limited amount of time in a medical office; some who would benefit the most may not come in at all.

Nationwide Children's Hospital, like many other institutions, has wrestled with those obstacles for years. In the words of Kelly Kelleher, MD, MPH, the hospital's vice president of Community Health, Nationwide Children's has wanted to adjust its perspective "from health care to health," or from a focus on the delivery of individual services to a focus on population-level wellbeing.

This is part of the motivation behind Partners For Kids®, Nationwide Children's accountable care organization, which uses quality improvement, care coordination and other programs to help 400,000 children covered by Medicaid managed care in Ohio. It's also driven the Healthy Neighborhoods Healthy Families initiative, which uses high-quality housing, workforce training, student mentorship and other methods to improve some of Columbus, Ohio's most at-risk neighborhoods.

These are important moves toward population health, but they still can't reach an entire region's children. So what could? How could every child's health be accounted for and improved?

That is the audacious goal of Nationwide Children's Pediatric Vital Signs project. In the same way that traditional vital signs such as temperature and blood pressure give an indication of an individual child's

health, Pediatric Vital Signs is an effort to meaningfully measure the wellbeing of all children in Franklin County, Ohio across eight metrics that span childhood. That mindset is being used to define and implement interventions to improve overall outcomes, regardless of where or how children receive health care.

These metrics are: infant mortality, kindergarten readiness, high school graduation, obesity, teenage pregnancy, suicide, all-cause child mortality and a hybrid measure called preventive services delivery (including measurements of lead screening, primary vaccination series, breastfeeding and various behavioral and physical health screenings).

Some of the metrics, such as kindergarten readiness and high school graduation rates, aren't even strictly health care-related – but they do impact a child's life and health. All of the metrics have elements of racial and ethnic disparity that must be addressed. All need a broad coalition of stakeholders, including public health officials, schools, non-profit agencies, civic organizations and local governments, to come together to make a difference.

"We don't want to restrict ourselves to what would be easy, or what could just be accomplished by a children's hospital acting alone," says Alex Kemper, MD, MPH, MS, division chief of Primary Care Pediatrics at Nationwide Children's, professor of Pediatrics at The Ohio State University and lead author of a commentary piece in the *Journal of Pediatrics* introducing Pediatric Vital Signs. "We are deeply committed to 'health,' with every meaning of that word. A children's hospital has the resources to be able to lead, but it takes everyone."



"We don't want to restrict ourselves to what would be easy, or what could just be accomplished by a children's hospital acting alone. We are deeply committed to 'health,' with every meaning of that word. A children's hospital has the resources to be able to lead, but it takes everyone."

– Alex Kemper, MD, MPH, MS, division chief of Primary Care Pediatrics at Nationwide Children's Hospital



“Take a mom who is 8 months pregnant, doing her best, who takes off from work to ride the bus to the hospital for a prenatal visit. Imagine the bus is late, so she’s late, and her provider can’t see her, so she has to reschedule. Think of all the barriers she faces, how many systems are involved. Health care, insurance, public transportation, workplace. All of those need to be represented.”

— Mysheika W. Roberts, MD, MPH, health commissioner for the City of Columbus

If Nationwide Children’s can prove that it works in central Ohio, the hope is that other children’s hospitals and regions will take on the challenge too.

“This is very difficult. It’s why no one has done it before,” says Richard Brill, MD, Nationwide Children’s recently retired chief medical officer, who helped develop Pediatric Vital Signs. “We’re on a journey to make it happen, and there’s no reason to think this couldn’t work in any other city.”

THE MODEL FOR ACTION — INFANT MORTALITY

Well before Pediatric Vital Signs took shape, Nationwide Children’s and public health leaders, city and county government officials and the four largest Franklin County health care systems convened a task force that proved how the project could work in practice. By 2013, Columbus had one of the highest infant mortality rates among the United States’ largest cities, and Black babies were 2.5 times more likely to die than white babies.

Nationwide Children’s did not have as much direct influence on infant mortality as the area’s birth centers or prenatal care providers, but the hospital cared deeply about the issue and the racial inequities it highlighted, says Christine Sander, MHA, Nationwide Children’s director of Infant Wellness and a core member of the Pediatric Vital Signs team.

“Infant mortality was an early step into this space,” Sander says. “Nationwide Children’s role was and is to convene, to influence and push, but not to control. Everyone who could have an influence needed to be around the table and to have skin in the game. No one can do this kind of work alone.”

The “convening” work was crucial, and sometimes difficult, says Mysheika Roberts, MD, MPH, health commissioner for the City of Columbus. Hospitals and family-centered organizations understood the issue clearly, but some businesses did not understand how infant mortality affected them or the effect they could have on it.

Andrew Ginther, then the Columbus City Council president and now the city’s mayor, became a champion for the effort to reduce infant mortality. When stakeholders heard stories of the people who needed help, they began to understand the depth of the challenge — and who needed to be at the table as part of the solution, says Dr. Roberts.

“Take a mom who is 8 months pregnant, doing her best, who takes off from work to ride the bus to the hospital for a prenatal visit,” she says. “Imagine the bus is late, so she’s late, and her provider can’t see her, so she has to reschedule. Think of all the barriers she faces, how many systems are involved. Health care, insurance, public transportation, workplace. All of those need to be represented.”

People representing those systems and many more ultimately came together in a Columbus-wide initiative called CelebrateOne (focused on the goal of reaching a child’s first birthday) and a related initiative called Ohio Better Birth Outcomes (focused on health care). Through a wide range of interventions, from safe sleep education to tobacco cessation programs to greater long-acting reversible contraception access, the overall infant mortality rate declined from an average of 8.1 deaths per 1,000 live births from 2012 through 2016 to 7.1 deaths per 1,000 in 2019 — eventually reaching 6.9 deaths per 1,000 in late 2019.

The issue has in no way been solved — the Black/white racial disparity actually widened in 2019 — but CelebrateOne and Ohio Better Birth Outcomes allow for a vigilance and focused plan of action that didn't exist before. They have also pointed the way to Pediatric Vital Signs.

