

..... Everything Matters In

Patient Care



Creating Best Outcomes:
for GU/GI Patients

At Nationwide Children's, we create Best Outcomes for patients thanks to multidisciplinary teams, like the Center for Colorectal and Pelvic Reconstruction.



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Pictured left: The Center for Colorectal and Pelvic Reconstruction (CCPR) is one of the first centers in the world to formally integrate all specialties involved in providing complete care of the colon, rectum and pelvis.

Inter-Disciplinary Work Creating Best Outcomes for Children with GU/GI Anomalies



Linda Stoverock
DNP, RN, NEA-BC,
Senior Vice President,
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According to an article published by Levitt and Wood, 2001, children born with anorectal malformations (ARMs) occur at approximately a rate of one in 5,000 live births. Additionally, children born with an ARM defect have a 25 to 30 percent probability of additional genitourinary congenital defects.

Surgeons at Nationwide Children's Hospital have a long-standing history of treating the various genitourinary and anorectal malformations. In the past four years, the Center for Colorectal and Pelvic Reconstruction (CCPR) at Nationwide Children's has grown and has been recognized internationally. This multidisciplinary team coordinates the care and follow-up of patients to improve continence, prevention of additional comorbidities and monitoring for long-term reproductive ability.

Many health care professionals orchestrate the coordination of care to ensure patients receive the highest quality of care in

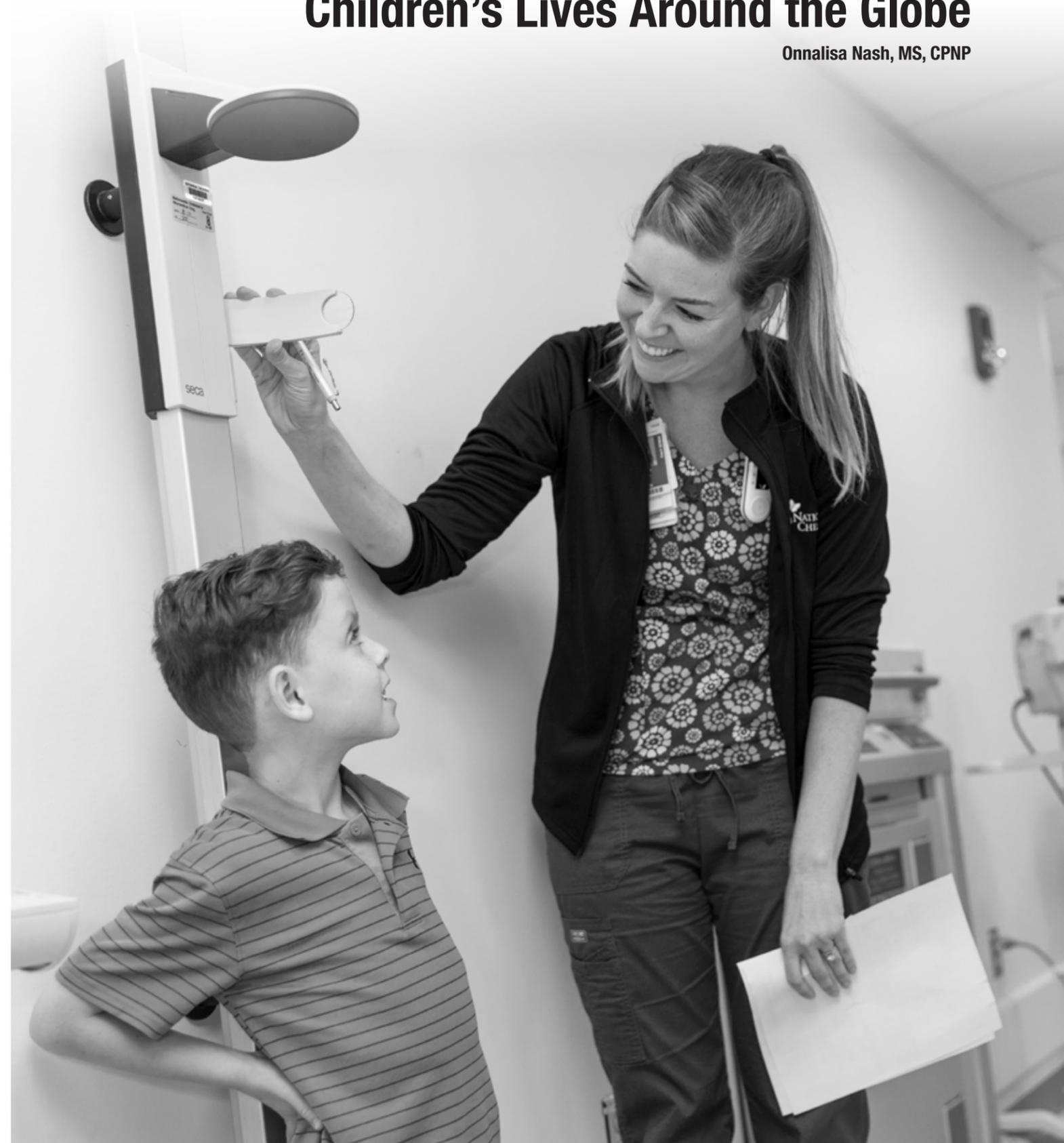
CCPR. This coordination begins prior to the arrival of a patient from another state or country and progresses through surgical interventions and post-surgery to continence management programs. The multiple success stories demonstrate the amazing teamwork and attention to detail by each professional. Outpatient, surgical services and inpatient units work together to coordinate care with patients and families to achieve best outcomes.

Since the beginning of the CCPR team, patients have been referred from 50 states and more than 11 countries. The team works to ensure the cultural needs and interpretive services are part of the process to providing a great experience. Their great work and outcomes are shared annually in international conferences to ensure their work benefits children around the world. Enjoy reading more details about our program in this issue of *Everything Matters in Patient Care*.

In the past four years, the Center for Colorectal and Pelvic Reconstruction (CCPR) at Nationwide Children's has grown and has been recognized internationally.

The CCPR Bowel Management Program: Improving the Quality of Children's Lives Around the Globe

Onnalisa Nash, MS, CPNP





The CCPR has had almost **3,000** patient inquiries from all 50 states and more than **70** countries.



CCPR staff fielded more than **13,000** phone encounters in 2017.



CCPR has welcomed **217** faculty visitors to learn about the center.

The Center for Colorectal and Pelvic Reconstruction (CCPR) at Nationwide Children's Hospital started in May 2014. It is a specialty center for patients with anorectal malformation, Hirschsprung disease (absence of ganglion cells and presence of hypertrophic nerves), neurogenic bowel and severe functional constipation. CCPR is one of the first centers in the world to formally integrate all specialties involved in providing complete care of the colon, rectum and pelvis in children by joining surgeons and specialists from the fields of Colorectal Surgery, Gastroenterology, Gynecology, Urology and many other collaborating providers.

