

Fall/Winter 2019

Pediatrics

NATIONWIDE

Advancing the Conversation
on Child Health

BIAS DO YOU SEE WHAT INFLUENCES YOU?



20 BIAS: DO YOU SEE WHAT INFLUENCES YOU?

We are all influenced by a steady stream of subconscious judgements that we make each day about the people, places and things that surround us. This happens to everyone, everyday – even health care providers in the clinic. But what happens when a child’s care is negatively affected by these judgements?

The American Academy of Pediatrics recently released a statement on the impact of racism on child health. This pervasive problem is only made worse by rampant implicit racial biases that affect care delivery and health outcomes.

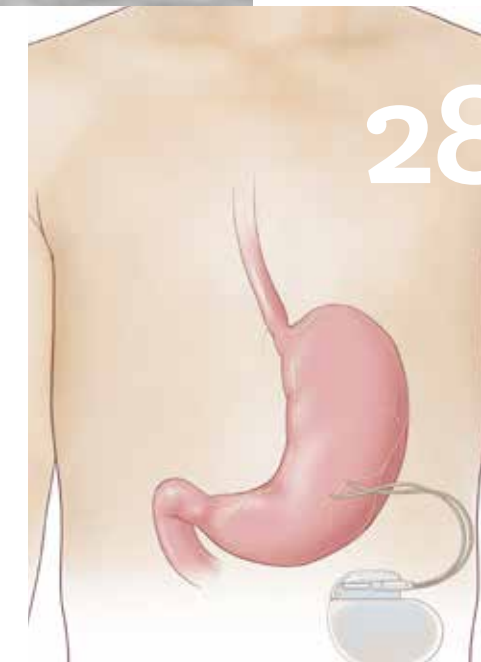
In our quest for best outcomes for all children, we’re increasingly asked to look in the mirror and ask: Do you know what influences you? Self-reflection, challenging assumptions and engaging in honest conversations can move biases from the subconscious to the conscious, where they can be confronted.



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“If children don’t respond to behavioral and lifestyle interventions or medication, often the only options left are surgical. Neuromodulation has the advantages that — even though it can require surgery — it is usually adjustable and reversible, which is ideal for children.”

– Peter Lu, MD, MS, pediatric gastroenterologist at Nationwide Children’s Hospital

“We’re looking at trajectories of suicidal ideation and behavior and trying to identify early intervention opportunities.”

– Arielle Sheftall, PhD, principal investigator in the Center for Suicide Prevention and Research at Nationwide Children’s Hospital

What Can We Learn From the Co-occurrence of a Genetic Disorder and Cancer?

Researchers investigate an unusual case of concurrent genetic and somatic diagnoses.



In a new paper in the *European Journal of Medical Genetics*, researchers from Nationwide Children's Hospital discuss the case of a 4-year-old with both a rare genetic disorder and medulloblastoma. Genetic analyses allowed them to evaluate the cause of the genetic disorder and provided support for the role of the mutated gene in tumor suppression.

"We are using new technologies in the diagnosis of brain tumors that may shed some light on genetic changes of which we were not previously aware," says Mohamed AbdelBaki, MD, a pediatric neuro-oncologist at Nationwide Children's and one of the study's authors. "We have seen that molecular biology and genetic sequencing help in identifying correlations between brain tumors and some genetic syndromes."

Dr. AbdelBaki and his colleagues describe a patient with Klippel-Feil syndrome, a rare congenital bone disorder, who was then diagnosed with medulloblastoma, a common malignant brain tumor. The patient was found to harbor a mutation in the gene *MYO18B*.

"*MYO18B* was recently described as a rare genetic cause of Klippel-Feil syndrome, and it is reported to be a tumor suppressor in multiple adult solid tumors,"

says Kathleen Schieffer, PhD, a postdoctoral fellow at the Steve and Cindy Rasmussen Institute for Genomic Medicine at Nationwide Children's and the study's lead author. "Since malignant brain tumors are not associated with Klippel-Feil syndrome, the co-occurrence of medulloblastoma was of interest, given the putative role of *MYO18B* as a tumor suppressor."

Through genetic analyses, the co-existing genetic disorder and cancer diagnoses in this patient allowed the researchers to elucidate the genetic causes of Klippel-Feil syndrome and expand understanding of the development of the disease. Their findings also provide further support for the role of *MYO18B* in tumor suppression.

"What is truly important – and unique to our institution – is the close relationship we have with the Institute for Genomic Medicine," says Dr. AbdelBaki, who is also assistant professor of pediatrics at The Ohio State University College of Medicine. "Their technologies and expertise help us incorporate molecular biology into our understanding of these tumors, from diagnosis to development of targeted therapies."

"Genetic variation should be considered when evaluating pediatric tumors in the setting of precision medicine," agrees Dr. Schieffer. "In some cases, somatic mutations within the same biological pathway as the genetic disorder may implicate targeted therapeutic management. While in other cases, identifying underlying cancer predisposition may alter surveillance or help us better understand tumor development and growth."

Schieffer KM, Varga E, Miller KE, Agarwal V, Koboldt DC, Brennan P, Kelly B, Dave-Wala A, Pierson CR, Finlay JL, AbdelBaki MS, White P, Magrini V, Wilson RK, Mardis ER, and Cottrell CE. Expanding the clinical history associated with syndromic Klippel-Feil: A unique case of comorbidity with medulloblastoma. *European Journal of Medical Genetics*. 2019 Aug 6;62(8):103701.

— Mary Bates, PhD



Do Seizure Action Plans Make a Difference for Patients and Families?

Families given a written plan were more comfortable with seizure care and missed fewer appointments.

Caregivers for children with epilepsy were more likely to bring their children to regularly scheduled clinic visits if they had previously been given a printed seizure action plan tailored to help them understand their child's condition, manage it at home and know what to do in an emergency.

A year after receiving the action plan, caregivers whose child experienced fewer than 12 seizures annually said they were significantly more comfortable with seizure care than caregivers who did not receive the plan.

The findings, published in the *Journal of Child Neurology*, come from what researchers at Nationwide Children's Hospital believe is the first randomized controlled study of a seizure action plan.

"Seizure action plans have been used for a while now... but are families benefitting?" asks Dara Albert, DO, a neurologist at Nationwide Children's and lead author of the study.

"The idea behind these plans is if a person is better educated to help manage epilepsy, they may go to the emergency department less and be admitted less," Dr. Albert says. "But we did not find a statistical difference in unplanned health care utilization between families who received the plan and those who did not."

In their prospective study of 100 patients, researchers found that 45% of patients who received the action plan made all of their clinical appointments in a year, compared to 25% of patients who received no written plan.

The researchers modeled their seizure action plan after an asthma action plan created and verified by Nationwide Children's Pulmonary and Primary Care clinics. The plan is divided into color-coded sections: green outlines care for a child when seizures are under control; yellow when a parent has concerns, such as a missed dose of medication or brief seizure; and red in case of emergencies, such as a prolonged seizure or seizure clusters.

Beyond determining health care utilization, the researchers looked at quality-of-life measures at enrollment and 3 and 12 months afterward. Families filled out the Impact on Families questionnaire, which was modified to include epilepsy-specific questions. The seizure comfort score of families whose child had fewer than 12 seizures per year averaged 18.8 if they had been given a plan and 17.5 if not.

"Less health care utilization isn't the only thing families want," says Anup Patel, MD, section chief of Pediatric Neurology at Nationwide Children's and study co-author. "If you have a newly diagnosed child, a seizure action plan can help reduce anxiety and help the family feel more confident. They can be more comfortable with an action plan."

Drs. Albert and Patel suggest a large, multi-site study may help explain the findings and reveal whether action plans are effective in other ways or more useful for certain subgroups of patient families.

Albert DVE, Moreland JJ, Salvator A, Moore-Clingenpeel M, Haridas B, Cole JW, Glynn P, Fulst M, Dawson MZ, Moreland P, Patel AD. Seizure action plans for pediatric patients with epilepsy: a randomized controlled trial. *Journal of Child Neurology*. 2019 Jun 2;883073819846810.

— Kevin Mayhood



New Model Provides Novel View of Congenital Heart Disease

The small animal model helps researchers to interpret genomic findings.

Researchers at Nationwide Children's Hospital have developed the first mouse model of congenital heart valve disease using a human gene carrying a disease-causing mutation. Using this model, they were able to follow the human valve disease phenotype from birth to adulthood and identify developmental deficits that led to improper valve development.

The study, published in *Disease Models & Mechanisms*, identified potentially targetable genetic pathways and will continue to provide a basis for future studies of valve disease.

"As approaches for human genome analysis become easier, interpretation is going to be a challenge," says Vidu Garg, MD, senior author of the study and director of the Center for Cardiovascular Research in the Abigail Wexner Research Institute at Nationwide Children's. "When figuring out if a sequence variant is causing a particular disease, these types of model systems are critical."

Dr. Garg had previously identified an association between a genetic variant in the gene *GATA4* and atrial septal and ventricular septal defects, effectively holes in the heart, in a large family. This association was also verified in other independent studies of families with heart defects.

"We know that this version of *GATA4* produces a partially functional protein. So, instead of using a complete gene knockout model, we utilized a model that actually contains the partially functional mutant allele that we see in our patients," says first author Stephanie LaHaye, PhD, a postdoctoral researcher in the Institute for Genomic Medicine at Nationwide Children's.

To further characterize the role of *GATA4* in heart valve development, the investigators conducted echocardiographic and histological examinations of the hearts of mice that carried one copy of the disease-associated human *GATA4* allele. This revealed that heterozygous mutant mice had narrowing of the aortic valve opening predominantly caused by thickening and severe extracellular matrix disorganization of the valve tissues.

Furthermore, the team used 3D reconstruction to model the embryonic hearts based on histological sections. The volumetric measurements of the reconstructed aortic valve tissues showed that they were abnormally shaped in the mutant mice compared with the controls, a finding that could not have been made using histological examination alone.

By comparing gene expression in the embryonic tissue from the developing heart valves of mutant mice and control littermates, the researchers identified changes in genes involved in the extracellular matrix and cell migration as well as dysregulated signaling pathways.

Few treatment options exist for patients with this serious heart valve defect. Dr. Garg explains that having a mouse model and an understanding of the physiological and genetic changes that occur in the diseased heart valve now allows researchers to investigate potential novel therapeutic options, such as drugs that modify signaling pathways to assist in normal valve remodeling."

LaHaye S, Majumdar U, Yasuhara J, Koenig SN, Matos-Nieves A, Kumar R, Garg V. Developmental origins for semilunar valve stenosis identified in mice harboring congenital heart disease-associated *GATA4* mutation. *Disease Models & Mechanisms*. 2019;12(6):dmm036764.

— Lauren Dembeck, PhD

Skin-to-Skin Care Safe for Infants After Surgery

A quality improvement project shows that skin-to-skin care can be safely integrated into the treatment of infants who require surgery.

Multiple barriers prevent routine skin-to-skin care for infants in the neonatal intensive care unit (NICU), particularly for infants requiring surgical consultation.

A recent quality improvement project, published in the *Journal of Pediatric Surgery*, shows that routine skin-to-skin care is possible for infants in the NICU who have had surgery.

"Skin-to-skin care improves brain development, stabilizes infant vital signs, decreases risk of infection and improves parent-infant bonding," says Lorraine Kelley-Quon, MD, MSHS, FAAP, an assistant professor in the Division of Pediatric Surgery at Children's Hospital Los Angeles and lead author of the new study. "We did not want surgical infants to miss out on those benefits."

Dr. Kelley-Quon, who is also an assistant professor in the Department of Surgery and Preventive Medicine at Keck School of Medicine of the University of Southern California, led a team that used quality improvement methodology to address the issue while she was a Pediatric Surgery fellow at Nationwide Children's Hospital.

"Instead of simply issuing a policy from on high and then assuming things will get better, quality improvement methodology involves identifying a problem, pinpointing barriers, developing interventions and measuring those interventions in a systematic way," says Thomas Bartman, MD, PhD, associate chief medical officer at Nationwide Children's and a co-author of the study.