CHOOSING THE PEDIATRIC VITAL SIGNS

In 2015, the National Academy of Medicine (NAM) introduced a set of 15 standardized core metrics that could be used to evaluate the country's health, and they mirrored and helped shape the thinking of Dr. Brill, Dr. Kelleher and their team. NAM called the metrics "Vital Signs." Many of those signs seemed tailored for adult health, but the overall concept made sense to use as a model, so Nationwide Children's called its project "Pediatric Vital Signs."

"We have a whole population health infrastructure with Partners For Kids, with Healthy Neighborhoods Healthy Families, our school-based health programs and so much more," says Dr. Kelleher. "They all feed this vision of 'Best Outcomes' for everyone. They all roll up into what we wanted for Pediatric Vital Signs."

One of the greatest challenges was selecting the signs, says Dr. Brill. They all needed to be relevant to large numbers of children across the entire period of childhood, so that improving any of them would mean a broad improvement across the population. They also must be measurable, with reliable data underlying any interventions, just as with the infant mortality efforts.

Over the course of 15 months, the Pediatric Vital Signs team chose the eight metrics, all of which have lifelong implications. The team also developed or gathered ways to measure the signs; created individual teams to address them, including external community partners; chose ambitious improvement goals for 2020, 2025 and 2030; and identified interventions to achieve each goal, spelled out through a series of key driver diagrams.

Some of the Pediatric Vital Signs, such as infant mortality, have years of collaboration and intervention already pointing the way to the future. Some, such as high school graduation, have only scratched the surface. But what happens from here on is clear.

"We've done all this work to build coalitions. We developed the signs," says Sander. "Now we have to execute."

2030 PEDIATRIC VITAL SIGNS GOALS FOR FRANKLIN COUNTY, OHIO

VITAL SIGNS

AIM

Infant Mortality	Decrease the overall infant mortality rate from 7.1 to 5.9 per 1000 births and decrease racial disparities by 50%
Kindergarten Readiness	Increase the percentage of kindergarteners who pass Ohio's Kindergarten Readiness Assessment from 41% to 50%
High School Graduation	Increase the percentage of students who graduate high school in ≤ 4 years from 85% to 93%
Teenage Pregnancy	Decrease the teenage birth rate from 17.9 to 6.0 per 1000 women 15-19 years of age
Obesity	Decrease the overweight or obesity rate among children 2-17 years of age from 38.4% to less than 33.4%
Suicide	Decrease the suicide rate from 3.6 to 2.5 per 100,000 children 5-19 years of age
Child Mortality	Decrease all-cause mortality rate from 26.7 to 25.7 deaths per 100,000 children 1-19 years of age
Preventive Services Delivery*	Increase composite score of recommended preventive services including maternal depression screening, breast-feeding, fluoride varnish application, lead screening, primary vaccination series, adolescent depression screening, and screening for sexually transmitted infections

**Specific aims and quality improvement interventions have been developed for each of these preventive services.*



“I’m not daunted. In fact, I’m inspired. We don’t have it all figured out. But think how much of an impact this could have to help every child achieve their full potential.”

– Richard Brill, MD, Nationwide Children’s recently retired chief medical officer

THE FUTURE, AND WHY OTHER REGIONS SHOULD MONITOR THEIR OWN PEDIATRIC VITAL SIGNS

The COVID-19 pandemic and this year’s spotlighting of racism and racial inequities have only emphasized the importance of Pediatric Vital Signs.

“We now have these measures that will help us know exactly where kids are falling behind — in immunizations, in kindergarten readiness, in all of the other areas — and allow us to creatively develop ways to catch them up,” says Dr. Kemper. “Social determinants of health and racial disparities have always been built into the Pediatric Vital Signs work, and we can only be successful if we’re successful in addressing them.”

The national events of 2020 have heightened the national appetite for measures like Pediatric Vital Signs, says Benard Dreyer, MD, director of the Division of Developmental and Behavioral Pediatrics at NYU Langone Health and a past president of the American Academy of Pediatrics.

“As an example, we know that for children not ready to start school because of poor self-regulation and basic skills, it’s very difficult to make up that difference later,” he says. “Children who are behind in kindergarten are likely going to be behind in fifth grade and eighth grade. If you could really do something for kindergarten readiness, it would do a lot for the trajectory of a child’s life.”

The issue, Dr. Dreyer says, is so many of the Pediatric Vital Signs represent what are considered “intractable problems.” Too big, too complicated.

“If you can get the right people in the right coalitions and show that you can move the needle, that would be a great stimulus to other people throughout the country,” he says.

Along with improving the wellbeing of children in central Ohio, inspiring others is a primary goal of Pediatric Vital Signs, according to Dr. Brill. Such an enormous project can seem paralyzing, but Nationwide Children’s hopes to show that it’s possible — and that a children’s hospital, with a service mission and deep community goodwill, is the perfect organization to make it happen.