The need for such a center was enormous. Anorectal malformation and Hirschsprung disease affect about 1 in 5,000 babies born each year worldwide. Thousands of children have bowel troubles related to spinal issues, and functional constipation affects as many as 1 in 10 children in the United States. Since its inception, the CCPR has had almost 3,000 patient inquiries from all 50 states and more than 70 countries.

The center has cared for more than 1,500 patients at Nationwide Children's and three-quarters of these patients live outside the state of Ohio. In 2017 the staff fielded more than 13,000 telephone encounters. The center also draws the attention of medical teams from around the country and the world. Each month the CCPR hosts faculty from outside hospitals who come to visit and learn about the center and the bowel management program. The center has welcomed 217 visitors from around the country and the world, including 22 different countries and 11 U.S. children's hospitals.

The CCPR is a surgical center; however, the patients diagnosed with the illnesses described may experience lifelong effects on their motility and continence after surgery and require skilled care. These patients are often desperate for help as few centers across

the world specialize in the long-term care and treatment of this patient population. The bowel management program (BMP), offered at the CCPR, is a week-long outpatient program to treat constipation, hypermotility and fecal incontinence. The week is comprised of three clinic visits, six consecutive days of abdominal X-rays and patient reports are reviewed daily. The goal of the program is finding a regimen that achieves social continence and allows the patient to resume normal daily activities and wear normal underwear.

The BMP week begins with a nursing led educational session for parents, while the patients attend a session facilitated by the psychosocial team comprised of licensed social workers and Child Life specialists. Social bonding and interaction is encouraged and facilitated for both the parents and the patients. Many families report this is the first opportunity they have had to meet others living with the same challenges. Often, lifelong friendships are forged.

The next day, each patient has a clinic visit with a colorectal surgeon or advance practice nurse practitioner who determines the treatment they will need. This first clinic visit is preceded by a contrast enema to evaluate the anatomy of the colon. The treatment plan is individualized to the patient based on diagnosis, age, current symptoms and previous therapies tried. Patients are placed on either a medical regimen (laxatives) or a mechanical regimen (enemas or flushes). The team of colorectal surgeons, nurse practitioners and nurse clinicians meet each day to review the X-rays and discuss parent reports. The team works together to determine the patient's plan for the next day. The nurse clinician then communicates the plan to the parents. The patients are seen midweek in clinic after obtaining their daily abdominal X-ray. The last day of the program is a final clinic visit where the patient is sent home with a daily bowel regimen that empties their colon

and keeps them clean. Additional sessions throughout the week are facilitated by the psychosocial team along with the center's psychologist.

The team vividly remembers one such case: An eight-year-old boy was told at the end of the week, he would be clean and dry and in normal underwear. He was doubtful. At the end of the week, he walked in proudly and said: "You make good promises!" The program truly impacts patient's quality of life in a very significant way.

Upon completion of the intense bowel management "boot camp" week, patients are scheduled for follow-up at routine intervals. Each patient is scheduled for a one-month

"You make good promises!"

and three-month clinic or telephone visit. Finally, the patients return to the clinic annually for a comprehensive assessment and to meet with our collaborative team. The information from the assessment allow us the opportunity to look at the objective data related to our patient outcomes.

Bowel Management Program



DAY 1

- Nursing led educational session for parents.
- Patients attend a session facilitated by the psychosocial team comprised of licensed social workers and Child Life specialists
- Social bonding and interaction is encouraged and facilitated for both the parents and the patients.



DAY 2

- This first clinic visit is preceded by a contrast enema to evaluate the anatomy of the colon.
- Each patient has a clinic visit with a colorectal surgeon or advance practice nurse practitioner who determines the treatment they will need.
- Patients are placed on either a medical regimen (laxatives) or a mechanical regimen (enemas or flushes).



DAYS 3-6

- The team of colorectal surgeons, nurse practitioners and nurse clinicians meet each day to review the X-rays and discuss parent reports.
- The team works together to determine the patient's plan for the next day.
- The nurse clinician then communicates the plan to the parents.
- The patients are seen midweek in clinic after obtaining their daily abdominal X-ray.



DAY 7

- A final clinic visit at which the patient is sent home with a daily bowel regimen that empties their colon and keeps them clean.

Psychosocial sessions are throughout the week and are facilitated by the psychosocial team and the center's psychologist.



Regardless of the type of follow-up visit (in-person or telephone), the families obtain an abdominal X-ray image and any other appropriate testing in preparation for the visit. If the child is found to be unsuccessful with their current regimen at any time throughout the follow up process, the family is encouraged to reach out to the center as soon as possible so an improved regimen can be achieved. About 30 percent of patients require surgical intervention after bowel management to improve their bowel regimen with either an antegrade option for flushes and/or a colon resection based on colonic manometry studies.

The bowel management program, developed by the CCPR, has successfully helped change the lives of children across

the country and the world. The program is possible because of a dedicated leadership team and committed staff who spend endless hours at clinic visits, on phone calls and emails to families who previously thought there was no hope. Now there is a solution to their child's incontinence.

Our success stories include kids who, like Dalten, (read his story on the next page) can now play sports and go to sleep overs without the fear of embarrassing social situations. Our families come to us with very few resources or support in their lives, and leave our center with a team of experts ready to support their child and their family for the rest of their lives.

Meet Dalten



Dalten is a 7-year-old boy from Texas with a history of anorectal malformation. An anorectal malformation (also known as imperforate anus) occurs when a child is born without an anal opening or with an opening in the wrong location. Dalten had his surgery as an infant, but struggled with constipation and daily soiling. His parents sought help from their local providers, but no one seemed to know how to help. One day, Dalten's mom was searching online and came across a YouTube video of Dr. Marc Levitt describing the bowel management program at CCPR. She immediately reached out to the center and completed the initial intake process. Dalten needed a comprehensive workup upon his arrival because

there were gaps in his medical history of known associated malformations that had yet to be assessed and treated. While Dalten's family initially reached out for bowel management to help with soiling, they received much more. His mother described the care he received as:

“Without the awesome staff this wouldn't have become reality. What was once false hope is now an answered prayer. Just by attending the program and all of the investigating of his anatomy, [Nationwide Children's] found muscles we were told he didn't have. And then [Nationwide Children's] fixed him giving him a chance at normalcy.