The team identified several key areas as targets for improvement, including NICU culture, nursing engagement, surgeon endorsement and parental empowerment. Interventions included education of physicians, nurses, and families; adding orders for skin-to-skin care to electronic health records; and partnering with the communication department to promote skin-to-skin care throughout the hospital.

As a result, overall rates of skin-to-skin care in the NICU showed a sustained increase for 12 months.



"The most effective intervention was talking about skin-to-skin care on daily rounds," says Dr. Kelley-Quon. "This helped remind the family and everyone on the care team that it was just as important to discuss as the dosing of antibiotics or the ventilator settings."

Although "every institution is different," according to Dr. Bartman, "this sends the message that if you take a systematic approach to the problem, any institution should be able to find solutions that can work for them to increase skin-to-skin care in surgical infants."

Dr. Bartman, who is also a practicing neonatologist, notes that there is still room to improve and expand the scope of the project. "We'll be continuing the interventions that worked and possibly coming up with more ideas to push our performance even higher," he says.

"The next question to answer would be, how does skin-to-skin care improve recovery for infants after surgery?" says Dr. Kelley-Quon. "We may see different benefits for infants who receive surgery and skin-to-skin care that have not been observed before."

Kelley-Quon LI, Kenney BD, Bartman T, Thomas R, Robinson V, Nwomeh BC, Bapat R. Safety and feasibility of skin-to-skin care for surgical infants: A quality improvement project. *Journal of Pediatric Surgery*. 2019 Feb 28. [Epub ahead of print]

— Mary Bates, PhD

In Defense Against Peritonitis, Antimicrobial Peptides May Help on Multiple Fronts

Study suggests AMPs have potential as biomarkers for peritonitis, risk stratification and treatment.

Antimicrobial peptides (AMPs) in the Ribonuclease A Superfamily exhibit distinct patterns when children and adults undergoing chronic peritoneal dialysis (PD) suffer from peritonitis, researchers have found.

The findings, published in *Scientific Reports*, suggest that AMPs in peritoneal fluid are potentially useful as biomarkers to diagnose peritonitis, and they may provide a means to treat or prevent infections and to risk-stratify patients in the future.

The researchers also found that cells in the omentum (a layer of tissue that surrounds other abdominal organs) are expressing the AMPs. The discovery has brought

up questions about the relation of the organ to the immune system and the risk to develop peritonitis, especially given that the omentum is often partially or fully removed in children undergoing PD in order to prevent mechanical complications.

Despite improvements in PD techniques during the last decade, peritonitis remains the most common reason for hospitalization, conversion to hemodialysis and death among PD patients.

“Peritoneal dialysis is definitely the preferred technique...the alternative, hemodialysis, is very challenging in small children,” says Neha Pottanat, MD, a pediatric nephrologist at Riley Hospital for Children at Indiana University Health. Dr. Pottanat

led the study during her fellowship at Nationwide Children’s Hospital.

Children born with congenital kidney and urinary tract problems often need dialysis at a young age, in some cases to enable them to mature enough to receive a kidney transplant.

For young children on PD, “you have two worries: they will die from cardiovascular disease or infection,” says Rose Ayoob, MD, associate professor of Clinical Nephrology at West Virginia University, former director of the dialysis unit at Nationwide Children’s and study co-author. “If you take one of those out of the equation, that’s a big plus for these kids.”

The research team looked to the body’s immune system to find alternatives to antibiotics, which carry side effects and have limited effect against biofilm-protected infections that commonly occur in PD patients. In the peritoneal fluid of children and adults undergoing chronic PD, the team found the level of the AMP RNase 3 increased 55-fold, RNase 7 increased three-fold and RNase 6 remained unchanged during peritonitis.

The large increase in RNase 3 in all of 22 patients in the study holds promise for using the peptide as a peritonitis biomarker, says Brian Becknell, MD, PhD, pediatric nephrologist and principal investigator in the Center for Clinical and Translational Research in the Abigail Wexner Research Institute at Nationwide Children’s.

The study also indicates the potential for augmenting the defenses to prevent infections from occurring, Dr. Becknell says. “These particular AMPs have been shown to disperse biofilms or kill bacteria within biofilms.”

A larger study is needed to fully flesh out these AMP patterns, the researchers say, and determine whether patterns can indicate differences in peritonitis susceptibility among patients, types of peritonitis, or genetic polymorphisms of AMPs associated with risk.

Pottanat ND, Brook AC, Bartosova M, Cortado H, Gupta S, Li B, Jackson AR, Vonau M, Cohen S, Ferrara M, Ching CB, Spencer JD, Brauner A, Fraser DJ, Schmitt CP, Eberl M, Ayoob R, Becknell B. Analysis of the Ribonuclease A Superfamily of antimicrobial peptides in patients undergoing chronic peritoneal dialysis. *Scientific Reports*. 2019 May 23;9(1):7753.

— Kevin Mayhood

Family Support Linked to Resilience in Kindergarteners Born Preterm

Despite known adverse outcomes associated with prematurity, a large minority of kindergarteners born preterm exhibit none of them.



For years, medical researchers have dedicated countless hours to studying the adverse outcomes of premature births.

But in their attempts to illuminate the incidence of cognitive, behavioral and learning deficits in preterm and low-birth-weight infants, researchers have failed to address an equally important question: Why do some preterm infants manage to develop normally, despite the high-risk nature of their births?

H. Gerry Taylor, PhD, principal investigator in the Center for Biobehavioral Health in the Abigail Wexner Research Institute at Nationwide Children’s Hospital, seeks to rectify this omission from the developmental literature in a study published earlier this year in the *Journal of the International Neuropsychological Society*.

The study, which analyzed the development of 146 extremely low-birth-weight and preterm kindergarten children and 111 of their normal-birth-weight peers from the Cleveland, Ohio, metropolitan area, found that 45% of the children in the preterm group were “resilient” to the biological risks of being preterm, meaning they displayed age-appropriate behavior and academic learning. In comparison, 73% of the control group displayed these same characteristics.

“What about the kids that do well? How do they escape the negative consequences of this quite high-risk condition? No one has really focused on that part of the population,” Dr. Taylor says. “I see resilience as the flip side of the coin of looking at the effects of brain-related risk factors in children and their development.”

By measuring both the “proximal” family environment, such as the level of stimulation at each child’s home and the quality of the relationship between the mother and child, and more “distal” social risks such as median neighborhood income, the research team discovered that resilient preterm children were more likely to have grown up in “advantaged” family environments. Such environments are those that provide ample learning opportunities for their children, where parent-child relationships are positive and supportive, and where the parents themselves do not feel highly burdened or distressed.

According to Dr. Taylor, the development literature tends to apply the concept of “resilience” to children exposed to social risks, such as high poverty, who achieve well academically and are free of significant behavior problems. In his current position, he is interested in extending the concept of resilience to children at biological risk. Children at biological risk include not only those born preterm but also those with a broader group of neurodevelopmental conditions, such as traumatic brain injury and other acquired brain insults, congenital heart disease, epilepsy and muscular dystrophy. Dr. Taylor hopes to learn more about why many children with these conditions do well and he believes that this knowledge will help find ways to enhance the development of all at-risk children.

“This is something we need to be focusing on as much as the negative outcomes,” Dr. Taylor says. “We have different things to learn from the kids that do well.”

Taylor HG, Minich N, Schluchter M, Espy KA, Klein N. Resilience in extremely preterm/ extremely low birth weight kindergarten children. *Journal of the International Neuropsychology Society*. 2019 Apr;25(4):362-374.

— Adelaide Feibel



FORGING THE WAY FORWARD ON DSD

Experts are learning how a focus on behavioral health and psychosocial support can lead to better outcomes among youth with disorders/differences of sex development.

by Jeb Phillips

In some ways, the DSD field began only in 2006. That year, the phrase “disorders of sex development” was coined in a landmark consensus statement, the same publication that called behavioral health an “integral part” of patient care.

Of course, surgeons, endocrinologists and other medical specialists had treated children with atypical genitalia and “intersex” conditions for generations. But the 2006 publication was a reckoning with the piecemeal care and poor psychosocial outcomes that many patients had experienced – a reckoning that is continuing.

“In the old days, a child would be born, we’d do some tests to help a family determine what sex the child is, do some surgery, and then the family would go on their way,” says V. Rama Jayanthi, MD, chief of Urology at Nationwide Children’s Hospital. “We found out the hard way that’s a horrible mistake.”

Experts came to understand, with a big push from patient advocacy groups, that the appearance of the genitalia should not be the only measure of a good outcome; happiness and quality of life were even more important. That meant ongoing, developmentally sensitive discussions to support patients throughout childhood and adolescence, when concerns about personal identity, sexual function and fertility emerge.

The 2006 publication may have marked a new way of thinking, but the field continues to look for the best way forward. Programs like THRIVE at Nationwide Children’s – Team-driven Health care that Respects the Individual and Values Emotions – are part of the answer. So is an increased focus on research.

But right now, the path to the best possible outcomes for patients with DSD isn’t completely clear.

WHO LEADS THE CARE?

There are now more than 50 pediatric DSD programs in the United States, or there may be fewer than 20. The difference in estimates is a kind of microcosm of the flux in the DSD field.

The smaller number is from David Sandberg, PhD, a professor of Pediatrics at the University of Michigan and a prominent pediatric psychologist and clinical researcher working in DSD. It reflects his opinion about what an effective DSD program should be.

Nearly everyone recognizes the need for “team-based” care, he says. Surgical specialists aren’t enough. Endocrinology, behavioral health and social work should be on the team, too. Genetics experts, neonatologists and others are included in some circumstances. But how does the team function?

“The consensus statement is describing an interdisciplinary team more than a multidisciplinary one,” says Dr. Sandberg, who participated in the 2006 consensus process. “A multidisciplinary team is hierarchical, with each specialist owning their own territory. Each expert is a consultant to the others. An interdisciplinary team has tight coordination. Each specialist may need to modulate their recommendation based on the experience of another specialty. The psychosocial elements are seen as equivalent or even more urgent than the medical piece.”

Over the last several years, this is exactly the direction THRIVE has moved at Nationwide Children’s.

THRIVE started in 2012 as an effort to bring behavioral health and other services into DSD and gender concerns. But when Jennifer Hansen-Moore, PhD, a pediatric psychologist, joined the program in 2013, she was not part of an integrated clinic. Medical specialists often saw the patients first, then referred to her.

“We found, through trial and error, that it was stigmatizing for families to see me outside of their medical meeting, as if behavioral health were different from their regular care,” Dr. Hansen-Moore says. “Decreasing stigma is my biggest role in the early months, and we continue to learn how best to accomplish that.”

THRIVE’s current, evolving model recognizes that psychosocial care may be the critical factor in patients’ long-term outcomes.

THE THRIVE MODEL

Many families are in shock when the THRIVE team first meets them, says Leena Nahata, MD, an endocrinologist at Nationwide Children’s and member of the THRIVE team. Families may have not known that DSD conditions exist. They may have announced to friends and relatives the sex of a child during pregnancy and don’t know what to say once a child is born.

In the worst case scenarios, families will have had a

traumatic experience at a birth hospital with a provider who has never seen a child with a DSD and does not know how to proceed. Many families will come to THRIVE with the idea that the issue needs to be “fixed.”

THRIVE begins by slowing the process down. DSD is not a diagnosis but a descriptor of a group of conditions. It may take weeks or months to determine what has caused the atypical genitalia, and in many cases a specific diagnosis is still not clear. One condition, congenital adrenal hyperplasia, can lead to adrenal crisis and needs prompt recognition and treatment. But most other specific DSD conditions are not medical emergencies and require no immediate physical intervention.

What the conditions do require is some immediate psychosocial support for families.

“I always say that we are not going to talk about surgery yet,” says Dr. Jayanthi. “Realistically, those families have a grieving and acceptance process that they need to go through. They need to have a clinical and emotional discussion with us. We have to talk about the child’s future sexual function and fertility. We spend the first few months talking about these sorts of things before we make any decision on surgery.”

Diagnosis and the education process can help guide a family and the interdisciplinary team toward the appropriate sex of rearing (or a decision to further delay the decision). In the meantime, Dr. Hansen-Moore, clinical social worker Allison Whittington, MSW, LISW, and others help the family problem solve. What do you tell your friends? How do you prepare daycare for diaper changes?