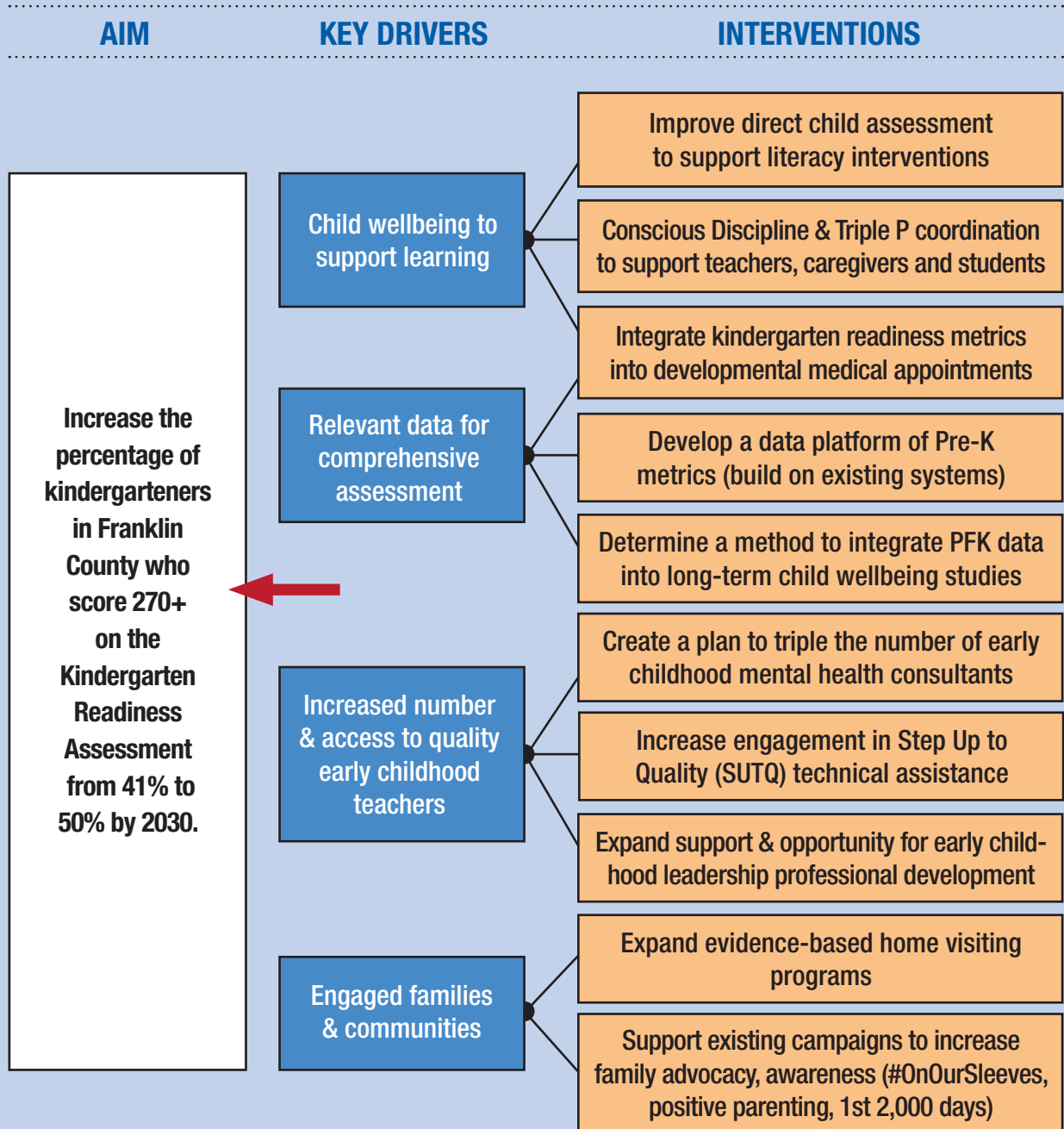
Eight vital signs may be too many for some to take on at first, Dr. Brill says. Other signs may fit a certain region better than the ones Nationwide Children’s has chosen. The important thing is to make the effort.

“I’m not daunted. In fact, I’m inspired,” Dr. Brill says. “We don’t have it all figured out. But think how much of an impact this could have to help every child achieve their full potential.”

Kemper AR, Kelleher KJ, Allen S, Sander C, Brill RJ. Improving the health of all children in our community: the Nationwide Children’s Hospital and Franklin County, Ohio, Pediatric Vital Signs project. *The Journal of Pediatrics*. 2020 Jul; 222:227-230.

KINDERGARTEN READINESS

Using quality improvement methodologies and tools, such as key driver diagrams, teams plan and track aims, key drivers and interventions for each Pediatric Vital Sign. The main diagram for kindergarten readiness is shown below.



Adapted from *The Journal of Pediatrics*. 2020 Jul;222:227-230.

OBSESSED WITH ZERO

REFLECTIONS ON THE CAREER AND ACHIEVEMENTS OF RICHARD J. BRILLI, MD

John Barnard, MD, chair of Pediatrics at Nationwide Children's Hospital, takes a look back at Dr. Brill's leadership toward the audacious goal of zero preventable harm.

In 2008, Richard "Rich" Brill, MD, was recruited to Nationwide Children's Hospital as its chief medical officer. Among other physician executive duties, he was charged with lowering the rate of preventable harm as leader of the hospital's quality and safety programs.

After a few months of learning about our organization's culture and assessing our potential, Rich made an audacious decision: zero preventable harm events as an institutional goal. We were the first pediatric hospital in the United States to establish such a quality and safety program and to make zero preventable harm its transparent, public goal.

Many of us were privileged to watch from front row seats as a remarkable revolution occurred on our campus. Catalyzed by its catchy moniker, the Zero Hero program caught fire, stoked by Rich's passion and zeal for quality improvement. He led visibly and relentlessly as a safety culture revolution took hold in our hospital.

Our entire staff of 9,000 and all new employees since (we're now at more than 13,000 employees!) have been trained in principles of quality and safety and the vocabulary of the Zero Hero program. Under Rich's watchful eye, we developed and implemented tracking systems to better identify, measure and analyze harm events. We appointed multidisciplinary teams to establish best practices and monitor compliance with care practice changes.

Initially, our harm events seemed to increase as staff began to report and identify events that, in the past, had not been reported. However, about year later, we started

seeing a shift. In the years since, so much has been accomplished. Principles and practices that originated at Nationwide Children's spread to other Ohio children's hospitals in a statewide collaborative, and nationally under the aegis of Solutions for Patient Safety. Among Rich's many other accomplishments are the following:

- Our Quality Improvement Services staff increased from 8 individuals when he started to now more than 60.
- In 2009, we were experiencing a serious safety event once every 11-13 days. Now, we average one every 183 days.
- He led the creation of a new way of being transparent and driving accountability, the Pediatric Harm Index, now used by more than 140 other children's hospitals.
- Our Preventable Harm Index has shown a decrease in harm events of 68% since 2010, the equivalent of saving 2,500 children from harm during that time.
- Now, 145 hospitals share our zero preventable harm goal through the Children's Hospitals Solutions for Patient Safety Network. Nationally, 17,000 children have been spared serious harm. Rich was an inaugural member of the network's Clinical Steering Committee.
- Under his guidance, Nationwide Children's has trained 413 individuals at our hospital and other health care organizations in a formal educational program called Quality Improvement Essentials (QIE). Alumni have become improvement leaders in their own hospitals.