The entire Colorectal program is outstanding. Who will stay on the phone for two hours with a parent just to make sure every question they have is answered? Who will contact your child's school and help make sure they are in the right education program? Who does everything possible to lighten the load of costs to get to Columbus? Who makes your child feel at ease and beyond welcome? The CCPR doctors, nurses and staff. The absolute care and respect we received before ever arriving in Columbus is exactly why we knew this is where our son needed to come. And it is the best decision we as parents have ever made. Without this program we would have never found Dr. Leonard and never knew Dalten had a tethered cord that needed to be repaired. It was never even mentioned by anyone at home. Nor that he was missing parts of his sacrum or coccyx. We would have never found Dr. Grischkan and known we could potentially ease his breathing by bringing Cardiac surgery on board because an artery from Dalten's heart is compressing his trachea. All of these things more than likely would have gone unnoticed. Thank you for creating a program that is not only fixing our child but thousands of others!”

Non-operative Management of Simple Appendicitis

Nicole Jenkins, RN, MSN NP-C, Nurse Practitioner Clinical Leader Pediatric Surgery

Each year, the Pediatric General Surgeons at Nationwide Children's Hospital operatively treat an average of 600 cases of appendicitis. Of these cases, approximately 70 percent are uncomplicated or simple acute appendicitis. The remainder of appendicitis cases are complex or ruptured appendicitis.

There are two treatment options for children diagnosed with simple appendicitis. A child can have their appendix removed surgically or treated non-operatively with antibiotics. In the past, the treatment for simple appendicitis was operative management only. Families did not have the option to choose non-operative management.

With advances in health care and research, the options for management of appendicitis have greatly expanded. Researchers at Nationwide Children's and The Center for Surgical Outcomes participated in a multi-site study involving non-operative management of uncomplicated or simple appendicitis in the pediatric population. Katherine Deans, MD and Peter Minneci, MD, both skilled pediatric surgeons and researchers, lead this investigation at Nationwide Children's.

There are several different inclusion criteria to be able to participate in the non-operative appendicitis study. This ensures maximum patient safety while minimizing the risk of a missed diagnosis of complex appendicitis. The children must have imaging consisting of an ultrasound or CT scan demonstrating a non-ruptured appendix, no abscess or phlegmon. The diameter of the appendix must be less than 1.1 cm. There should be no evidence of appendicolith or fecalith, which is calcified stone consisting of feces and minerals located within or outside the appendix. Children must have symptoms for less than 48 hours, need to be between 5 and 18 years of age, and have a white blood cell count of less than 18.

If a child meets these qualifications, a physician from the research team will come and speak with the family regarding the risks and benefits of both surgical and non-operative management. Current statistics regarding the success/failure rate of patients who have chosen the non-operative arm of the study will also be discussed. The family chooses between antibiotic therapy alone or operative intervention to have the appendix removed.

If non-operative management of simple appendicitis is chosen, the child is treated with intravenous antibiotic therapy of either Piperacillin-Tazobactam® or Ciprofloxacin®. Metronidazole® is prescribed for children with a penicillin allergy. The antibiotic is administered for a minimum of 24 hours. During this time, the child remains NPO and the physicians, advanced practice nurses and nursing staff routinely assess symptoms.



If the child's symptoms worsen or the child fails to improve with intravenous antibiotics alone, a decision is made on whether or not an appendectomy is warranted. If symptoms improve after 12 hours, the patient's diet advances, even though the child may still experience some abdominal pain. The child will continue to be monitored over a 24 hour period and will continue on IV antibiotics. After 24 hours of successful IV antibiotic treatment and advancement of diet, the child is discharged home on an oral antibiotic either Amoxicillin®, Clavulanic Acid® or Ciprofloxacin® and Metronidazole® if penicillin allergy to complete a total of seven days of therapy. Prior to discharge, thorough patient and family education is given regarding the importance of completing the antibiotic regimen and the signs and symptoms to monitor to determine if the appendicitis returns. If the child does return with recurrent appendicitis, the appendix is removed.

After discharge from the hospital patients are followed by the study team via a phone call or email. The study team follows them at day two through five, 10 through 14, one month, six months, one year, then annually after discharge. These preliminary findings of this study are encouraging.

The potential benefits of avoiding an operation in this pediatric population are very positive. Children avoid potential complications of surgery which can include bleeding, infection, postoperative ileus or bowel obstruction and postoperative nausea and vomiting. Potential complications of anesthesia are avoided as well. No opioids are prescribed upon discharge and minimal, if any, they are administered during the hospital stay. Moreover, patients may return to normal activity and competitive sports sooner as compared to patients who have undergone a laparoscopic appendectomy.

Treatment Options for Simple Appendicitis



Surgical



Non-operative

Medical Child Abuse

Kristin Garton Crichton, DO, MPH, Child Abuse Pediatrician, Nationwide Children's Hospital, Child and Family Advocacy

Medical Child Abuse (MCA) occurs when a child receives unnecessary medical care that is harmful or potentially harmful based on a caregiver's actions, which may include exaggeration of the child's symptoms, fabrication of the history or physical findings, or purposeful induction of symptoms in the child. MCA has been described using many different terms, most commonly "Munchausen syndrome by proxy."

MCA is the preferred term as it focuses on the possible harm to the child regardless of the perpetrator's intentions. Like other forms of child maltreatment, MCA manifests in many ways and varies in severity. For example, a victim of MCA may be subjected to unnecessary diagnostic imaging or blood tests, be prescribed unneeded medications, or undergo major surgery based on the history provided by the caregiver.

While limited evidence exists on the epidemiology of MCA, research has demonstrated that victims of MCA are typically younger than 5 years old, true medical illness frequently coexists, and victims of MCA often have complex medical presentations with multiple symptoms being reported by the caregiver. Unlike other forms of abuse, in MCA the child's mother is usually the perpetrator and perpetrators often have medical knowledge.

Identification of MCA is challenging and it typically takes time for the medical provider to recognize a pattern of the caregiver reporting symptoms that are not objectively seen. Common features of MCA include the caregiver's history varying from the provider's observations of the child, symptoms only observed in the presence of the caregiver, varied histories provided by different caregivers, and recurring symptoms that are persistent, unexplained or atypical and do not respond to interventions as expected. Victims of MCA undergo many medical evaluations and procedures without improvement of symptoms and are often seen by multiple subspecialists. In cases of induction of

symptoms, the victim's clinical presentation will improve with removal from the perpetrator's care. Amongst cases of MCA seen by the Child Assessment Team (CAT) at Nationwide Children's Hospital, gastrointestinal symptoms such as diarrhea and anorexia and neurological symptoms such as seizures are commonly described in children who are ultimately found to be victims of MCA.