“A family’s social, ethnic and religious cultures play large roles in how we navigate these conversations, so there is no cookie-cutter approach to any of it,” Whittington says. “That has made the development of evidence-based guidelines difficult because of how fluid

“We found, through trial and error, that it was stigmatizing for families to see me outside of their medical meeting, as if behavioral health were different from their regular care. Decreasing stigma is my biggest role in the early months, and we continue to learn how best to accomplish that.”

– Jennifer Hansen-Moore, PhD, pediatric psychologist, THRIVE Program, Nationwide Children’s Hospital

the interactions have to be. These are rare conditions, and we work with these families every week. It helps the families feel less isolated and more able to navigate these conversations with others.”

After extensive counseling, some families in the THRIVE program who have a baby with a DSD ultimately decide to have some type of surgery in the first six to 12 months of a child’s life, according to the team. There are some practical reasons: better wound healing, less remembered physical pain for the child. These are often complicated surgeries that sometimes require surgical follow-up. Once the surgeries are over, however, that would have been the end of care in past decades.

But it’s just the beginning of a new phase in THRIVE. Regular meetings with the family continue. There may be no medical indications for families to see the team for years at a time, but THRIVE brings every family in at least once per year. The team stresses the need for parents to disclose developmentally appropriate information to the child. If a child’s condition may affect fertility, the team suggests talking about it from the earliest time a child can understand, including having conversations about different ways families are built.

Once puberty begins, questions about sexual function tend to arise, and some questions about gender identity may too. Research from Dr. Nahata, Dr. Hansen-Moore, Dr. Jayanthi and Canice E. Crerand, PhD, a principal investigator in the Center for Biobehavioral Health at Nationwide Children’s, has shown higher incidences of anxiety, depression and other markers of internalized stigma in patients with DSD as they grow into adolescence, so targeted behavioral health care services are crucial then.

Some families may not know that a child has a DSD until the teen years, when a delay in or absence of puberty sends them to THRIVE. A considered, deliberate diagnosis, education and decision-making process happens then as well, tailored to an adolescent’s needs.

This overall model is a clear step in the right direction, and anecdotal evidence indicates that the families and children cared for in THRIVE have a better quality of life than those who experience more sporadic, unintegrated care. But there is still so much that isn’t known.

“Our goal is to give these youth their best chance at a happy, healthy life,” says Dr. Nahata. “The research is

limited. We have some short-term data in pediatrics, but long-term data are lacking. Throughout the field, people are actively engaged in better characterizing outcomes and developing ways we can achieve the best outcomes.”

FUTURE DIRECTIONS IN DSD

The DSD field remains in a near constant state of change. “DSD” itself has evolved over the last several years to stand for “differences of sex development” as much as “disorders of sex development,” because some patients and families feel the latter phrase stigmatizing. Stigma, and its reduction, remain top of mind for most behavioral health experts who work in DSD, says Dr. Hansen-Moore.

She and Dr. Sandberg at the University of Michigan are on the front lines of elevating DSD issues in the national behavioral health circles; together, they founded a special interest group focused on DSD in the Society of Pediatric Psychology to connect behavioral health providers working in the field. Dr. Sandberg is also part of an American Psychological Association task force charged with, in part, helping the behavioral health community better understand how it can care for children with DSD.

Dr. Sandberg, Dr. Hansen-Moore and their DSD colleagues around the country have a list of goals that are the focus of current research: standardization of diagnosis and description of specific DSDs; a standardized process for shared surgical decision-making; relatively simple ways of assessing patient and family quality of life and coping, in an effort to develop better anticipatory guidance; better education of obstetricians and primary care providers so that families feel supported from the beginning of the DSD journey.

Those goals can seem like a long way off. For now, even families who have experienced poor care in the past can benefit from engaging with a program like THRIVE as their children develop. And experts in the DSD field plan to keep pushing the field forward.

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Hughes IA. Disorders of sex development: a new definition and classification. *Best Practice & Research: Clinical Endocrinology & Metabolism*. 2008 Feb;22(1):119-34.

DSD CLASSIFICATIONS

As part of an effort to better standardize nomenclature, the 2006 consensus statement proposed three broad DSD classifications based on karyotype. Many subsequent publications have used these same classifications, while noting that each includes many discrete conditions and causes. Some are apparent at birth; some aren’t evident until adolescence or adulthood; some are never diagnosed.

While admitting that “no system is perfect,” a 2008 publication based on the 2006 consensus suggested subdividing the classifications into conditions and causes. This chart is adapted from that 2008 publication.

DSD CLASSIFICATION

CAUSES AND/OR CONDITIONS

46,XX DSD

- A. Disorders of gonadal (testicular) development
- B. Disorders in androgen synthesis or action
- C. Other (syndromic associations of male genital development; persistent Mullerian duct syndrome; vanishing testis syndrome, isolated hypospadias, etc.)

46,XY DSD

- A. Disorders of gonadal (ovarian) development
- B. Androgen excess
- C. Other (syndromic associations; Mullerian agenesis/hypoplasia; uterine abnormalities; vaginal atresis; labial adhesions)

Sex chromosome DSD

- A. 47,XXY (Klinefelter syndrome and variants)
- B. 45,X (Turner syndrome and variants)
- C. 45,X/46,XY (mixed gonadal dysgenesis)
- D. 46,XX/46,XY (chimerism)



FINDING THE REASONS WHY: Looking for Answers in Trends of Child and Youth Suicides

EPIDEMIOLOGICAL STUDIES ARE THE FIRST STEP TO LEARN HOW TO PREVENT SUICIDE ATTEMPTS AND DEATHS

by Kevin Mayhood

Suicide is the second-leading cause of death among 10- to 24-year-olds. And even as awareness grows, the suicide rate continues to climb, according to national statistics. But those national statistics don't tell the whole story. For decades, researchers around the country have been digging into the available data to look for patterns that could help them understand why so many youth continue to be affected.

At the Center for Suicide Prevention and Research in the Abigail Wexner Research Institute (AWRI) at Nationwide Children's Hospital, this search has led to several papers revealing unique patterns in suicide for specific populations of children and young adults. The researchers have uncovered differences based on age, sex, race and more, and they are using the findings as a first step toward developing prevention strategies.

"If we can identify a pattern, if the epidemiology of suicide has changed over time and rates are increasing... these descriptive papers allow us to start asking what are some of the factors that might have changed that are driving the increase," says Jeff Bridge, PhD, an epidemiologist, director of the Center for Suicide Prevention and Research in the AWRI and author of many suicide-epidemiology publications. "That allows us to home in on potential mechanisms that we or others might be able to target."

USING SCIENCE TO DRIVE CHANGE

From small hospital-based research to deep dives in national databases, these studies have helped reveal vulnerable populations and challenge generally-held beliefs.

One notable study was published in May 2019, in the *Journal of the American Academy of Child and Adolescent Psychiatry*. The team at Nationwide Children's was among several to investigate, and the first to publish their results on, whether or not the Netflix series "13 Reasons Why" could be linked to increased suicides. And what they found was compelling.

"We discovered in our analysis of national suicide rates that in the months following the release of the first season, suicides among youth aged 10-17 years increased by almost 30%," says Dr. Bridge.

Following the "13 Reasons Why" study, Netflix removed the graphic suicide scene aired during the first season, saying it was "mindful about the ongoing debate around the show" and based on advice from medical experts.

"We hope that the actions taken, based on the evidence provided, are a proof of concept for how taking action to reverse trends where a clear association has been established can help save lives," says John Ackerman, PhD, suicide prevention coordinator at the Center for

Suicide Prevention and Research, and a co-author of the study.

"We have the opportunity to reduce the number of young people that die by suicide and the media certainly can play a role in that effort," says Dr. Ackerman. "Contagion is a real concern when it comes to reporting about deaths by suicide and suicide research."

To try to prevent suicide contagion – a process in which the suicide of one person or multiple people can contribute to a rise in suicidal behaviors among others – from media exposure, Dr. Ackerman worked with the E. W. Scripps School of Journalism at Ohio University and numerous suicide prevention collaborators to update guidelines on reporting suicide in traditional and on social media. The American Association of Suicidology not only supported this effort but adopted the guidelines this year as part of a media partnership toolkit.

The "13 Reasons Why" study is among six in the last year in which AWRI researchers have identified and studied subpopulations of youth who have attempted suicide or died by suicide, and the majority of the studies have shown an increase among youth is present.

A NARROWING GENDER GAP

Among the alarming trends uncovered in the past year is the decreasing gap between the number of suicides among boys and girls, as reported in *JAMA Network Open*.

Historically, girls have more suicidal thoughts and suicide attempts than boys, but boys use more lethal means and die more often by suicide.

"Overall, we found a disproportionate increase in female youth suicide rates compared to males," says Donna Ruch, PhD, a postdoctoral researcher in the Center for Suicide Prevention and Research and lead author on the study.

Her analysis of youth suicide from 2007 to 2016 from the Wide-ranging Online Data for Epidemiological Research records showed a 12.7% increase among girls ages 10 to 14, however for boys, the increase was 7.1%. The rate among girls 15 to 19 rose 7.9%, and for boys 3.5%. The study also found that rates of hanging and suffocation by girls is also approaching that of boys.

In another study, published in *The Journal of Pediatrics*, Henry Spiller, MS, D.ABAT, director of the Central Ohio Poison Center at Nationwide Children's, and Dr. Ackerman found suicide attempts by self-poisoning more than doubled among 10-to 19-year-olds from 2011 to 2018, using data from the National Poison Data System. Among 10 to 15 year old girls, the rate more than tripled.

"The data is stunning...attempts were flat from 1990 to 2010-2011, then there was a significant increase that didn't stop," Dr. Spiller says.

"We can't answer 'why?' from the available data, but this sharp increase in self-poisonings is being driven by girls at increasingly younger ages and the attempts are more severe," Dr. Ackerman says.

REVEALING AGE-RELATED RACIAL DISPARITIES

When looking at suicides by race, reported suicide rates had consistently been higher for whites of all ages than for blacks. But that's not the whole story.

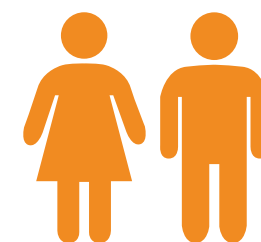
The Nationwide Children's research team's deeper look into Centers for Disease Control and Prevention data from 2001-2015 uncovered age-related racial disparity.

Suicide rates for black children ages 5 to 12, they reported in *JAMA Pediatrics*, are nearly twice that of white children. The trend is reversed in children 13 to 17.

"While we lacked information on key factors that may

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RESEARCH SHOWED

Suicide rates for black children aged 5–12 are nearly twice that of white children.



The trend is reversed in children aged 13–17 years old.

underlie racial differences in suicide, including access to culturally acceptable behavioral health care or the potential role of death due to homicide among older black youth as a competing risk for suicide in this subgroup, the results are illuminating,” says Dr. Bridge. “However, it will require additional studies to find out whether risk and protective factors identified in studies of primarily white adolescent suicides are associated with suicide in black youth and how these factors change throughout childhood and adolescence.”

Leading the charge on several of those studies is Arielle Sheftall, PhD, a principal investigator in the Center for Suicide Prevention and Research.

“We’re looking at trajectories of suicidal ideation and behavior and trying to identify early intervention opportunities,” she says.

Dr. Sheftall, who is a member of the work group providing education to the Congressional Black Caucus Task Force on Black Youth Suicide and Mental Health, and her team members at Nationwide Children’s are now looking at what makes black children under 12 more apt to die by suicide than young white children. Among several factors, she’s studying emotion regulation/reactivity and neurocognitive functioning, familial cohesiveness and adaptability, and parenting style. The team will examine how these risk and protective factors may vary by race.

YOUNG CHILDREN AT RISK

A myth persists that young children don’t plan or attempt suicide, the researchers say. But in a recent study, screening for suicidal thoughts and behaviors revealed that 7% of 10-to-12-year-olds who came to three

children’s hospital emergency departments for medical complaints such as headache, back pain or seizures were at risk for suicide.