“It is unacceptable that medicine is ever considered dangerous or that errors are considered routine — we all must reach for a higher standard, and for the sake of our children, strive to become Zero Heroes...”

— Richard Brilli, MD
U.S. News & World Report, March 14, 2017



- He launched the first quality journal dedicated solely to pediatrics, *Pediatric Quality and Safety*.
- His patient safety principles have been expanded to staff safety. This inclusive approach to safety now permeates our hospital facilities as an important dimension to our Zero Hero program.

This issue of *Pediatrics Nationwide* focuses on the Pediatric Vital Signs project, a community quality improvement initiative. It should come as no surprise that Rich is front and center in this bold commitment to improve health for all children in a way that requires our hospital and community leaders to align and synergize on interventions to achieve a common goal of improving the health of children in our community.

Earlier this summer, Rich retired from his position as chief medical officer, having transformed this institution’s vision and the very idea of quality in pediatric health care. The COVID-19 pandemic has reinforced just

how crucial his staff and patient safety principles are. Fortunately for us, and for every family we serve, Rich is the rare leader who can make the impossible seem possible. What has happened in his tenure is one of the most important chapters in Nationwide Children’s history, and it has had a profound impact on other children’s hospitals across the country. Rich, humble as always, credits the Nationwide Children’s team from the front-line care providers to his executive teammates.

We will now honor Rich by an annual Richard J. Brilli Visiting Professorship in Pediatric Quality and Safety to recognize outstanding achievement in research, implementation, advocacy and education in the field of pediatric clinical quality and safety. He will continue to work at Nationwide Children’s on special projects, continue to advance the mission of the *Pediatric Quality and Safety* journal, and continue his professional obsession with zero.



MORE TO TELEHEALTH THAN MEETS THE SCREEN

Telehealth has become essential to American health care during the COVID-19 pandemic, but is it really the solution to our biggest access-to-care problems?

by Abbie Roth

When COVID-19 ignited stay-at-home orders, public and private insurers quickly relaxed the rules for covering telehealth visits. Health care systems responded in kind by rapidly expanding their telehealth capacity and training.

Expanding telehealth wasn't as simple as giving the clinicians the "all clear."

"Telehealth is one of those things that has been evolving slowly over the last 15 to 20 years — especially in terms of using video in addition to voice," says Jeffrey Hoffman, MD, chief medical information officer at Nationwide Children's Hospital. "Before COVID-19, I thought that telehealth was a great idea with limited applications. I couldn't imagine doing specialty care or gaining acceptance of telehealth from providers and patients across the board."

After the pandemic hit, Dr. Hoffman says he was surprised at how quickly the initial reluctance and resistance faded away. "Groups and individuals who I never would have thought would embrace telehealth now talk about how they can't imagine a world without it," he says.

Nationwide Children's was a few months into a two-to-three-year plan to expand telehealth access across the institution. That plan was immediately fast tracked to bring providers in every outpatient service online for telehealth. Between mid-March and mid-June, more than 100,000 telehealth visits had been completed.

"We talk a lot about 'One Team' as part of our culture here at Nationwide Children's. In the case of getting telehealth up and running, it couldn't have been truer," says Libbey Hoang, vice president of Planning and Business Development at Nationwide Children's. "Experts in technology, EPIC and MyChart, along with

experts in patient education, scheduling, marketing, planning, compliance, legal and reimbursement came together with clinical staff in new ways to streamline processes, share information and get the job done.”

“It’s amazing how much stuff we let get in the way of getting things accomplished. We did in three weeks what we initially expected to take three years,” says Dr. Hoffman. “Our COVID-19 telehealth response really showed that we can do innovative, quality work very quickly. Projects like this typically take forever because we allow them to take forever.”

With all of telehealth’s successes during the COVID-19 pandemic, health care experts — from those in large institutions to those in small private practices — may be wondering how to keep a good thing going. Could this be the solution for access to care problems that have been plaguing health care for decades? What are the considerations needed to make telehealth work for everyone, all the time?

TEACHING WITH TELEHEALTH

As an academic center, how telehealth would impact trainees — residents, medical students and fellows — was an important consideration.

“Before COVID, I had no personal experience with telehealth,” says Rebecca Wallihan, MD, infectious disease specialist and pediatric residency program director at Nationwide Children’s. “The majority of our trainees also had zero experience, so there has been a lot of learning for everyone.”

How to best involve trainees in the telehealth process was a challenge that required some creative problem solving.

“At first, the priority was just to get telehealth up and running. How to bring in the trainees came next,” says Dr. Wallihan. “For most areas, it really wasn’t that difficult — it was just a matter of bringing them into the telephone or video call and figuring out the best way to do that.”

Most residents were able to react to telehealth positively, says Dr. Wallihan. “They are used to FaceTime and other video chat technologies — video telehealth is really an extension of that.”

“One of the things I love about telehealth is the ability to spend more time directly observing how our trainees interact with our patients and families. I’m able to give specific feedback on their ‘bedside’ manner and communication skills,” she adds.

DEVELOPING A WEB-SIDE MANNER

Once the teams had the technology and capabilities to do telehealth, training and follow up were still needed. Providing family-centered care via a phone call or video call provides its own unique challenges for providers.

“Training in ‘web-side manners’ was crucial for telehealth,” says Ujjwal Ramtekkar, MD, MPE, MBA, psychiatrist and associate medical director for Partners For Kids®, Nationwide Children’s accountable care organization. “Demonstrating to our providers how to establish good eye contact, perform effective assessments and build rapport changed the way it was adopted by providers and families.”



“We talk a lot about ‘One Team’ as part of our culture here at Nationwide Children’s. In the case of getting telehealth up and running, it couldn’t have been truer.”