Diagnosis of MCA depends on the provider's recognition the caregiver is exaggerating, lying about or inducing symptoms in the child which is leading to harmful or potentially harmful medical interventions thus causing the provider to become an unwitting part of the abuse. Once the concern for MCA has arisen, providers should document the caregiver's history as compared to their own objective findings and results of diagnostic testing.

The CAT can be consulted to help with a thorough review of the history to determine if a suspicious pattern of unnecessary medical care based on caregiver's assertion of symptoms exists. Our team will facilitate a multidisciplinary meeting with all providers involved in the child's care to get consensus on appropriate medical care for the child. If MCA is identified, a report to child protective services (CPS) is mandated and is made in collaboration with the providers who have been involved in the child's care. The caregiver is typically informed of the concern and that a CPS report was made, provided the child's safety can be ensured. Next steps include securing a safe environment for the child with the guidance of CPS, removing unnecessary interventions, such as medications or a feeding tube, continued monitoring of the child with good communication between medical providers, and providing family support to help rehabilitate the perpetrator.

Pediatric Sepsis: Early Recognition and Intervention Saves Lives

Erin Ahrens, BSN, RN, Informatics Services, Clinical Informatics
Kathryn Nuss, MD, Division of Clinical Informatics



Suspect Sepsis

Stop & Resolve

.....
provider education resources to achieve life-saving results.

At Nationwide Children's, with the leadership of Mark Hall, MD, Division Chief Critical Care Medicine, and Michelle McKissick, Vice President Clinical Services, our multidisciplinary sepsis steering committee is the driving force for a hospital-wide sepsis program. Initiated in 2016, our program sought to deploy standard screening tools and treatment bundles in a series of department based implementations. In alignment with the national IPSO collaborative, we have opted to cycle implementations based on five clinical care areas including the emergency departments, general medicine and surgical inpatient units, oncology inpatient units and the pediatric intensive care units.

The sepsis program began its first department-based implementation during spring 2017. We carefully chose to focus initial screening and intervention efforts in the Emergency Department (ED). Our main campus ED is one of the busiest pediatric emergency departments in the nation, with nearly 90,000 emergency visits a year. In addition, the ED serves as the primary entry point of health care for most of our hospitalized patients. Historically, at Nationwide Children's, more than 90 percent of patients with severe sepsis meet clinical criteria during their time in ED.

Like our peers across the nation, analysis of clinical data reflected our struggle with early and accurate identification of severe sepsis. The high census and high acuity patient care environment of the ED further complicates detecting severe sepsis among many non-

Each year, more than 75,000 children in the United States develop severe sepsis. Studies suggest approximately 6,800 children will die from sepsis annually – more than pediatric cancers. But sepsis is treatable, especially with early recognition and intervention. At Nationwide Children's Hospital, we work with other national experts to raise awareness and save children's lives.

Sepsis is a clinical condition resulting from systemic inflammatory response in the presence of an infection. Children with sepsis are at risk for deterioration due to rapid onset of severe sepsis or septic shock. Vital sign instability and physiologic markers of organ dysfunction are key signs of severe sepsis and septic shock. Studies have shown mortality increases by 8 percent with every hour in delay of sepsis treatment. Early identification of severe sepsis, followed by prompt treatment interventions, are critical to reducing sepsis related mortalities. Nationally, sepsis identification tools have focused on adult-based screening models. Despite increased efforts in the last decade, a pediatric screening tool that provides high accuracy for sepsis identification has yet to be developed. Faced with the challenge at hand, Nationwide Children's and more than 50 other institutions have joined together to improve pediatric sepsis identification and intervention efforts.

Nationwide Children's Chief Medical Officer, Richard Brill, MD, is a national co-chair of Improving Pediatric Sepsis Outcomes (IPSO). IPSO is a quality and patient safety collaborative of Children's Hospital Association. Under the guidance of Dr. Brill and more than 60 pediatric sepsis experts across the nation, the collaborative seeks to reduce pediatric sepsis mortality and hospital onset of severe sepsis. Participating children's hospitals of IPSO are using data driven quality improvement methods to develop sepsis-screening tools, evidence based treatment bundles and

Each year, more than
75,000
children in the U.S.
develop severe
sepsis

Approximately
6,800 children
will die from
sepsis annually



septic patients with abnormal vital signs. During the upcoming fall and winter months, many children will present to our EDs with fever, tachycardia and concern for infection. However, only one in every 300 patients in the ED will have severe sepsis, requiring admission to the pediatric intensive care unit.

Our emergency department nurses are on the front line of early sepsis detection. In a systematic manner, these nurses collect pertinent information to the patient's presenting complaint, complete a patient assessment and escalate findings to the provider team. In 2015, the ED adopted a sepsis identification tool from the Pediatric Septic Shock Collaborative of the American Academy of Pediatrics to aid sepsis screening efforts. This tool provides vital sign and

clinical assessment parameters concerning for severe sepsis or septic shock. During initial and subsequent patient assessments, the ED nurse applies the tool for at risk patient populations. However, this manual application of the tool was suboptimal in supporting nurses' quick synthesis of clinical data during patient assessments in our fast-paced ED environment.

Our sepsis team recognized the need for an innovative approach to support providers, regardless of experience and environmental influences in early sepsis detection. In collaboration with the Clinical Informatics and Business Intelligence teams, our sepsis program set out to create an automated pediatric sepsis screening tool in the electronic health record (EHR). With the goal of minimizing provider

Automated Pediatric Sepsis Screening Tool Process



AUTOMATED PEDIATRIC SEPSIS SCREENING TOOL IN EPIC

Automatically analyzes patient specific information to identify increased risk for sepsis in Epic™.



BEST PRACTICE ADVISORY (BPA)

The BPA from the monitoring tool alerts the bedside nurse and provider to the patient's relevant risk factors for sepsis.



BEDSIDE SEPSIS HUDDLE

The ED clinical team then perform a bedside sepsis huddle to establish a plan of care.

workflow disruption and maximizing use of patient data entered in Epic™, our team designed a robust, automated monitoring system. The electronic sepsis-screening tool automatically analyzes patient specific information such as medical history, problems and home medications to identify patients at increased risk for sepsis. Children with malignancies, immunosuppression, and those dependent on devices such as ventilators and central lines are at increased risk for developing sepsis. Throughout the patient's ED visit, the tool constantly monitors routine patient observations such as vital sign entries and assessment findings. When the monitoring tool determines the risk-screening threshold has been met, the bedside nurse and provider receive a Best Practice Advisory (BPA), alerting the team to the patient's relevant risk factors for sepsis. The ED clinical team performs a bedside sepsis huddle. The huddle process

has shown to be an effective method of conducting and communicating a multidisciplinary patient assessment. During the sepsis huddle, the ED team establishes a plan of care with prioritization placed on interventions such as fluid and antibiotic administration.