More than half of children in the same age group presenting to the emergency department with psychiatric complaints such as depression, violent behavior or panic disorder screened positive for suicide risk.

“In this study, we uncovered risk,” says Dr. Bridge, who is also a professor of Pediatrics, Psychiatry, and Behavioral Health at The Ohio State University College of Medicine. “Most of these kids come to the emergency department for medical complaints, not because they are thinking about or have attempted suicide.”

The suicide prevention team at Nationwide Children’s, which has worked with 125 high schools and middle schools, has also expanded training to staff in elementary schools, to help them recognize children at risk and know what steps to take to keep them protected. The team is in the early stages of developing a specific curriculum for 4th and 5th graders, to help them recognize when their peers or they themselves show signs of unusual unhappiness or stress, and to tell a trusted adult.

Nationwide Children’s Emergency Department and the Big Lots Behavioral Health Services now screen all children as young as 10 for suicide risk. Dr. Bridge and colleagues are developing a screening tool and intervention protocols that can be used in all medical settings.

RISK ASSOCIATED WITH JUVENILE DETENTION

Studies by others have sometimes provided the team a target to investigate. When a U.S. Department of Justice Survey showed incarcerated youth commit suicide two to three times more often than the general population,

“It never hurts to ask if a child or young adult is thinking about suicide, I say it in every interview – asking won’t hurt. It can only help.”

– Jeff Bridge, PhD, epidemiologist, director of the Center for Suicide Prevention and Research in the AWRI

Dr. Ruch led a comparative analysis using data from the National Violent Death Reporting System.

The investigation, published in the *Journal of the American Academy of Child and Adolescent Psychiatry*, showed no significant difference in history of suicide attempts, mental health issues or other traditional risk factors exists between those who killed themselves in juvenile facilities and those outside.

“Youth who were incarcerated and died by suicide were no more likely to have mental health conditions than those who died by suicide in the community,” Dr. Ruch says. “That surprised us. And that led us to question whether there may be something about the environment that contributed to the increase in suicides.”

She suggests that the immediate shock of confinement and disruption to a youth’s regular life can be traumatic and increase the risk for suicidal behavior, especially for incarcerated youth with existing risk factors.

TAKING ACTION TO IMPROVE PREVENTION EFFORTS

For most of the studies, the researchers are now investigating what increases suicidal behavior in each of the identified populations.

They already found the increase is not associated with the 2007-2009 financial crisis or the opioid crisis. They suspect it has to do with the spread of smartphones, increasing screen time and the reach of social media around the clock.

“We’re looking for solutions – there won’t be a one size fits all answer for all of these populations,” says Dr. Bridge.

Ongoing prevention efforts include expanding access to behavioral health care, reducing stigmas for mental health conditions and suicide, and better equipping primary care providers, families and schools to help children in need.

“It never hurts to ask if a child or young adult is thinking about suicide,” emphasizes Dr. Bridge. “I say it in every interview – asking won’t hurt. It can only help.”

GET HELP NOW:

If you need immediate help due to having suicidal thoughts, go to your local emergency room immediately, call the National Suicide Prevention Lifeline at 1-800-273-TALK (8255) or reach out to the Crisis Text Line by texting “START” to 741-741.

Go online to download the 10 things the experts want you to know about suicide based on recent research. PediatricsNationwide.org/Suicide-Reasons-Why

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PHARMACISTS: THE 'NEXT BIG THING' in Population Health Management

ONE OF THE NATION'S LARGEST PEDIATRIC ACCOUNTABLE CARE ORGANIZATIONS HAS EXPANDED PHARMACISTS' ROLE IN QUALITY IMPROVEMENT EFFORTS, WHICH COULD SUBSTANTIALLY IMPACT PRESCRIBING PATTERNS AND PATIENT MANAGEMENT.

..... by *Katie Brind'Amour, PhD*

Partners For Kids (PFK), one of the country's oldest and largest pediatric accountable care organizations, is a provider-based organization dedicated to population health management with three key aims: improved patient care experience, better population health and lower per capita health care costs. Because medications are a key factor in health care expenses, more than half of accountable care organizations use pharmacists to help achieve their three aims. PFK, however, has made pharmacists an increasingly integral part of their efforts to improve care quality, offer clinician training, improve patient satisfaction, reduce costs, and even boost patient adherence and high-risk behavior identification.

"The pharmacy role has evolved over time," says Charitha Gowda, MD, MPH, MSCE, an associate medical director of PFK. "It went from predominantly being focused on pharmacy expenditures in the PFK population — such as finding ways to reduce costs by promoting generic prescribing over brand names — to more network- and practice-level interventions, working with quality improvement specialists on disease-specific management processes."

Pharmacists now co-lead many of the organization's quality improvement projects in asthma, reproductive health, ADHD, depression and other diseases that de-

pend greatly on appropriate medication management. For example, the program's pharmacists have used patient adherence to asthma medications (via data on prescription pick-up) as a marker of disease control. By bringing prescription-related data to the prescribers, patients with risk factors — such as filling too many rescue inhaler prescriptions — can get the extra attention they need before they end up with even bigger health problems.

"Pharmacists have extensive education and training in drug and disease nuances as well as patient-specific scenarios that impact the affordability and practical adherence issues for a medication," says Brigid Groves, RPh, PharmD, MS, a clinical pharmacist at Nationwide Children's Hospital and one of two PFK pharmacists. She co-authored an invited review paper about the involvement of pharmacists in PFK work, published in *Children* in July. "Pharmacists have the data and the background to really help physicians and other care providers — the diagnostic experts — by working with them to identify the most appropriate, efficacious, cost-beneficial and patient-friendly medications to use."

Other PFK pharmacist-led endeavors include in-office chart review, prescription management education for participating providers, evaluation of provider-based prescribing habits, and prescription guideline development

for common diseases. PFK pharmacists are now establishing partnerships with community pharmacists who can build long-term relationships with local providers to share data on their patients' prescription behaviors, reinforce appropriate medication use and adherence when patients fill a prescription, and even relieve some physician burden by providing immunizations and other injection therapies.

"Our pharmacists have focused on and committed to developing evidence-based practice in pharmacy," says Dr. Gowda, who is also an infectious diseases physician at Nationwide Children's. "That has become the gold standard for how we manage patients clinically, and it's the same rigor they're trying to apply in pharmacy, using data to guide their actions and practices."

This effort has brought pharmacists out of the historically transaction-related role to one deeply embedded in disease management and patient care. It is an endeavor that PFK leaders hope will result in demonstrable improvements in health outcomes, cost and quality in numerous disease categories.

"Pharmacists have that unique ability to see specific medication-related problems that might arise and to develop and implement solutions for both individual patients and their patient population as a whole," says Dr. Groves, who is also president of the Ohio Pharmacists Association.

PFK aims to set the tone for other accountable care organizations by publishing current and future data on health outcomes. They also hope to grow the network of pharmacists involved in patient care in Ohio and beyond.

"Through the work I've been able to do with our pharmacists, I've come to have a greater appreciation for how they can really come alongside the clinician to optimize care for patients," says Dr. Gowda. "They are often an underrecognized or underutilized resource. To the extent clinicians and others can partner with the pharmacists, they may identify innovative ways to improve patient health."

Drs. Gowda and Groves and their PFK colleagues also hope to delineate ways in which pharmacists can account for their time educating and administering medications to patients in the wake of 2018 Ohio legislation acknowledging pharmacists as health care providers.

"If PFK is a catalyst across the state or even the nation to showcase the positive impact a pharmacist can have on patient care through education and information," says Dr. Groves, "I think we can take things to the next level of providing great care in partnership with physicians, and maximize our impact on kids."

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— Charitha Gowda, MD, MPH, MSCE, associate medical director of Partners For Kids

BIAS DO YOU SEE WHAT INFLUENCES YOU?

Confronting racism and implicit racial bias on the road to health equity

by Abbie Roth

In the United States, children of color have worse clinical outcomes than white children. Racial disparities have been documented in nearly every pediatric specialty. Among the most studied and most widely perpetuated disparities are those between black and white children.

For example:

- The infant mortality rate, while declining overall, is nearly three times higher for black babies than for white babies.
- Black children are less likely to get adequate pain control compared to white children.
- Providers often assume black children are older than they are.
- Black school-age youth are more likely to die by suicide than white youth, though the trend is reversed for teens.
- Black children with moderate to severe congenital heart disease (CHD) are less likely to continue follow-up care with a CHD specialist compared to white counterparts.
- For children with Down syndrome, the life expectancy for white patients is nearly double that of black patients.

These differences are not the result of any inherent biological differentiator. The studies' analyses show they are not purely driven by differences in socioeconomic backgrounds, such as education, income and zip code. They are at least in part the result of race, or more specifically the socioeconomic, psychological, and physiologic outcomes of toxic race relations.

The idea of race is not clinical or biological in nature. It's a social construct that, in the United States, was institutionalized in the late 1600s to make legal distinctions between "white" and "black" residents. And it's a social construct still at work today. In most studies that look at disparities in care and outcomes based on race, the term is meant to identify a cultural group defined by ethnic heritage, skin color and personal identity.

"Race and racism in America is an issue in every part of life. And for children, our most vulnerable population, it affects health outcomes even before they leave the womb," says Adiaha Spinks-Franklin, MD, MPH, attending physician in Developmental-Behavioral Pediatrics at Texas Children's Hospital. "Only by talking about these issues openly, relying on facts and evidence, and confronting bias head on will we make progress toward health equity for children everywhere."

Beyond Social Determinant to Adverse Childhood Experience

In July 2019, the American Academy of Pediatrics released a policy statement calling for pediatricians to confront the impacts of racism on children. According to the policy statement, racism – the implicit prejudicial treatment of someone based on race – has a "profound impact" on the health status of youth and their families.

The statement goes on to add, "Although progress has been made toward racial equality and equity, the evidence to support the continued negative impact of racism on health and well-being through implicit and explicit biases, institutional structures, and interpersonal relationships is clear. Failure to address racism will continue to undermine health equity for all children, adolescents, emerging adults, and their families."

The experience of racism and racial bias should be considered an adverse childhood experience (ACE), like abuse, neglect or traumatic events that predispose a child to a negative outcome later in life. Dr. Spinks-Franklin, who is also an associate professor of Pediatrics at Baylor College of Medicine, and Jennifer Walton, MD, MPH, attending physician in Developmental Behavioral Pediatrics at Nationwide Children's, and their colleagues spend the first part of their wildly popular workshop "Racism: Another Adverse Childhood Experience," laying out the evidence for why this is true. The workshop was developed for and by the Society of Developmental & Behavioral Pediatrics in 2018. It was presented to a standing-room-only crowd at the Pediatric Academic Societies Meeting in April of 2019, and it has been shared around the country since then.

"The lived experience of racism – witnessing its impacts, experiencing it firsthand – has serious consequences to the emotional, physical and mental well-being of children, in addition to the known disparities in care that can arise as a result of provider bias," says Dr. Walton, who is also an assistant professor of Clinical Pediatrics at The Ohio State University.



"The lived experience of racism - witnessing its impacts, experiencing it firsthand - has serious consequences to the emotional, physical and mental well-being of children, in addition to the known disparities in care that can arise as a result of provider bias."

— Jennifer Walton, MD, MPH, attending physician in Developmental Behavioral Pediatrics at Nationwide Children's and assistant professor of Clinical Pediatrics at The Ohio State University

How and When Do Children Become Aware of the Construct of “Race”?

Researchers have shown that babies of color are just as likely to experience bias as adults of color. But very young children don't interpret that experience in the same way as older children.

“Children become aware of differences in physical characteristics of human beings when they are 3 years old. They notice differences in sex (male vs female) height, weight, hair texture, skin color and so on. These differences in physical characteristics are all normal human variations, and by age 3, children are aware of them,” says Dr. Spinks-Franklin.

By age 4, children are aware of the social construct of race. They begin to recognize their own racial group and those of others. Depending on home and community experiences, they may start to discriminate between certain human variations in selecting playmates.

“Children at 4 years of age are still in an early stage of racial identity development, where children of color tend to relate more to the dominant culture – in the United States, white American culture – rather than their own culture. This is called the “Pre-encounter Phase of Racial Identity Development for children of color,” Dr. Spinks-Franklin explains.