— Libbey Hoang, vice president of Planning and Business Development at Nationwide Children’s Hospital



VIDEO TELEHEALTH TIPS FOR PROVIDERS

- Make sure you are in a quiet, well-lit space with minimal distractions.
- Avoid backlight such as windows or lamps in the background.
- Ensure no protected health information is visible in your background.
- Remove any reflective surfaces from the background.
- Stay in the frame.
- Look into the camera when you are talking to the patient, not at the screen. This will look like you are making eye contact with the patient.
- Engage directly with the patient. They may fidget or be uncomfortable. Allow them time to warm up to the camera.
- Minimize interfering sounds including printers, air conditioners, fans, traffic, pen tapping or keyboard clicking.
- Integrate nonverbal communication such as waves, nods and fist bumps to mimic in-person interaction.
- Avoid talking over the patient or the family.
- Maintain an open and upright posture, leaning slightly forward to convey attention.
- Take advantage of the opportunity to see into the patient's world — their home, pets, siblings and other environmental factors you can see on camera can give you valuable insight.

Interacting via video or phone call can require a different type of energy, too. Some providers describe feeling more emotionally drained after starting telehealth.

“I was surprised how draining telehealth appointments can be for providers. There is anxiety about technology not working, about delays in the connection, about awkwardness in conversation due to spotty connectivity. I am always surprised when I feel worn out after a 1-to-2-hour telehealth visit,” says Emily Viall, RN, clinical research coordinator in the Abigail Wexner Research Institute at Nationwide Children’s, who has been using telehealth for her ongoing clinical study. “I think that may be related to the learning curve and could be addressed as an opportunity for education for providers.”

The same may be true for families. According to Viall, while families overwhelmingly appreciate the option to use telehealth — especially during the pandemic — technical difficulties can be frustrating. It’s important to make sure that each family feels heard and cared for.

TELEHEALTH AND CLINICAL RESEARCH

Conducting clinical research visits during a global pandemic brings a whole new set of challenges. Researchers at the AWRI have embraced telehealth, from phone visits to video visits and secure emails for photos. By utilizing telehealth, clinical researchers were able to continue many studies. It also gave families involved in many different studies a way to access the study teams for questions and support.

Before COVID-19, clinical research studies sometimes included telephone call visits in the protocol. For one particular study, Viall would use phone visits for education and to replace in-person visits for completing questionnaires, collecting safety data, reviewing adverse events and so on. These phone call visits were used to increase study retention and make it easier for families to participate.

“Families were always happy to learn about the option for a phone visit rather than having to come into the clinic every time,” she says. “Video visits are a new and welcome addition to our toolbox.”

Even with video visits, Viall says that they’ve also had to rely on families taking and sending pictures to

document some physical side effects of the medication they are studying.

“We have really relied on the families to communicate with us and work with us through the pandemic,” she says. “It has also been really wonderful to see patients in their home environments. You get to see what their room and house looks like, their favorite toys, their neighbors, friends and siblings, and you can tell they are more comfortable on their couch in their pajamas. You understand their life better. We do a great job making our kids and families feel comfortable in the research clinic, but this has been really nice to see. On the other hand, my patient population has many behavioral challenges so it is hard for me to watch tantrums happening on the screen and not be able to offer comfort or distraction to the child, as I would if they were in clinic with me.”

OFF AND RUNNING – TELEHEALTH FOR BEHAVIORAL HEALTH

Telehealth was already earmarked as a priority for meeting a growing need for behavioral health providers. At the behavioral health Summit in March 2020 cosponsored by the Children’s Hospital Association and Nationwide Children’s, telehealth was a topic addressed by many of the breakout sessions.

At Nationwide Children’s, the integration of telehealth in the psychiatry clinic was underway when COVID-19 hit.

In the case of psychiatry and behavioral health, the utility of telehealth has been described across the United States, especially for rural communities.

“Whether that’s provider-to-provider telehealth like Project ECHO, where specialists can work with larger groups of primary care providers, or provider-to-patient telehealth, telehealth can increase a patient’s ability to access specialty care, even when there are no specialists in their area,” says Dr. Ramtekkar. “When a family does not have to travel four hours and can get their concerns addressed by experts, it bridges the gap and barriers in care. Using telehealth to achieve this now and in the future is a priority to meet the needs of children.

Patti Markham agrees. Markham is a mother of three, and her youngest son, Leo, is currently receiving care from the Behavioral Health team at Nationwide Children’s.

“A lot of the locations are kind of far away from us. And appointments fill up fast, so you really have to take what you can get,” she says. “So before telehealth, Leo was missing a lot of school. And his dad and I were taking turns missing work, so only one of us could attend the appointment.”

She adds that with telehealth, it’s easier for both parents to be there, to participate fully and add insights. “I feel like everyone is getting a much more comprehensive view of what’s happening.”

Markham also says that doing telehealth visits with her son has its challenges, but the pros outweigh the cons. “My son is a teenager, so we want him to have privacy for the call, but we also need to make sure that he stays on camera, makes eye contact and engages with the doctors and therapists,” she says. “That can be a challenging balance to achieve.”



“When a family does not have to travel four hours and can get their concerns addressed by experts, it bridges the gap and barriers in care. Using telehealth to achieve this now and in the future is a priority to meet the needs of children.”

— Ujjwal Ramtekkar, MD, MPE, MBA, psychiatrist and associate medical director for Partners For Kids®, Nationwide Children’s accountable care organization



“Telehealth cuts both ways in the push for health equity. The good news is that we can better reach populations who previously struggled to access care because of transportation or household logistics. However, for those with limited internet or device access, telehealth creates a new barrier to accessing care.”

— Deena Chisolm, PhD, director of the Center for Innovation in Pediatric Practice and vice president of Health Services Research in AWRI at Nationwide Children’s Hospital

TELEHEALTH IN A POST-COVID-19 WORLD

Telehealth has been a tremendous tool during the COVID-19 crisis. But as anyone who has been using it is quick to point out — it’s not a panacea for health care.

Additionally, while telehealth is viewed by some as increasing access to care by reducing problems such as travel time, childcare for other children, reduced missed work and school time, that’s not true for everyone.