To validate the automated tool for sepsis would perform as well as providers manually screening a patient's risk for developing severe sepsis, we deployed our automated pediatric sepsis-screening tool in Epic™ behind the scenes of our clinical staff. In an eight-week study period, our automated tool identified all patients that ED providers identified with severe sepsis. Notably, the automated screening tool accurately identified these patients, on average, 68 minutes early than providers using the manual process. With confidence in our ability to deploy an automated sepsis-

monitoring tool in the EHR, the BPA and subsequent huddle documentation tools were implemented in July 2017. Since the implementation, our ED team has identified a nearly two-fold increase in septic patients, while working to decrease the overall mortality rate.

This month, the inpatient sepsis team will deploy a similar automated screening tool designed for optimal performance on patients admitted to inpatient units outside of the intensive care units. In collaboration with several medical services including Hospital Pediatrics, Infectious Disease and Oncology, our informatics and data analytics team members sought to design a screening tool that would be specific for acute, early onset deterioration due to sepsis. In March, the inpatient sepsis-screening tool was implemented as part of a small pilot study on the infectious disease and general medical inpatient units. Our sepsis team sought to determine the automated tool's performance and inpatient provider interaction with a bedside sepsis huddle. Through learnings of this study, our inpatient team has optimized the tool's performance and designed a series of Epic tools to support provider interaction with sepsis screening and treatment interventions.

Recognizing the distinguishing features of patients with early onset severe sepsis can be a complex process, requiring astute observation, assessment skills and role experience. Implementation of a computerized monitoring system supports bedside staff in rapid synthesis of documented information in Epic. These



systems can empower bedside staff with relevant risk factors for deterioration due to sepsis, while doing so promptly to determine appropriate interventions.

Our innovation and diligence to this important effort at Nationwide Children's is setting national precedence. Our emergency department pediatric sepsis-screening tool has become a foundational tool of Epic™ Systems Corporation. Our work at home has provided opportunities for institutions across the nation to increase timely detection and rapidly intervene – to save lives of children.

Learn more about the signs and symptoms of pediatric sepsis and our effort to develop innovative screening and interventions tools by visiting [ANCHOR](#) and searching Sepsis.

Stool Colors Decoded

Steven L. Ciciora, MD, Attending Physician, Gastroenterology, Hepatology and Nutrition

Imagine the shock a parent must feel when their child says his poop is pink. Or red. Or blue. While normal stools are usually brown, green or yellow, there are reports from around the world of oddly colored poops due to uniquely colored foods and food additives.

To understand peculiar stool colors, especially in babies, it is helpful to know why stools are the color they are. Stools are normally brown due to bilirubin. Bilirubin is made in the liver and is a byproduct of hemoglobin degradation. Bilirubin starts off as a greenish-yellow liquid produced in the liver. From there, it is secreted into the small intestine via the bile ducts with meals. Some bile is also stored in the gallbladder as well.

As it travels through the intestine, bilirubin is broken down by bacteria in the gut to produce urobilinogens and urobilins. These compounds cannot be reabsorbed by the intestine. They will stay inside the intestine and colon and eventually be eliminated in the stool. One hemoglobin metabolite produced in this microbe driven process, stercobilin, is what gives stools their characteristic brown color. As infants have less diverse bacteria in their intestines than older children and adults, they are more likely to resorb bilirubin from their intestine. Different pigments can be seen in the stool of infants (think of the yellow, seedy stool of a newborn) versus adults.

If bilirubin is unable to leave the liver due to a blockage of the bile ducts (due to a gallstone for example), stools will turn white, which is always something that should be addressed. Since it is not excreted from the liver into the intestine, bilirubin accumulates in the body leading to jaundice and an elevation in direct bilirubin.

While intestinal bacteria and bilirubin metabolism contribute to the routine brown stool we see in children and adults, certain food dyes and naturally occurring colors cannot be broken down by the body and may produce oddly colored stools. If food dyes are only partially broken down, peculiar colors may come out in the stool as well. From beets to cranberries to cereals to candies to hamburger buns, numerous foods have all been associated with weird stool colors.

Surprisingly, some medicines prescribed by providers can actually turn stool certain colors. The oral antibiotic cefdinir is notorious for turning stools a brick-red. Likewise, over-the-counter Pepto-Bismol™ and oral iron preparations can make stools black. It is important to note these color changes are temporary. When the medicine is stopped or the offending food is out of the child's system, the stools should return to a normal brownish color.

Poop Consistencies

Infant poop is typically on the softer side. If your infant has watery or hard poop, consult your pediatrician. Toddlers have a broader range of poop consistencies. Here are some things to watch for:



CORN ON THE COB

These are considered an **ideal consistency** for poop.



SNAKE/SAUSAGE



BUNCH OF GRAPES



RABBIT DROPPINGS

These types of poop are hard to pass and may indicate your child has constipation.



GRAVY



PORRIDGE



CHICKEN NUGGETS

These looser stools may happen from time to time, especially during a diarrheal illness. They may be seen with irritable bowel syndrome or inflammatory bowel disease.

It's icky, but we all do it. What's normal when it comes to baby and toddler poop? You've probably seen more than one color and consistency. But what do all those different types of poop mean? Don't worry, we've got you covered.



Baby poop



Toddler poop

YELLOW-BROWN: Common in breast-fed babies and toddlers. Loose and seedy.

BROWN: Pasty and light brown is common in formula-fed babies. This is a normal color for toddlers.

GREEN-BROWN: Breast-fed babies can have poop that is green-brown to yellow-brown.

GREEN-BLACK: Color of babies' first stool after birth. Contains meconium.

GREEN: Babies and toddlers who eat large amounts of spinach, green JELL-O® or iron supplements can have green poop.

CONCERNING COLORS

WHITE OR PALE: Persistent white or lightly colored stool may indicate an issue with the ducts in the liver.

BRIGHT RED: Call your doctor because this can be consistent with blood that is coming from the intestines, but not always. Has your toddler eaten beets, tomatoes, cherry JELL-O® or Kool-Aid®? If it has red food dye in it, expect the poop to look the same.

BLACK: Toddlers who eat dark foods like Oreo® cookies, licorice or grape juice can have very black poop.

RED STREAKS: May indicate blood in stool.

Complex Bladder Augmentation: What All Medical Personnel Need to Know

Cheryl G. Baxter, MSN, RN, Pediatric Nurse Practitioner, Center for Colorectal and Pelvic Reconstruction



Congenital anatomic abnormalities in the genitourinary tract (GU) are more common than those of any other organ system. The congenital malformations of the GU tract include patients with spina bifida, anorectal malformations, posterior urethral valves and bladder exstrophy. Acquired bladder problems can also occur with spinal cord trauma and spinal tumors. Another group of patients without GU anatomic abnormalities or acquired bladder issues are patients who have cerebral palsy, muscular dystrophy

and other neurological conditions. All of these problems are often referred to as a neurogenic bladder.