Children at age 9 years become aware of their racial groups' status within larger society. For children of color, this is called the Encounter phase. By this age, children are aware if their group is treated unfairly or differently – or if their group is in a position of power. The Encounter phase is a big developmental leap because it occurs during many other aspects of identity development – including gender identity development.

Dr. Spinks-Franklin shares how this overlapping phase of identity development can contribute to conflicts: Around age 9, boys who identify as male will see their fathers and the men in their lives as “superman.” They'll start to challenge female authority – mothers and teachers. Now, imagine that the male student of color challenges the authority of a white female teacher – will his behaviors be viewed and addressed as developmentally appropriate or as aggressive and threatening?

These phases in the development of racial identity and in childhood development can contribute to biases and are important reminders that children are not motivated in the same way adults are. Appropriate responses to children and appropriate supports against racial bias should consider a child's developmental stage.

Implicit or Explicit? Understanding Bias

The way one person interacts with another is influenced by a myriad of factors, guided by complicated algorithms our brains have developed over our evolutionary and personal histories.

“We all make assumptions and categorize people in every way – gender, race, age – and all those assumptions are often useful and helpful in getting us through the day. We don't have time to think through every encounter, so we use categories as shortcuts,” says Deena Chisolm, PhD, director of the Center for Innovation in Pediatric Practice and director of the Center for Population and Health Equity Research at the Abigail Wexner Research Institute (AWRI) at Nationwide Children's.

Those quick assessments can become the basis for stereotypes and biases. Implicit bias refers to the unconscious attitudes and stereotypes that affect our understanding, feelings and actions – whether in a positive or negative way.

“Unchecked, bias erodes quality of care and eats away at our ability to provide care at the therapeutic level,” says Kelly Kelleher, MD, MPH, vice president of Community Health and principal investigator in the Center for Innovation in Pediatric Practice in the AWRI at Nationwide Children's.

Bias is looking at a family and first asking for a Medicaid card instead of a card for private insurance. It is asking certain patients about drug use and not others. It is assuming an injury was caused by abuse in one patient and happened during a sporting event for another. In short, bias is allowing assumptions to override evidence.

“These small slights are sometimes referred to as micro-aggressions. When they happen to a patient, it builds scars and callouses and negative feelings,” says Dr. Chisolm, who is also vice president for Health Services Research in the AWRI. “Once or twice it's irrelevant, but when it's daily, weekly and monthly for a lifetime, it creates barriers to interacting. And it can create mistrust of the health care system and the people in it.”

When Bias is Exacerbated

“Bias becomes more profound, more exacerbated, when providers are tired, stressed or overwhelmed,” says Dr. Kelleher, who is also a distinguished professor of Pediatrics and Public Health at The Ohio State University. “The more cognitive demand we have, the more biased we are.”

A series of studies led by Tiffani Johnson, MD, MSC, attending physician in Emergency Medicine at Children's Hospital of Philadelphia, investigated the role of implicit bias in the pediatric emergency department. In 2013, she published an article in *Academic Emergency Medicine* that showed how stress and fatigue influence bias. The study found that increased stress was associated with greater implicit racial bias.

In 2016, Dr. Johnson published a follow up in *Academic Pediatrics* investigating if ED physicians were less biased against children compared to adults and if the age, race, gender or level of training of the provider mattered. She and her colleagues found that most residents had pro-white/anti-black bias on both the child and adult implicit bias tests used. They also showed that the residents' biases did not vary based on personal characteristics and mirrored the biases shown in other specialties.



“Ultimately, we won't get to health equity by just fixing disparities at the health care system level. But that doesn't mean we shouldn't fix it there.”

—Deena Chisolm, PhD, director of the Center for Innovation in Pediatric Practice and director of the Center for Population and Health Equity Research at the Abigail Wexner Research Institute at Nationwide Children's

Even more recently, a study published in *JAMA Network Open* in 2019 showed that as burnout symptoms increased so did racial bias. The study followed non-black medical residents who self-reported symptoms of burnout during their second and third years of residency. The medical residents completed tests aimed to identify explicit and implicit biases.

“With increasing rates of burnout and a growing focus on the mental and emotional health of health care providers, we should be considering how functioning in this state affects the bias experienced by patients of color,” says Dr. Walton, who is also chair of the Pediatric Section of the National Medical Association.

Equality Is Not Equity

At a system level, algorithm-based care, protocols and standardization of care help reduce variation in care that could be caused by bias. This is particularly helpful in reducing variation due to implicit bias when a provider is tired or stressed. But experts warn that all care being equal does not necessarily achieve equity.

“If you look at disparities in life expectancy and infant mortality rates, those won’t be overcome with giving everyone the same care,” says Dr. Chisolm, who is also a professor of Pediatrics at The Ohio State University.

“Infant mortality has declined equally for everyone – but that still means there’s a three-fold difference between black and white outcomes.”

The first step to achieving health equity is to provide excellent care for populations who don’t always get it. And one of the hurdles to that care is the perception that some providers look down on some people.

“Patient perspective is critical to providing high quality care. Culture differences, the general stress of interacting with the health care system and bias experienced by patients are all reasons that patients might not feel like they are getting good care,” says Dr. Kelleher, who is also the ADS/Chlapaty Endowed Chair of Innovation in Pediatric Practice in the AWRI.

He shares a story about a public pediatric psychiatry clinic where patients reported that they were getting terrible care. All of the families assumed that they were being disrespected because they were poor or black.

“It matters a lot if you think the system doesn’t care for you or respect you,” Dr. Kelleher says. “We have to address that perception as well as providing consistent, quality care.”

People of color may choose to go to lower quality



“When our faculty and staff reflect the community around us, when we interact daily with the community outside of the hospital walls through mentoring, festivals and other events, it’s no longer them versus us.”

– Kelly Kelleher, MD, MPH, vice president of Community Health and principal investigator in the Center for Innovation in Pediatric Practice in the Abigail Wexner Research Institute at Nationwide Children’s

providers to avoid feeling judgment or disrespect, says Dr. Chisolm. They may avoid a more highly rated facility in favor of another provider because the other provider has more people who look like them and because they feel more welcome. A lot of the disparities in health care outcomes can be traced to the places that people choose to get care, she adds.

Part of the solution, Dr. Chisolm says, lies in making the highest quality institutions places where all people want to go to get care. Not just because families want to receive the best, but because they feel welcome and safe there.

To do so, hospitals and institutions must become explicitly welcoming to all communities. In some instances, this means holding focus groups and developing relationships with community organizations that can help navigate cultural differences. And most importantly, it means listening to and incorporating the feedback, says Dr. Kelleher.

Some of that feedback might require hospitals to become more open to new models of care, which could improve outcomes and lead to more health equity for certain patient groups. Would home visits or telemedicine options help to address the needs of a diverse population? Would they help to build trust between the community and the health care institutions? These are big questions that experts are looking to answer, but they aren’t the only ways to address bias and inequity in health care.

“Ultimately, we won’t get to health equity by just fixing disparities at the health care system level. But

that doesn’t mean we shouldn’t fix it there,” says Dr. Chisolm. “The biggest hurdle to eliminating health disparities has little to do with the provider. It’s getting to the underlying social problems so that more people, particularly those of color, can have a lived experience where they don’t feel like they are constantly under attack – from bill collectors, from schools, from society and so on. Constant stress has biological outcomes.”

Bridging Social Distance

To get beyond the health care system level, Dr. Kelleher suggests providers and health care employees consider interpersonal interactions with patients. The social distance between the patient and the provider is an important component in how bias manifests, says Dr. Kelleher. “The more distant we are, the less likely I am to understand your culture and needs. The less likely I am to control your pain adequately, the more likely I am to prescribe one thing and not another. This social distance and the resulting impacts on care result in lower quality care.”

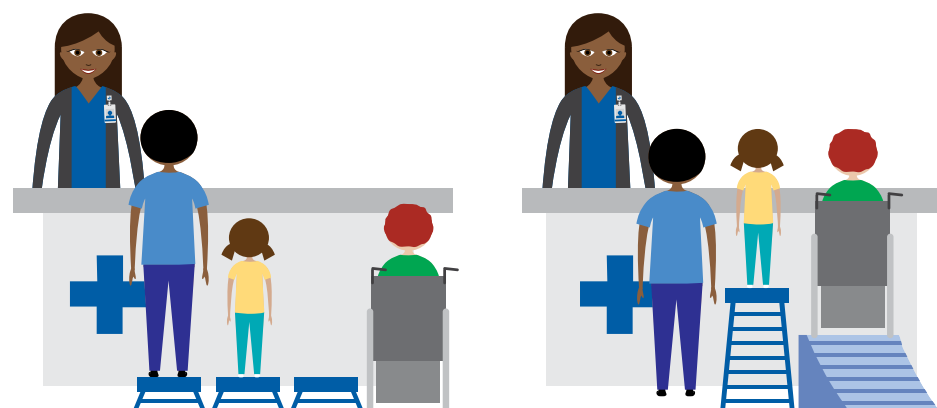
One way to address the challenges of social distance is to “change who we are,” suggests Dr. Kelleher.

“When our faculty and staff reflect the community around us, when we interact daily with the community outside of the hospital walls through mentoring, festivals and other events, it’s no longer them versus us. It’s just us,” says Dr. Kelleher. “That alone takes away so many of the feelings of fear, anxiety and uncertainty that surround issues of race, racism and implicit bias.”

Reflecting the community also comes down to hiring practices. At Nationwide Children’s, a concerted effort

EQUALITY VERSUS EQUITY

Health equity researchers recognize that giving everyone the same care or “help” doesn’t result in equal outcomes. According to Dr. Chisolm, a health equity approach starts with the idea that everyone should have a fair opportunity to live a long, healthy life that is not compromised by race, ethnicity, gender, income, sexual orientation, neighborhood or other social condition. Health equity researchers combine clinical data and community input to test interventions and learn what works best for different populations – so that everyone can reach their best outcome.



to hire members of the community in the zip codes surrounding the hospital campus has had good success. According to Dr. Kelleher, the next focus is retention.

“We’ve gotten really good at being ‘corporate.’ We need to make sure that we don’t stop being good at being part of the community,” says Dr. Kelleher. “The whole idea of becoming ‘us’ points to becoming a front porch for the community. Until we are able to achieve that, we’ll continue to struggle with social distance and implicit bias.”

Challenge Yourself

Looking at changes that can be implemented at the health care system level and the provider level are the first steps to changing outcomes. But what will it take for significant, lasting change to occur?

“For a provider, where you start is recognizing your bias. Acknowledging that you have a first impression of a person or situation, but then being willing to set that impression aside and look at the specific evidence in front of you,” says Dr. Chisolm. “It might turn out that you were exactly right on your first impression, but maybe more often you might be surprised and find out that you were totally wrong.”

So, how do you identify your biases?

Implicit bias awareness tests, including the Harvard Implicit Association Test, are designed to help individuals understand personal biases.

“Using these tests is often helpful, whether people think they have bias or not,” says Dr. Walton. “Because we all have biases – it’s important to identify them.”

In their workshop, Drs. Spinks-Franklin and Walton and their colleagues lead participants through role playing exercises.

“These role playing activities are an essential part of putting what you learn into action,” says Dr. Spinks-Franklin. “Sometimes people are uncomfortable in these scenarios, doing it in a safe setting like the workshop can help them feel more comfortable when they have to deal with bias and racism in the clinic.”

Being uncomfortable, asking questions, being open to being wrong, these are all the themes that were repeated by the experts. They are the truths that are necessary to move from where we are to where we need to be.

“We invite the audience to get comfortable being uncomfortable,” Dr. Spinks-Franklin adds. “That’s how you become an active anti-racist.”

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Unsure about where to start?

CHECK OUT THESE TIPS FROM THE EXPERTS INTERVIEWED FOR THIS ARTICLE.