Social Determinants of Health

Telehealth is not immune to social determinants of health. While it can level the playing field in some areas, it also broadens the technological divide between some populations and health care.

“Telehealth cuts both ways in the push for health equity,” says Deena Chisolm, PhD, director of the Center for Innovation in Pediatric Practice and vice president of Health Services Research in AWRI. “The good news is that we can better reach populations who previously struggled to access care because of transportation or household logistics. However, for those with limited internet or device access, telehealth creates a new barrier to accessing care.”

Areas in rural southern and southeastern Ohio, which are part of the Nationwide Children’s service area, don’t necessarily have access to broadband or wireless internet. They’re using the data plan for their cell phone — which might not get a clear signal even in their home. Some providers have shared stories about patients in these areas driving to a library or Walmart parking lot to use the Wi-Fi for their visit. With this creative solution to the barrier that telehealth introduces, some

of these families reported that the telehealth option was still preferable to driving multiple hours each way for an in-person visit.

“As we move forward, we will need innovation to use modalities beyond videoconferencing to get true advantage of virtual care that includes other digital health modalities to connect families, emergency departments and schools with the ‘hub’ for timely care,” says Dr. Ramtekkar, who was recently named medical director for Tele/Virtual Health for Behavioral Health at Nationwide Children’s.

Telehealth is more than a video conference with a provider — though that has been the biggest area of growth and most common form during the COVID-19 pandemic. Telehealth also encompasses the use of auxiliary tools (i.e., blood pressure cuffs, scales, etc.), remote monitoring devices (i.e., continuous glucose monitors, heart rate monitors, etc.) or mobile apps that help manage chronic conditions.

“We will be doing our field and our patients a great disservice if we limit telehealth to phone calls and video chats,” says Dr. Hoffman. “Telehealth can truly be about remote care, and that will manifest in a lot of ways if telehealth is to live up to its promise.”

Reimbursement

“The advancement of telehealth has historically been crippled by reimbursement-related decisions,” says Dr. Hoffman. “This approach to avoiding fraud and abuse is short sighted, and it applies to both commercial and public payors. Telehealth has a place in U.S. health care — it’s useful, effective and desirable for many situations.”

Furthermore, Dr. Hoffman suggests that telehealth reimbursement rates should be comparable to those of in-person visits.

“The idea that a telehealth visit should be billed at only 80 cents on the dollar is wrong. Just as much, if not more, work and risk and decision making is involved in a telehealth visit compared to a traditional visit,” he says.

As providers and insurers work out which types of visits are most amenable to telehealth, many wonder if the pendulum will swing to the point of requiring telehealth visits.

Keeping it Optional

“I appreciate having the telehealth option — but if my child or I feel more comfortable coming into the office for a visit, we should have the option to do so,” says Maria Angel, a parent on many family advisory committees at Nationwide Children’s.

Angel’s two sons are on the autism spectrum and getting to appointments can be a time-consuming and difficult process for everyone.

“By the time we transition out of the house, into the car, commute, and into the doctor’s office or clinic, just for 15 minutes with the provider — that can be a lot,” she says. “For my son’s recent medication change appointment, telehealth was very helpful. My son could stay in bed and we could talk with our doctor and get the appropriate medication prescribed.”

On the flip side, her older son (17 years) wanted to see the doctor in person, so they rescheduled his yearly appointment after the stay-at-home order had passed.

“Seeing the doctor in person was important to him, so we are making that happen,” Angel says. “Telehealth options are important, but they should be just that — options. Some kids will have a hard time with video conferencing. Some really hate seeing themselves on the screen.”

“This new era of telehealth is as consumer-focused as it gets,” says Dr. Hoffman. “Even if a visit is amenable to be a telehealth visit, the patient or family should be able to choose an in-person visit if that’s what they prefer.”

Paying for Telehealth

As telehealth progresses, experts are all painfully aware that the ability to build upon successes and experience obtained during the COVID-19 pandemic will depend greatly on how telehealth reimbursements play out. To learn more visit

PediatricsNationwide.org/Paying-For-Telehealth



“The advancement of telehealth has historically been crippled by reimbursement-related decisions. This approach to avoiding fraud and abuse is short sighted, and it applies to both commercial and public payors. Telehealth has a place in U.S. health care – it’s useful, effective and desirable for many situations.”

— Jeffrey Hoffman, MD, chief medical information officer at Nationwide Children’s Hospital