A neurogenic bladder is the terminology used to define dysfunction of the urinary bladder that lacks normal innervation from the central nervous system. Congenital anatomic abnormalities in the GU and neurogenic bladders can lead to chronic renal disease. Advances in medical and surgical management of the bladder are cited as the major factor in reduction of chronic

renal disease. End-stage renal disease (ESRD) has been reported in 15 percent of myelomeningocele patients and the mean age for transplantation in this patient population is 27 years of age as of 2010.

One of the first lines of medical management to guard against renal damage is the implementation of clean intermittent catheterization (CIC) to regularly empty the bladder. CIC inevitably results in the introduction of bacteria into the bladder, which can result in persistent colonization and potential increased rates of urinary tract infections. The concept of CIC was introduced by David Lapedes, MD in 1972 and remains the gold standard of the management of neurogenic bladders. Surgical interventions such as a bladder augmentation, bladder neck reconstructions and Mitrofanoff catheterizable channel have resulted in an increased number of persons with a neurogenic bladder becoming continent of urine and decreased ESRD in the populations of neurogenic bladders.

A bladder augmentation cystoplasty is a surgical procedure utilizing the intestine to increase the size of the bladder. This may be needed in children and adults who lack an adequate bladder capacity or who have a problem with the bladder muscle expanding, which may lead to poor compliance. Poor bladder compliance can cause increased pressure in the bladder, which can lead to upper tract deterioration resulting in chronic renal insufficiency. Persistent urinary incontinence may occur in those whose bladder capacity is inadequate or have an ineffective sphincter mechanism.

One significant complication of a bladder augmentation cystoplasty is a bladder perforation. In a population of patients who often have impaired sensation of the lower extremities including the bladder, a bladder perforation can result in a significant rate of morbidity and mortality. To prevent bladder perforation, individuals should schedule bladder emptying per CIC every three to four hours and before any sporting activity. Older patients should limit their alcohol consumption.

One of the most challenging areas in pediatric and adult urology is patients with inadequate bladder neck closures during bladder filling. Normally, the bladder neck must remain closed during storage of urine for continence. In children with neurogenic bladders, surgical reconstruction may be undertaken to improve urinary continence.

Bladder neck incompetence can be improved with bladder neck reconstruction (BNR) procedures. If a BNR is done, a mechanism for catheterization other than the native urethra is surgically created. The creation of a catheterizable channel is often referred to as a “Mitrofanoff.” Paul Mitrofanoff, professor and pediatric surgeon, developed the operation in 1980, and it is referred to as a continent catheterizable channel. The appendix is typically used and acts as a conduit between the bladder and the abdominal wall, creating a continent valve. The continence is created by tunneling the appendix through the wall of the bladder approximately four to five centimeters. As the bladder fills, the pressure of the bladder wall compresses the channel and continence is maintained. CIC is then performed in a similar manner as urethral catheterization every three to four hours.

If the appendix is not available, a portion of the ileum is used and this is referred to as a Monti channel. Paulo Monti developed this procedure in the 1990s. Once BNR has been performed, a patient is no longer able to catheterize per urethra due to risk of damage to the repair. It is important to educate the patient, families and medical care providers of the need to perform CIC per catheterizable channel (Mitrofanoff, Monti) and not the native urethra.

The patient and the families are your best resource for determining the correct size and type of catheters to access a catheterizable channel and when not to perform urethral catheterization. You can also refer to the problem list in Epic™ which can guide you to a Best Practice Advisory for an individual patient.

Gastrointestinal Dysfunction in Children with Autism

Kent Williams, MD, Director of Endoscopy, Assistant Professor of Pediatrics, Division of Pediatric Gastroenterology, Hepatology, and Nutrition

Gastrointestinal (GI) symptoms are common in children with Autism Spectrum Disorders (ASD). Exactly what percentage of children with autism suffers from GI symptoms is unclear. Published rates of GI disorders in Autism range from 9 to 91 percent. This wide range is due to how the various studies survey and define GI disorders in children with autism. However, a meta-analysis of various studies on the occurrence of GI symptoms in children with autism indicates GI symptoms occur at a higher rate in children with autism as compared rates of GI symptoms in neuro-typical children or children with other developmental disorders.

The most common GI disorder in children with autism is constipation. A chart review of 726 patients indicates that constipation is diagnosed over half of patients (about 55 percent) referred to the Autism GI Clinic at Nationwide Children's Hospital. Nausea/vomiting (6.5 percent), abdominal pain (5.6 percent) and reflux (5.1 percent) were the next most common diagnoses in this clinic.

The causes of GI disorders in children with autism are unclear. Various studies indicate that GI disorders are highly associated with many of the behaviors and traits that occur in children with autism. Rigid compulsive behaviors and sensory disorders have been known to be associated with GI disorders in neurotypical children. Studies of these behaviors and disorders in those with autism indicate that an increase in rigid compulsive behaviors and increased over responsiveness are associated with an increase of GI symptoms in children with autism. These findings would indicate that the neurobehavioral changes associated with autism are also associated with an increase incidence of GI dysfunction, particularly constipation.

Studies of microbiome in the gastrointestinal tract of autistic children indicate that type and amount of bacteria in the GI tract of children with autism

differs from those without autism. A study performed at Nationwide Children's found not only does the microbiome differ, but the microbiome may differ between children with autism who have abdominal pain from those with autism who do not have abdominal pain.

This study also found the changes of microbiome in children with autism are associated with differences in serotonin signaling pathway and cytokines that may affect neuronal activity. This study indicates ways microbiome may help identify children with abdominal pain and how changes in microbiome may cause changes in behaviors commonly seen in children with autism, such as anxiety, rigid compulsive behaviors and/or sensory disorders. Currently, studies at Nationwide Children's are looking to better clarify what microbial changes are associated with various GI disorders in children with autism and whether microbiome focused therapies could help improve ASD behaviors, particularly anxiety.



Reducing Pressure Injuries: The Results of Team Approach

Stephanie Stafford, MSN
Brenda Ruth, RN, BSN, CWON

In 2008, every child at Nationwide Children's Hospital was assessed head to toe for skin injuries. In a single day, 44 skin injuries from pressure were found. A pressure injury reduction committee formed in response to the high number of injuries and the hospital's commitment for zero harm beginning in 2009. This multidisciplinary team, led by Michelle Mckissick, MSN, RN, Vice President Clinical Services and Michelle Miller, MD, Chief of Physical Medicine, assembled in-house experts and key stakeholders with the goal of decreasing preventable harm from pressure injuries to zero. Key members included Leah Keller, BSN, RN, Quality Improvement Analyst (2009 to 2015), Stephanie Stafford, MSN, RN, RNC-NIC, Quality Improvement Analyst (2016 to 2017), and Brenda Ruth, BSN, RN, CWON, Wound Ostomy Specialist. The team investigated and developed initiatives and evidence-based strategies to reduce these injuries.