- **If you are not sure, ask.**
 - For example, ask families how they prefer that you speak to their children.
 - It’s always better to ask than assume.
- **Attend a class or workshop.**
 - Many are now available at professional conferences.
 - Invite one to come to your institution.
- **Get involved in diverse communities.**
 - Closing social distance is good for everyone.
- **Take time to reflect on your personal biases and commit to changing your actions.**
 - Take care of yourself so that you can have the emotional and cognitive energy to do the work.
- **Speak up for others.**
 - Be an advocate.
 - If you see something, say something.

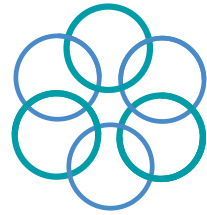


Photo credit: Texas Children's

“We invite the audience to get comfortable being uncomfortable, that’s how you become an active anti-racist.”

—Adiaha Spinks-Franklin, MD, MPH attending physician in Developmental-Behavioral Pediatrics at Texas Children’s Hospital





A NEW THERAPEUTIC ERA in Pediatric Functional and Motility Disorders

20 YEARS AGO, TREATMENT OPTIONS WERE LIMITED FOR CHILDREN WITH FUNCTIONAL GASTROINTESTINAL (GI) AND MOTILITY DISORDERS. NOW, A GROWING LIST OF DRUGS, BEHAVIORAL AND DIETARY CARE PLANS, AND AN ADVANCED, FORWARD-LOOKING TECHNIQUE – NEUROMODULATION – ARE TRANSFORMING PEDIATRIC GI CARE.

..... by Katie Brind'Amour, PhD

Gastrointestinal (GI) disorders are notoriously difficult to diagnose. Virtually all functional and motility-related GI problems present with common symptoms: nausea, vomiting, abdominal pain, bloating, gas, diarrhea or constipation. Many patients wait months or even years for the right diagnosis, and even then, management of functional (often sensation-related) and motility (transit-related) disorders can be difficult. That's why recent advancements in therapeutic options and outcomes research have been critical.

"In the late 90s and early 2000s there was really no treatment available to children with the most severe motility disorders," says Carlo Di Lorenzo, MD, chief of the Division of Gastroenterology, Hepatology and Nutrition at Nationwide Children's Hospital. "Now, we have medications, neuromodulation, surgical interventions, dietary treatment, and behavioral treatment – five different types of interventions that have the potential to help."

Pharmaceutical treatments offer the most straightforward medical approach to some symptom relief, but some children require additional or alternate treatments, including surgery. Many emerging therapies, such as behavioral therapies and neuromodulation techniques,

offer unique – often less invasive – strategies for reducing symptoms and even curing disease.

BOTOX® FOR KIDS

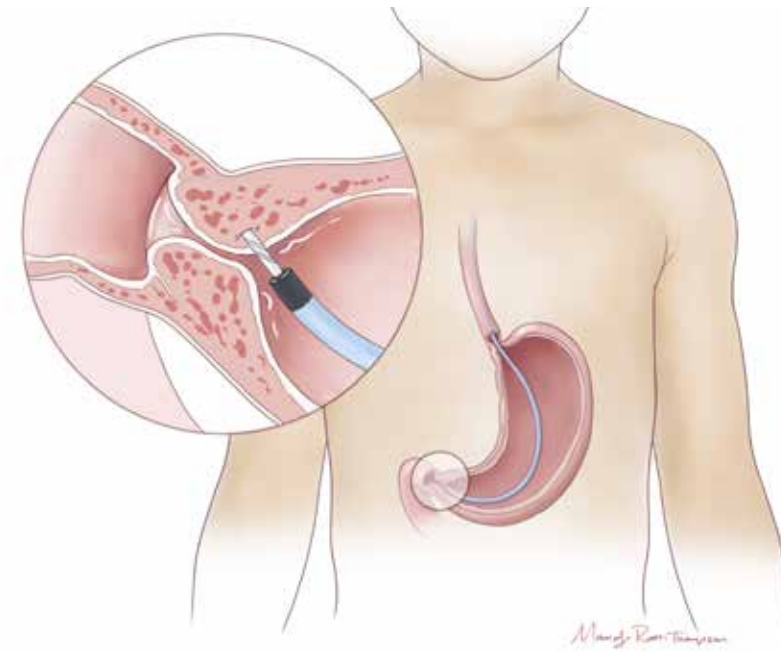
It's true. Botox® has a place in modern GI motility therapy for children with certain motility issues, such as Hirschsprung's disease and delayed gastric emptying. In these cases, a quick Botox injection directly into the anal or pyloric sphincter, respectively, may offer sufficient muscle relaxation to improve motility.

Long used in the treatment of Hirschsprung's disease, anal Botox is also appropriate in children with severe functional constipation, according to a 2019 *Journal of Pediatric Surgery* study by Nationwide Children's physician-scientists. And although pyloric Botox requires an endoscopy, it is less invasive and carries fewer risks than many surgical procedures.

Injections in either sphincter often produce lasting responses, sometimes relaxing the muscles long enough for GI concerns to resolve entirely.

DIET

Many GI care programs now include dietitians to help manage the unique nutritional needs of patients with functional and motility disorders. From managing feeding tubes to the low-FODMAP diet (a diet plan low



PYLORIS BOTOX®

Botox injections into the pyloric or anal [not pictured] sphincters may help alleviate GI disorders such as gastroparesis and internal anal sphincter achalasia. It is a low-risk procedure often offered for children with severe symptoms prior to exploring surgery.

in the fermentable carbohydrates that create irritating gas in the GI tract) for children with irritable bowel syndrome (IBS), these highly specialized GI dietitians significantly impact the care of patients seeking to manage or even resolve sensitivity-related GI symptoms through dietary management.

The Nationwide Children's GI nutrition team is currently working to publish data they presented at Digestive Disease Week in 2019 on the efficacy, safety and feasibility of the low-FODMAP diet for children with IBS.

"Especially for functional disorders like IBS, medications aren't the only way to go – behavioral therapy and diet can be just as effective, if not more so," says Peter Lu, MD, MS, a pediatric gastroenterologist and physician-scientist in the Center for Neurogastroenterology and Motility Disorders at Nationwide Children's.

BEHAVIORAL AND PSYCHOLOGICAL THERAPY

"GI psychology is increasingly being recognized as helpful in a lot of contexts as a non-medical option to treat many functional and motility conditions," says Ashley Kroon Van Diest, PhD, a pediatric psychologist at Nationwide Children's. "GI psychologists help fill a lot of needs in patient care."

Some GI conditions frequently coincide with anxiety, depression and increased sensitivity to pain, and even children without these problems often have psychosocial challenges – embarrassment about their symptoms, judgment or accusations from friends and family – that make this additional care beneficial.

"We do evaluations and provide treatment recommendations for the family, and explain that it's not all in their heads – the pain and symptoms are very real," says Dr. Kroon Van Diest.

Together, she and the treating gastroenterologist see all patients coming to the hospital's Functional Gastrointestinal Disorders Clinic to determine diagnoses and optimal treatment plans. She may also recommend follow up with additional therapy and program services such as massage therapy, therapeutic recreation, nutrition and more.

"To help many of these children, you have to approach the problem from a biopsychosocial model," says Desale Yacob, MD, medical director of the Center for Neurogastroenterology and Motility Disorders. "Psychologists have a huge role in treating these patients, not because they have classic psychological conditions, but because they can see patients' environmental and psychosocial influences on their physical health, and address them with gut-directed therapy."

– RUMINATION THERAPY

One diagnosis that benefits substantially from the involvement of psychological care is rumination syndrome, a rare GI disorder that makes it hard for children to consume anything by mouth without vomiting almost immediately due to learned but involuntary muscle contractions. Fortunately, rumination experts can work with children – some of whom have not kept down a bite of solid food for years and are reliant on feeding tubes – to teach them how to eat normally again.

Over the course of about a week, Dr. Kroon Van Diest, who is the lead psychologist for the pediatric Rumination Syndrome Program at Nationwide Children’s (the only one of its kind in the country), works with patients to retrain their muscles by dry swallowing again as soon as they feel their stomach start to contract. Children are also taught to use diaphragmatic breathing when they eat to relax the abdominal muscles and prevent the contractions that cause food to come up. The majority of patients leave the program no longer requiring feeding tubes.

“It’s a relatively short-term, intensive treatment, but we send them back home to school and sports and things they haven’t been able to do in years,” says Dr. Kroon Van Diest, who also has a study underway to expand the center’s current treatment outcome data, published in the *American Journal of Gastroenterology* in 2018, to a longer follow-up. “It’s very impactful and very rewarding.”

– COGNITIVE BEHAVIORAL THERAPY

Patients with pain-related conditions, such as IBS, may be offered cognitive behavioral therapy (CBT) to learn how to cope with and relieve some of their abdominal pain. With this psychology-led approach, children are taught strategies to activate the parasympathetic nervous system. This slows the heart rate and breathing, counteracting the body’s typical response to pain. As a bonus, the practice may distract children from focusing on their pain.

“Research shows that over the course of 6-8 weeks, children who practice CBT most days a week – even for very short periods each time – experience changes in the pain processing centers of the brain on fMRIs,” says Dr. Kroon Van Diest, who has research pending publication demonstrating similar effects of CBT on fMRI pain center activity in children with migraines. “Reduced pain center activity correlates with better school performance, a lower perceived pain score, improved functioning and other positive changes.”

– BIOFEEDBACK THERAPY

For patients with constipation and fecal incontinence, biofeedback can be used to teach children “defecation dynamics” – how to have a bowel movement. In the Motility Center’s Pelvic Floor Rehabilitation/Biofeedback program, Kimberly Osborne, CPNP-PC, meets with children to provide this form of behavioral therapy.

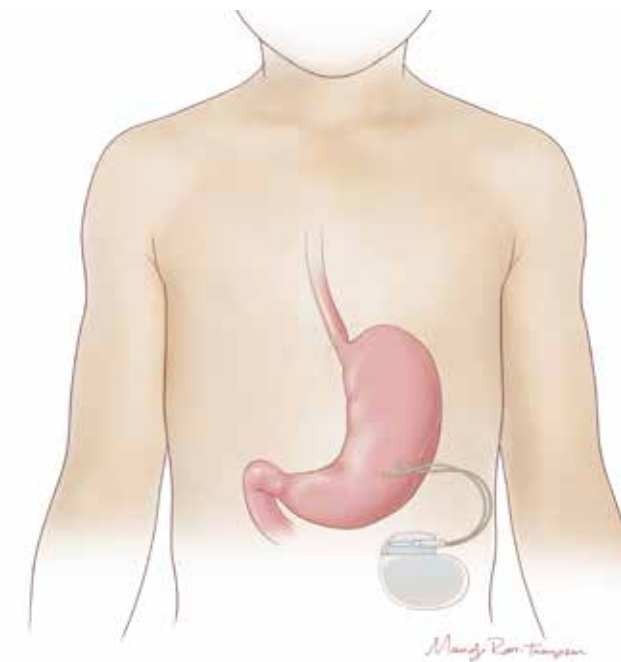
In each session, small electrodes placed around the patient’s stomach and/or anus are connected to a computer with an instructional screen. The nurse practitioner walks through how to relax and how to contract the area using the images on the screen. Over time, patients learn how to control the pelvic floor muscles in order to control defecation and relieve symptoms.



Members of the biofeedback team are working with a patient. Over time, the practice will help the patient learn how to control the pelvic floor muscles.

“If children don’t respond to behavioral and lifestyle interventions or medication, often the only options left are surgical. Neuromodulation has the advantages that – even though it can require surgery – it is usually adjustable and reversible, which is ideal for children.”

– Peter Lu, MD, MS, pediatric gastroenterologist and physician-scientist in the Center for Neurogastroenterology and Motility Disorders at Nationwide Children’s



GASTRIC ELECTRICAL STIMULATION

After thorough evaluation and a trial period with an external stimulator, a surgically implanted gastric pacer may be used to relieve nausea and stomach pain and to improve appetite in children with intractable gastroparesis or functional dyspepsia.

NEUROMODULATION THERAPY FOR GI ILLNESSES

No other treatment has generated as much excitement in the field of neurogastroenterology as neuromodulation – electric stimulation of the nerves to reduce pain, ease constipation and relieve nausea or other symptoms. And the experts believe this is just the beginning.