Intractable Epilepsy Linked to Brain-Specific Genetic Mutation

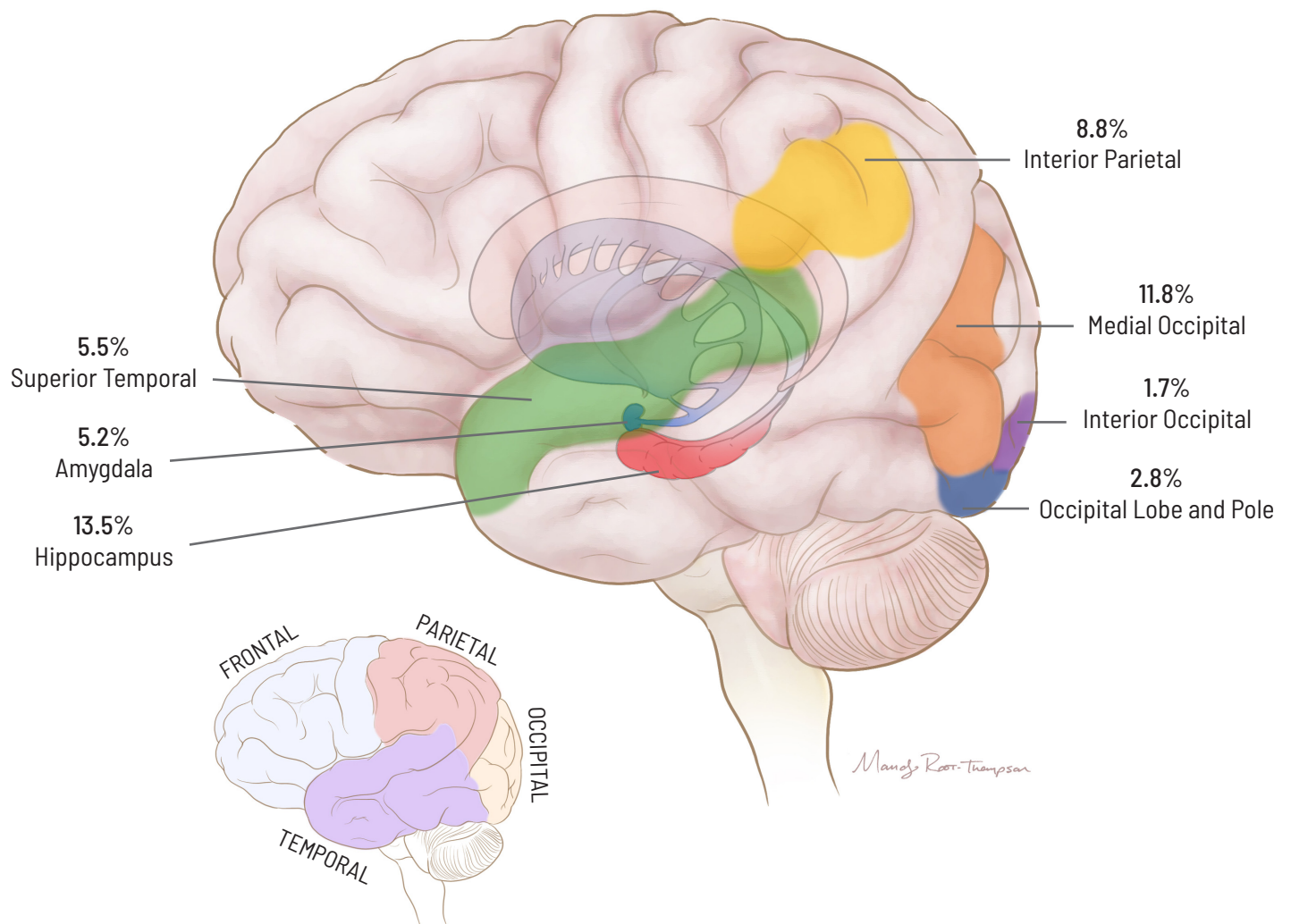
DNA replication errors during development are revealed by genomic study.

by Lauren Dembeck, PhD

As part of an ongoing, collaborative study between neurologists and genomics experts at Nationwide Children's Hospital, researchers have identified somatic mosaicism in the resected brain tissues of a child with treatment-resistant, intractable epilepsy. One

of the two genetically distinct cell populations identified carries a pathogenic genetic variant that correlates with the severity of extracranial electroencephalography (EEG) abnormalities.

PERCENT OF CELLS WITH MUTATION





“We know that DNA replication is never perfect and mistakes happen. We postulate that during *in utero* development of this child, the genetic variant occurred and led to aberrant development in specific brain tissues, causing improper neuronal structure, and ultimately the epilepsy seizure phenotype.”

— Elaine Mardis, PhD, co-executive director of the Steve and Cindy Rasmussen Institute for Genomic Medicine at Nationwide Children's Hospital

The case report is published in *Neurology Genetics*.

“We know that DNA replication is never perfect and mistakes happen. We postulate that during *in utero* development of this child, the genetic variant occurred and led to aberrant development in specific brain tissues, causing improper neuronal structure, and ultimately the epilepsy seizure phenotype,” says Elaine Mardis, PhD, co-executive director of the Steve and Cindy Rasmussen Institute for Genomic Medicine at Nationwide Children's and co-author of the publication.

The patient, a 3-year-old male with West syndrome and intractable seizures, underwent multiple EEG studies and a single intracranial EEG to quantify neuronal activity. The latter procedure was a critical component of a two-stage epilepsy surgery to allow localization of epileptogenic brain regions for resection, a potentially curative surgical procedure to remove the disruptive brain tissue.

“This is a new way to look at a very common problem,” says Adam Ostendorf, MD, medical director of Epilepsy Surgery at Nationwide Children's and senior author of the publication. “The partnership between our Epilepsy Surgery Program and Institute for Genomic Medicine has been incredibly fruitful, and patients and families are excited to enroll due to the potential to learn more about their child's disease and epilepsy as a whole.”

Twelve tissues from different resected brain regions were used for DNA and RNA extraction for study by next-generation sequencing. For each tissue, the activity measured during the EEGs was correlated with the variant allele fraction, a measure that reflects the percentage of cells carrying a particular genetic variant.

“We got a number of brain tissues from the first case and started sequencing, and it worked the way it should,” says Dan Koboldt, MS, principal investigator at the Institute and study co-author. “We found a variant that is clearly disease causing and had a range of [allele] frequencies among the affected tissues. It's exciting to see this in practice. We're applying state-of-the-art genomics to what's already state-of-the-art surgical epilepsy care.”

The novel pathogenic variant, which was located in a known epilepsy gene called *SLC35A2*, was absent in the patient's blood cells, indicating it was not inherited, yet it was present in a range of variant allele fractions among the aberrant brain tissues, with more copies associated with more epileptogenic neuronal activity.

Prior to surgery, the child had tested negative on a clinical genetic testing panel of known variants in epilepsy-associated genes that used blood samples as the DNA source. Therefore, this study emphasizes the need to consider other, non-inherited, causes of epilepsy when assessing a patient with seizures.

The team has continued studying additional cases, which already has led to the discovery of novel genomic variations associated with epilepsy. In addition to providing answers for parents, these studies may guide future epilepsy treatment selection and could be used as a basis for innovative epilepsy therapies.

Miller KE, Koboldt DC, Schieffer KM, Bedrosian TA, Crist E, Sheline A, Leraas K, Magrini V, Zhong H, Brennan P, Bush J, Fitch J, Bir N, Miller AR, Cottrell CE, Leonard J, Pindrik JA, Rusin JA, Shah SH, White P, Wilson RK, Mardis ER, Pierson CR, Ostendorf AP. Somatic *SLC35A2* mosaicism correlates with clinical findings in epilepsy brain tissue. *Neurology Genetics*. Aug 2020;6(4):e460.