Early work of the team established successful reporting of Stage 2-4, unstageable and deep tissue injuries as well as institution of a modified Braden-q risk assessment. The team taught and empowered individual unit skin champions to perform weekly skin rounds and audit compliance of a pressure injury prevention bundle. These interventions allowed for prevention and assessment education to spread to all staff throughout the hospital. The initial annual survey conducted in 2008 changed to a quarterly survey in 2011. Brenda Ruth and Leah Keller initially led this change and every patient in the hospital is still surveyed once a quarter with our results being benchmarked with other similar hospitals for Magnet® re-designation.

Over a time span of three years, the team focused on early recognition of injuries caused by medical devices. They continued to assess the cause of injuries and developed small teams to intervene. These teams centered on CPAP injury prevention in our NICUs, tracheostomy injury prevention and nasogastric tube injuries system wide. Specific interventions included:

- Creation of a task force with Jennifer Aldrink, MD, General Surgery, to look at Pressure Injuries from NG tubes and how they are secured all over the hospital.
- Implementation of the Fisher-Paykel bubble CPAP in all NICUs.
- Implementation of MarPac trac ties across the institution as standard of care, and daily rounding for new tracheostomies and tie changes.
- Implementation of guidelines for daily assessments and dressing changes for G-tubes, especially during the first seven days post-op to assess for device pressure injury from post-op swelling.
- Development of a Pressure Injury Prevention Bundle, which includes: turning patients, proper bed and bed surfaces, padding and rotation of devices, moisture management for incontinent patients.

These efforts reduced Stage 2 injuries from
0.78 INJURIES PER 1000 PATIENT DAYS
..... to
0.6 INJURIES PER 1000 PATIENT DAYS

The results of these efforts were a significant reduction of Stage III injuries from a rate of 0.1 injuries per 1000 patient days to 0 for a 28 month span. There was also a reduction of Stage 2 injuries from 0.78 injuries per 1000 patient days to 0.6 injuries per 1000 patient days. For their efforts and successes the Pressure Ulcer Reduction Team was awarded the J. Terrance Safety Award for Safety.

Inflammatory Bowel Disease: A Piece of Chronic Illness Management

Jennifer Smith MS, RD, CSP, LD, LMT, Clinical Nutrition and Lactation
Marci Johnson, LISW-S, Clinical Social Work

Pediatric inflammatory bowel disease (IBD) describes chronic inflammatory disorders of the gastrointestinal tract in children and adolescents known as Crohn's disease, ulcerative colitis and indeterminate colitis. Managing this diagnosis is more than monitoring bowel movements, taking medications and coming in for office visits. IBD can involve many aspects of life including nutrition and school.

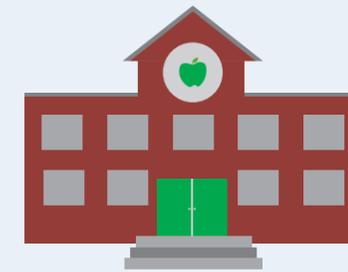


Nutrition

Nutrition is important for the growing child and teen. Eating a proper diet can help to improve poor or under nutrition from inflammation, poor appetite or other deficiencies which may occur as part of IBD.

Outside of eating well for optimal growth and nutrition, children and teens with Crohn's disease can use nutrition as primary treatment. Nutrition therapy or enteral therapy, as it is commonly called, has been proven to be effective in inducing remission. It is an all or mostly liquid diet which it typically done for three months, although some children choose to do nutrition therapy for longer than three months. Most choose to drink all of their requirements; however, if that is too difficult, nasogastric feeds can be done during the night. Having a different diet than peers can present a challenge, but the dietitians at Nationwide Children's Hospital work with our patients on

nutrition therapy to provide alternatives to social situations which would typically focus on eating. Children and teens in our program are able to eat a small amount of food, typically between 150 to 250 calories per day, along with the liquid diet of nutrition shakes, and are given information on how to make the most of these calories. Depending on the individual, they may choose to have a small packed lunch at school, along with a snack or a small dinner with their family. They are taught how to read labels to count calories and are given a cookbook created by the dietitians at Nationwide Children's. We offer additional support through a closed social media group which shares recipes for foods, ways to change up the flavor of the nutrition shakes, non-food related activities, and words of encouragement. By giving these options and support our patients can treat their Crohn's disease successfully with diet.



School

In addition to nutrition considerations, an IBD diagnosis can have an impact on a patient's school functioning. We recognize the importance of considering multiple aspects of a patient's life, including home and school life. Patients with IBD can often face challenges at school that their peers may not. There are some simple accommodations that can be put into place to assist IBD patients in the school setting. A formal way to put these modifications into place is called a 504 plan. The 504 plans are available to many patients with IBD and include medical, dietary and specific individual assistance related to IBD in the school setting. Common accommodations that are requested for patients with IBD include unlimited restroom access, ability to make up work from missed days of school, excused absences related to IBD and access to water in class. A parent can request a 504 plan for their child by speaking to their child's school. They may want to speak with

someone in special education, but their teacher may also be able to direct them to the correct person. The school will likely request some type of documentation of the child's medical condition and impact on school functioning. Once the school has the appropriate paperwork, they will meet with the parents, teacher and special education staff to implement the 504 plan. This plan should be provided to all teachers and should follow the child from grade to grade. The 504 plan should be updated regularly to ensure new accommodations can be included. Similar to grade school, most colleges offer medical accommodations as well, but must be requested in advance of the start of college and can include housing, dietary and academic assistance. With school accommodations we find patients can focus on their school work and studies and worry less about how their IBD will impact them at school.



Like any chronic illness, IBD can affect children and adolescents every day of their lives. Nationwide Children's Hospital Center for Pediatric and Adolescent Inflammatory Bowel Disease (IBD Center) focuses on comprehensive care for children with Crohn's disease and ulcerative colitis using a multidisciplinary approach. Nutrition and school functioning are two very important pieces of managing this illness.

Nurse Scientists at Nationwide Children's Hospital

Vicki von Sadovszky, PhD, RN, FAAN

We have several Nurse Scientists at Nationwide Children's discovering new knowledge to improve care of children and families. Many of these individuals are nationally and internationally recognized for their work and I would like to take time to introduce them and their important work here.