– GASTRIC ELECTRICAL STIMULATION (GES)

After other treatments fail, GES may be used in the care of severe nausea and abdominal pain caused by functional GI and motility disorders, such as gastroparesis and severe, intractable functional dyspepsia. Although its exact mechanism is not clearly understood, GES uses a device much like a pacemaker to provide gentle, frequent stimulation to the nerves of the stomach – not forcing the stomach muscle to contract or push food through, but perhaps numbing or calming the hypersensitive nerves.

Despite lacking a clear mechanism of action, GES often brings symptom relief, improving appetite regardless of any change in motility. Its external controls allow the device to be adjusted in strength and frequency of the stimuli, and many devices can stay in place 5-10 years prior to requiring reoperation to replace the battery.

“If children don’t respond to behavioral and lifestyle interventions or medication, often the only options

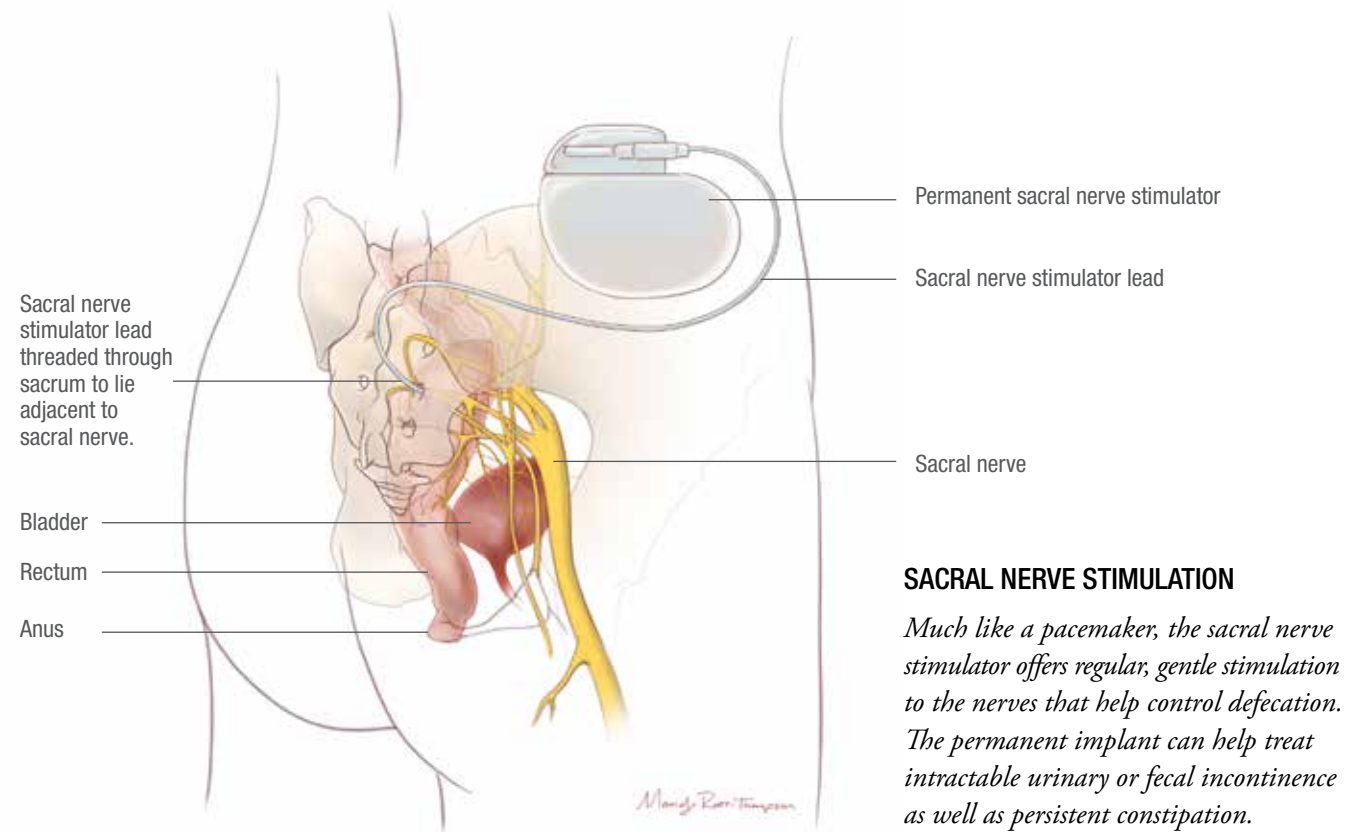
left are surgical,” says Dr. Lu. “Neuromodulation has the advantages that – even though it can require surgery – it is usually adjustable and reversible, which is ideal for children.”

The Nationwide Children’s Motility Center is one of the country’s largest programs in terms of implant volume and neuromodulation research. The team is planning to publish 10 years of outcomes data (also presented at Digestive Disease Week this year) for the patients who have received one of the 85 gastric pacers placed by Nationwide Children’s GI motility experts and surgeons since 2009.

“We have had GES patients who could not tolerate anything – even a slow-drip feeding tube,” says Dr. Lu. “Literally a couple of months after the procedure, they could tolerate full feeds and wanted to eat.”

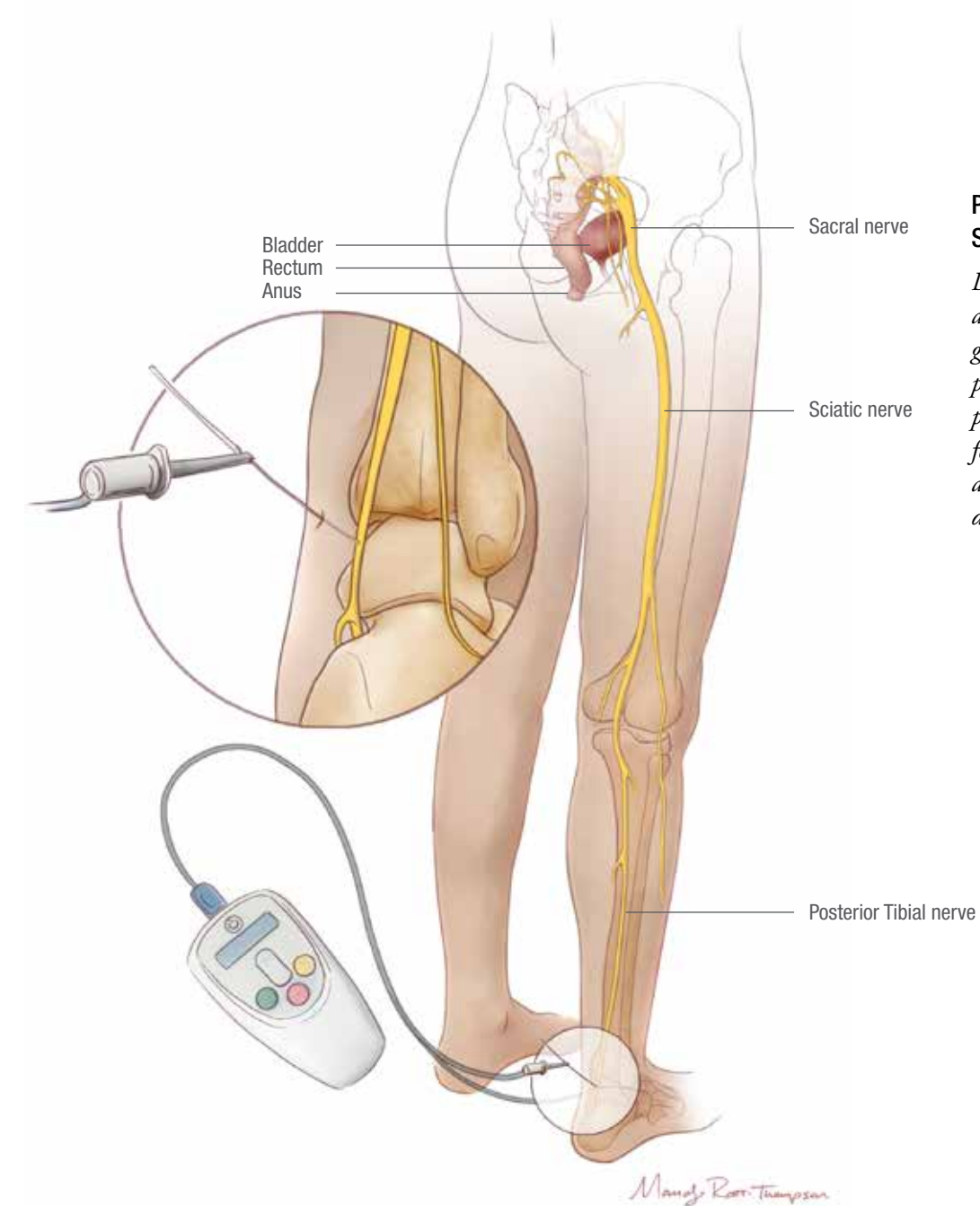
The motility team at Nationwide Children’s has begun using the procedure even in young children who qualify, and they have also developed an approach (called the CDiLo technique) to better secure the gastric pacer’s wire to the stomach during GES trials, allowing for a longer test period before permanent implantation.

“Seeing how patients respond to this intervention has been very rewarding, and it’s only a start,” says



SACRAL NERVE STIMULATION

Much like a pacemaker, the sacral nerve stimulator offers regular, gentle stimulation to the nerves that help control defecation. The permanent implant can help treat intractable urinary or fecal incontinence as well as persistent constipation.



POSTERIOR TIBIAL NERVE STIMULATION

During an outpatient visit, a small machine provides gentle stimulation through a precisely placed needle to the posterior tibial nerve, which feeds into the sacral nerve and may help treat pediatric defecation disorders.

Dr. Jacob, who is optimistic that long-term outcomes data, expansion of eligible patient groups and advancement in understanding of the mechanisms of GES will further cement its use in pediatric therapy. “I think there are a lot of patients who could benefit from this approach.”

– SACRAL NERVE STIMULATION

Although relatively new in the pediatric GI space, sacral nerve stimulation (SNS) has been offered for nearly a decade at Nationwide Children’s, starting in children with urinary incontinence and moving into cases of constipation and fecal incontinence.

Together, the urology and GI teams have implanted nearly 100 stimulators and have published regularly on their experiences with what is one of the largest SNS cohorts in the world. Recent work published

in *Neurogastroenterology and Motility* has established its long-term efficacy in relieving constipation and fecal incontinence and has demonstrated that the procedure results in lasting parental satisfaction.

“I find the sacral nerve stimulation data published by the Nationwide Children’s motility group and the myriad of individual and collaborative clinical and research endeavors they have undertaken to be empowering,” says Lusine Ambartsumyan, MD, director of the Gastrointestinal Motility program at Seattle Children’s Hospital. “Their work paves the way for novel diagnostic and therapeutic innovations and allows other motility specialists to establish similar programs and protocols at their own institutions, to improve the care and the quality of life of our patients.”

“Seeing how patients respond to this intervention has been very rewarding, and it’s only a start. I think there are a lot of patients who could benefit from this approach.”

– Desale Jacob, MD, medical director of the Center for Neurogastroenterology and Motility Disorders at Nationwide Children’s

– POSTERIOR TIBIAL NERVE STIMULATION

“We know from GES and SNS that electrostimulation of the GI tract can work,” says Dr. Lu. “But those approaches require implantation, so there is a lot of interest in how to do this without using a surgery.”

Like sacral nerve stimulation, posterior tibial nerve stimulation (PTNS) stimulates the nerve that feeds into the sacral nerve roots, which control bladder and bowel function. Although used for several years in the world of urology, PTNS for pediatric

constipation and fecal incontinence is still under the umbrella of clinical research. Dr. Lu and his colleagues suspect it acts on the anorectal area rather than higher up in the colon, which would suggest that children with constipation due to anorectal or pelvic floor issues may respond the best.

“Even if sacral nerve stimulation is slightly more effective,” Dr. Lu says, “PTNS is noninvasive – a huge advantage.”

“The idea of stimulating the ear or ankle and making your GI tract work better is very intriguing, and it helps a lot of people feel better with no side effects. These interventions differ from surgery and drugs in that, if they don’t work for you, you haven’t lost anything.”