A Collaborative Approach to Preventive Cardiology

..... by Andrew Tran, MD

Many of us have friends or family members who have had an early heart attack. The event is sudden, unexpected and sobering. Those who recover often make drastic changes to their diet and lifestyle, along with taking medications, and endeavor to delay and undo years of accumulated toll. However, these efforts can only go so far because calcified plaques cannot be reversed. Many of these cases are due to familial hypercholesterolemia (FH), which affects approximately 1.3 million people in the United States. Early diagnosis and treatment of FH could prevent many of these cardiovascular events.

We have all seen charts depicting the power of compound interest. A dollar invested early has much greater yield than a dollar invested later — to staggering effect. Like compound interest, early diagnosis and treatment of cardiovascular (CV) risk factors such as hypercholesterolemia and hypertension result in enormous benefits. Children stand to benefit the most from early intervention. A child with long-term untreated LDL-C of 200 mg/dL might have a myocardial infarction (MI) in their late 30s whereas a child with an LDL-C of 125 mg/dL might not have an MI until far later, after age 60. A recent study published in the *New England Journal of Medicine* found that children treated long-term with statins had fewer cardiovascular events at age 39 years than their affected parents at the same age.

Identifying children with FH has been challenging. The American Academy of Pediatrics recommended universal lipid screening for patients aged 9-11 and 17-21 years starting in 2011. Despite these recommendations, a study in 2017 by Dr. Sarah de Ferranti and team found that only around 30% of pediatricians regularly obtained

a lipid screen in healthy 9- to 11-year olds. Barriers to lipid screening and treatment included patients not returning for a fasting test, difficulty with patients adhering to diet and lifestyle recommendations, lack of comfort using statins, and lack of lipid specialists.

Given these barriers, how do we encourage healthy CV habits and increase access to preventive cardiology services? Behavior change is hard. The mountains of self-help books and guides on how to change habits published each year are testament to this. We have all had New Year's resolutions that were quickly forgotten or ignored after a few months. There are times when it is difficult for us to accept advice even when we know the advice is good. The same goes for our patients. As a cardiologist in the Preventive Cardiology Clinic at Nationwide Children's Hospital, I am convinced that an approach that extends, educates and empowers a multidisciplinary and community-driven team is essential to impacting the greatest number of children. Our Preventive Cardiology team includes cardiologists, an advanced practice provider, nurses, dietitians and exercise physiologists. Each member plays a vital role in finding discrete steps that patients can take to help move towards healthier CV habits. Our dietitians in particular craft nutritional plans that are cholesterol and hypertension specific and our exercise physiologists provide guidance on safe ways for our patients to be more active.

Collaboration between divisions is key. The large and growing number of children with CV risk factors means that one service or group cannot diagnose and treat them all alone. We are proud to partner with our colleagues in nephrology to extend care for hypertensive

“As a cardiologist in the Preventive Cardiology Clinic at Nationwide Children’s Hospital, I am convinced that an approach that extends, educates, and empowers a multidisciplinary and community-driven team is essential to impacting the greatest number of children.”

— Andrew Tran, MD, pediatric cardiologist in The Heart Center at Nationwide Children’s Hospital

patients and join with The Center for Healthy Weight and Nutrition for patients with multiple comorbidities. Partnership with primary care providers and community organizations are additional avenues to extend care to help diagnose and manage children with CV risk conditions. There is indeed strength in numbers.

It will take a concerted and sustained effort to turn the tide against the rise in CV risk factors in children, but it is possible. Preventing a heart attack or stroke is worth it. Just ask your friends and family members.

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Novel Intervention Helps Infants With Cerebral Palsy Develop Arm and Hand Function

Written by Abbie Roth

A new NIH-funded randomized controlled trial shows that an intervention combining a patented soft restraint harness, therapist coaching and parent training increases reach smoothness, fine motor skills and tactile sensation in the more-affected upper extremity. For the first time in infants with CP under 2, a clinical trial of this type of intervention was shown to also be safe for the tactile processing of the restrained extremity, and for the development of other motor skills.

[PediatricsNationwide.org/CP-Arm-Hand-Function](https://www.pediatricsnationwide.org/CP-Arm-Hand-Function)

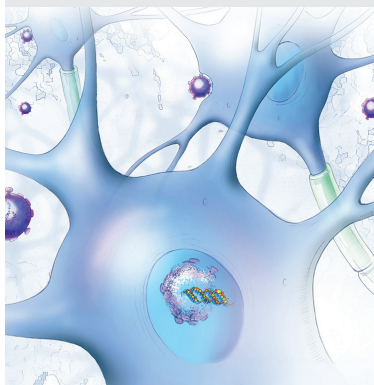


Assessing the Impact of COVID-19 on Pediatric Cancer Research

Written by Lauren Dembeck, PhD

COVID-19 has had an immediate and potential long-term impact on pediatric cancer research. During state lockdowns, many early-stage clinical trials were temporarily halted and other research activities were deemed nonessential, such as biospecimen collections, which could ultimately extend timelines to new discoveries. Recently, a panel of pediatric cancer advocates and experts published a special report focused on areas pertinent to continuing pediatric cancer research despite the impact of COVID-19 on the field.

[PediatricsNationwide.org/COVID-Impact-Cancer-Research](https://www.pediatricsnationwide.org/COVID-Impact-Cancer-Research)



An Expanded, Multicenter Look at Gene Therapy for Spinal Muscular Atrophy

Written by Mary Bates, PhD

In May 2019, the U.S. Food and Drug Administration approved a gene replacement therapy for the inherited, progressive neuromuscular disease 5q-linked spinal muscular atrophy (SMA). Approval included all children with SMA under the age of 2 years; however, the gene therapy had only been studied in children aged up to 8 months. Now, a new study discusses safety and early outcomes in a large cohort of SMA patients under the age of 2 years who were treated with gene therapy.

[PediatricsNationwide.org/SMA-Expanded-Multicenter-Study](https://www.pediatricsnationwide.org/SMA-Expanded-Multicenter-Study)

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