– Carlo Di Lorenzo, MD, chief of the Division of Gastroenterology, Hepatology and Nutrition at Nationwide Children’s Hospital

– AURICULAR NERVE STIMULATION

Recently approved by the FDA for the treatment of IBS, an electrical device called IB-Stim produces gentle stimulation of the auricular nerves, located just under the skin in the ear. While the exact mechanism is not fully understood, pain relief appears to result from the electrical impulses’ influence on the amygdala and spinal cord, and possibly other pain-control areas in the central nervous system.

The clinicians in the Motility Center are complimentary about the technology and believe it has a valuable place in the treatment paradigm for IBS.

“The idea of stimulating the ear or ankle and making your GI tract work better is very intriguing, and it helps a lot of people feel better with no side effects,” says Dr. Di Lorenzo. “These interventions differ from surgery and drugs in that, if they don’t work for you, you haven’t lost anything.”

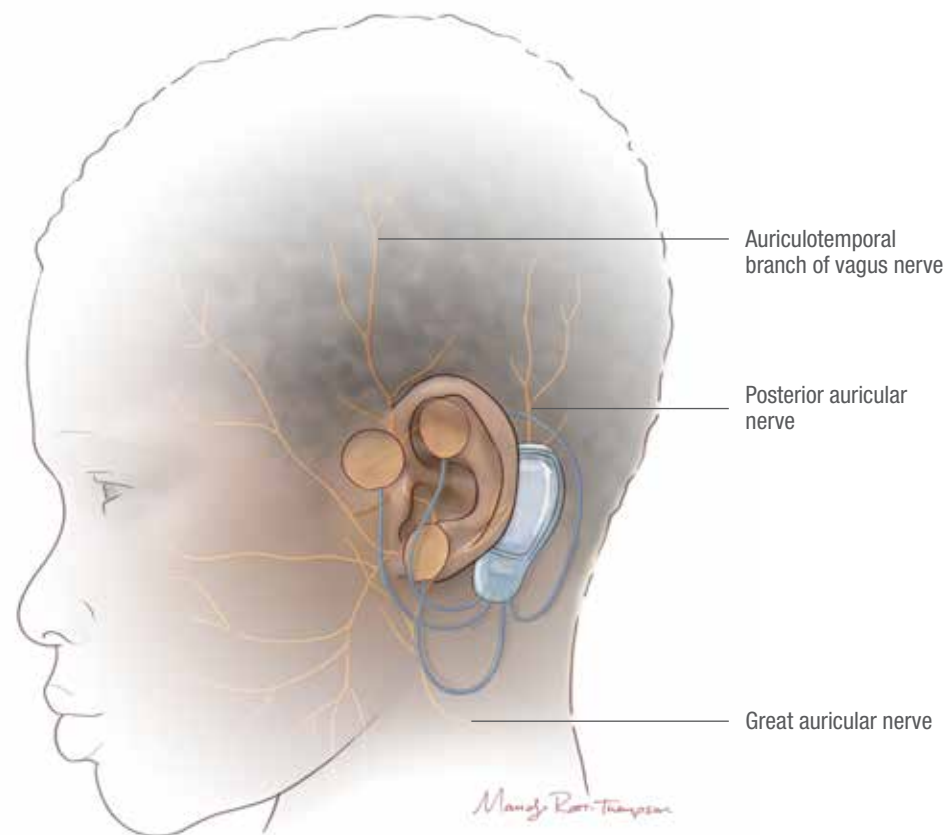
COLLABORATING FOR THE FUTURE

Taken together, the growing range of treatment options for functional and motility disorders offers patients unprecedented opportunities for clinical improvement.

“When it comes to both research and care, we do it as a group,” says Dr. Yacob. He, Dr. Di Lorenzo, Dr. Lu and attending pediatric gastroenterologists Karla Vaz, MD, MEd, and Neetu Bali, MD, MPH, complete the

AURICULAR NERVE STIMULATION

Due to the thin skin on and around the ear, an external auricular nerve stimulator can provide gentle and short-term (outpatient) electrical stimulation to nerves believed to be involved in pain sensation. It is approved for use in patients with IBS and may hold promise for other pain-related GI conditions as well.



“The field of functional and motility disorders is in a much better place than it was 20 years ago. There is still room for improvement, but by working together, we’re definitely getting better.”

– Carlo Di Lorenzo, MD, chief of the Division of Gastroenterology, Hepatology and Nutrition at Nationwide Children’s Hospital

team of five motility specialists, who also work with a Motility Center nurse practitioner, physician assistant, four dedicated nurses and two administrators. The team collaborates with pediatric surgeons, urologists, psychologists, dietitians, interventional radiologists and other experts to develop and discuss evaluation and treatment plans with each new patient. “We always try to focus on what is relevant and could help change how we treat these patients, then do our best to share our findings with colleagues around the country.”

Learning from other leading motility experts, such as Dr. Ambartsumyan, is crucial for continuing advancements, as well. Her use of 3-D high-definition anorectal manometry to better characterize the intra-anal pressure profiles of children with a normal anorectum and in those with anorectal malformations, published originally in the *American Journal of Gastroenterology* with another submission pending, should improve physiologic assessment of function in children with anorectal malformations who suffer from fecal incontinence. In time, she expects it will also help clinicians better tailor their treatment approaches for these patients.

Dr. Ambartsumyan is not alone in her potential to impact the future for children with functional and motility disorders. Other experts, as well as fellows trained through Nationwide Children’s functional and motility fellowship, are feverishly working to carry the knowledge currently concentrated in a handful of specialty centers to other burgeoning motility programs, increasing access to care for children at institutions closer to their homes.

“The field of functional and motility disorders is in a much better place than it was 20 years ago,” says Dr. Di Lorenzo. “There is still room for improvement, but by working together, we’re definitely getting better.”

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WHY ADVOCATE?



RAY BIGNALL, MD, PEDIATRIC NEPHROLOGIST AT NATIONWIDE CHILDREN'S HOSPITAL AND CHILD HEALTH ADVOCATE, SHARES WHY IT MATTERS FOR SPECIALISTS TO BE ADVOCATES FOR CHILD AND COMMUNITY HEALTH EQUITY.

..... by Ray Bignall, MD

Several months ago, I had the privilege of attending a panel discussion on health in the African American community hosted by my local church. It was an opportunity for our largely African American congregation to hear from black health professionals promoting health-seeking behavior in communities of color. Sitting in the audience, I listened as each panelist shared the challenges and triumphs of providing care to minority patients, where health inequities and adverse social circumstances often create barriers to care.

As the floor was opened for questions and comments, the queue for the microphones grew long as person after person patiently waited to share stories of mistreatment and disregard at the hands of medical professionals. Stories of delayed diagnoses and disrespectful interactions filled the sanctuary and received rousing affirmations by everyone in attendance. Many of the health professionals on the panel chimed in with similar stories of their own, each story reinforcing the feelings of hurt and distrust echoed by the others.

It was painful to hear how little faith my community had in health care professionals like me to be a part of their healing. It was painful, but not surprising.

As an African American pediatric nephrologist – a member of an increasingly shrinking pool of black men in medicine – I am accustomed to these stories; I even have a few of my own. Like many underrepresented minorities in medicine, an ambition to correct this injustice drove me to become a doctor in the first place. The heart of my work as a pediatrician is my role as an advocate for communities in need.

Perhaps no field of pediatrics sits more squarely at the

intersection of health and social justice than nephrology, and the capacity for me to impact the care of underserved populations is profound. The kidney's primary role in the body is the maintenance of homeostasis, and when acute illness or chronic disease challenges this balance, kidney injury often follows. My patients are frequently those on the frontlines of social disadvantage, where poverty, housing instability, food insecurity and structural racism have all been shown to impact kidney health outcomes. Therefore, the same adversities that challenge their social balance challenge their physiologic balance as well.

Nephrology is a natural fit for the physician-advocate, and our field has been engaged in advocacy at every level since the inception of the specialty. The federal government's decision in 1972 to cover end-stage kidney disease as a Medicare benefit for which every American is eligible – including children – was made possible in large part to nephrologists' advocacy efforts.

Today, pediatric nephrologists play an important role in national advocacy efforts on behalf of children and families. In support of this contribution, the American Society of Pediatric Nephrology is one of a handful of pediatric sub-specialty organizations to sponsor an advocacy fellowship designed to teach pediatric nephrologists how to advocate for patients. Nationwide Children's Hospital has had several pediatric nephrologists participate in this program: Drs. Brian Becknell, John David Spencer, and I are all proud alumni of the John E. Lewy Fund Advocacy Scholars (JELF Scholar) program. As JELF Scholars, we learn to advocate for our most vulnerable patients in a variety of arenas. We engage in research advocacy by lobbying the National

“The kidney's primary role in the body is the maintenance of homeostasis, and when acute illness or chronic disease challenges this balance, kidney injury often follows. My patients are frequently those on the frontlines of social disadvantage, where poverty, housing instability, food insecurity and structural racism have all been shown to impact kidney health outcomes.”

– Ray Bignall, MD

Institutes of Health to increase funding for child health research priorities. JELF Scholars join the ASPN in meetings with regulatory agencies such as the Food and Drug Administration and the Centers for Medicare and Medicaid Services to ensure that children are considered in major policy decisions. As legislative advocates, we've traveled to the Ohio Statehouse, the United States Congress and the White House to push for policies and legislation that would advance population health and fight inequalities that adversely affect children and families.

I am immensely proud to be a part of one of the most socially engaged divisions of pediatric nephrology in America. Our faculty, staff and fellows partner with organizations such as the National Kidney Foundation and American Heart Association to raise awareness about kidney disease. We travel around the world to build pediatric nephrology programs in developing countries. We meet with government officials to advocate for our patients, families and colleagues. We direct multi-national research collaboratives such as the Pediatric Nephrology Research Consortium, which has radically improved our understanding of childhood kidney disease.

I often say that, because there are no chameleons practicing pediatric medicine, I'm pretty sure that none of us are able to change our skin tone to reflect the rich diversity of the patients for whom we are privileged to care. Thankfully, being an effective advocate doesn't require that. It simply takes a community of pediatricians dedicated to developing durable relationships through patient care, community engagement and outreach. And that's something all of us can do!



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Nation's First Clinical Trial for Pediatric Stroke Rehabilitation

by Mary Bates, PhD

Nationwide Children's Hospital is participating in the nation's first multicenter pediatric stroke recovery trial. The Phase III clinical trial, called I-ACQUIRE, will evaluate an innovative therapy to increase motor skills in 8-month-old to 24-month-old infants who have suffered a stroke. The team developed a novel form of pediatric movement therapy, adapted from a type of treatment for adults known as constraint-induced movement therapy.

PediatricsNationwide.org/Stroke-Trial



Exercise as Medicine: What Does This Really Mean?

By Alyssa Schafer

Physical inactivity is a problem for Americans. According to James MacDonald, MD, MPH, sports medicine physician at Nationwide Children's Hospital, physical inactivity is ranked as the number 4 cause of death. He suggests that prescribing exercise to pediatric patients can decrease the development of chronic illnesses by setting them up for a healthy life.

PediatricsNationwide.org/Exercise-as-Medicine



Medicaid Patients With Common "Buckle" Fractures Have Less Access to Primary Care Physicians

By Katie Brind'Amour, PhD

Limits in access to specialty orthopedic care exist for children with Medicaid, in a large part due to many practices not accepting government insurance. Although many orthopedic injuries can be safely and appropriately managed outside of the orthopedic office, a recent study found that less than half of 250 contacted pediatric primary care offices nationwide accepted Medicaid "buckle" fracture patients, and those that did were less likely to schedule Medicaid patients for care of a simple fracture within 7 days compared to patients with private insurance.

PediatricsNationwide.org/Medicaid-Buckle-Fracture

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Meet Oluyinka Olutoye, MD, PhD

In August 2019, Nationwide Children's welcomed Oluyinka Olutoye, MD, PhD, as surgeon-in-chief. In a Q&A, the internationally renowned fetal surgeon shares his thoughts about the past, present and future of fetal surgery and the challenges and opportunities facing pediatric surgeons today.

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