In the neonatal clinical area:

- **Rita Pickler, PhD, RN, FAAN** is the FloAnn Sours Easton Endowed Professor of Child and Adolescent Health at The Ohio State University (OSU) and one of our contingent Nurse Scientists here at Nationwide Children's. Dr. Pickler's research focuses on quality of life and improved care for preterm infants in the NICU, especially in the area of neurodevelopmental outcomes.
- **Tondi Harrison, PhD, RN, FAAN** is an Associate Professor at OSU and has an appointment here in the Research Institute. Dr. Harrison's research centers on examining the effects of maternal caregiving on the development of stress neurobiology in full-term infants hospitalized shortly after birth.
- **Heather Tubbs-Cooley, PhD, RN** is an Associate Professor at OSU and has an appointment in the Research Institute. Dr. Tubbs-Cooley's research focuses on understanding factors that impede and enhance the quality and safety of care in the NICU. Her goal is to redesign systems to better support the critical work of front-line clinicians.
- **Christine Fortney, PhD, RN** is an Assistant Professor at OSU and one of our contingent Nurse Scientists. Dr. Fortney's work is on creating an improved palliative and end of life experience for infants in the NICU and their families by focusing on how perceptions of symptoms in critically-ill infants affect parent decision-making for treatment and changes in goals of care, as well as their distress and coping while hospitalized.
- **Marliese Nist, MS, RNC-NIC** is a Nursing Supervisor and doctoral candidate. Her research

focuses on mediators of NICU stress exposure and neurodevelopment in very preterm infants.

- **Debra Armbruster, PhD, APRN, NNP-BC, CPNP-PC** in Neonatology is working on a study regarding relationship among neonatal PICC tip insertion depth and a neonate's anthropometric measures of weight and length.

Hematology, Oncology and Bone Marrow Transplant:

- **Micah Skeens, PhD, RN, PNP** is a Nurse Practitioner who recently earned her doctorate. Dr. Skeen's work focuses on adherence in pediatric oncology and hematopoietic stem cell transplants.
- **Amy Garee, MS, RN, PNP** is an acute care Nurse Practitioner in Hematology and Oncology and doctoral candidate. Her research focuses on parental coping in pediatric oncology and palliative care patients.

In other clinical areas:

- **Grace Deyo, PhD, CPNP** is a Nurse Practitioner in the Neurosurgery Clinic. Dr. Deyo's research interests are in preventing non-accidental trauma, post-operative care of neurosurgical patients and the management of patients with hydrocephalus.
- **Kristen Greathouse, PhD, CPNP-AC** is a nurse practitioner in the cardiothoracic intensive care unit. Her research interest is evaluating the function of the immune system in children with congenital heart disease, specifically around time of surgery, and determining what aspects of immune function play a role in development of complications after surgery.

Finally, my research area centers around the development and testing of theoretically-based mobile applications for symptom management and the stress and coping of healthy siblings of children with chronic or life-limiting conditions.

It is an exciting time here at Nationwide Children's for the advancement of nursing knowledge through research. We are fortunate to have such a wonderful cadre of scientists.

What's So "Special" About Inflammatory Bowel Disease?

Megan McNicol, PharmD, PGY1 Community Care Pharmacy Practice Resident

Kelly Wise, PharmD, BCACP, Advanced Patient Care Pharmacist

The rapid growth of opportunities in modern health care has led to an increase in the number of medications on the market. Many of these medications are considered "specialty medications" because they require close monitoring, have unique administration techniques and treat complex disease states such as inflammatory bowel disease (IBD). The clinical studies and complex manufacturing practices for these medications has led to high costs associated with the drugs, often creating a barrier for patient access. Of the gastrointestinal (GI) pharmaceutical treatment options, the most significant cost expenditure is seen with biologic and biosimilar agents. In 2017 alone, the overall expenditure on biologics was over 252 billion dollars in the United States. Biologics are targeted medications that are isolated from living entities such as proteins, cells, or tissues.

Adalimumab and infliximab are biologics that are often used in place of, or in adjunct to, other agents commonly used to treat IBD, such as aminosaliclates and immunomodulators. Adalimumab is given as a subcutaneous injection, and typically dosed every other week. Infliximab products are given as intravenous infusions over a minimum of two hours. It is dosed at zero, two and six weeks, and then every eight weeks thereafter. As with many biologics, these agents are immunosuppressants and, therefore, have special precautions and monitoring parameters that must be considered.

Adalimumab and infliximab are among many that have passed, or are nearing, the end of their patents, opening the door for the development of biosimilars. A biosimilar has been defined as a "biotherapeutic product that is similar in terms of safety, quality, and efficacy to the original biologic product," and may offer more cost-effective options for patients. Infliximab-dyyb (Inflixtra®) was one of the first biosimilars to enter the market in the United States in early 2017.

Infliximab-dyyb was studied in patients with rheumatoid arthritis and ankylosing spondylitis, but its approval was extrapolated to use in ulcerative colitis (>18 years old), Crohn's disease (>6 years old) and psoriatic arthritis.

At Nationwide Children's Hospital, a specialty pharmacy was developed in an effort to provide high-cost medications to patients in a more streamlined fashion. The Nationwide Children's Specialty Pharmacy was first established in 2015 to provide care to cystic fibrosis patients, but a need for expansion was quickly recognized due to the use of specialty medications in other departments such as Rheumatology, Endocrinology, and GI.

In early 2018, Nationwide Children's Specialty Pharmacy received URAC accreditation, which means it is now recognized as a nationally certified specialty pharmacy. The Specialty Pharmacy was one of the first free-standing pediatric institutions to receive this accreditation. The Specialty Pharmacy staff helps patients and caregivers navigate the specialty pharmacy environment by completing prior authorizations, enrolling patients in copay assistance programs, providing medication and injection training, delivering medications to patients' homes on a monthly basis, and streamlining communication for providers and patients. With these services, the Specialty Pharmacy strives to simplify access to life-changing medications for patients with chronic conditions such as IBD.

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Daisy Award

Kaitlin Pavlik, RN, BSN

The 22nd Annual Nationwide Children's Hospital Daisy Award was presented to Kaitlin Pavlik, RN, BSN, of PICU H8B. The Daisy Award is given in appreciation of the important difference our nurses make in the lives of our patients and families at Nationwide Children's.

Kaitlin was nominated by a family who appreciated her ability to help them see their situation with a different perspective. Says her nominator, "In the midst of a storm of 'I don't know's' as we tried to figure out what was happening to [our son], our nurse, Kaitlin Pavlik, asked something profound. She asked a question from a perspective different than anybody else on the team, which sparked a chain of conversation and thought



taking us in brand new directions. She looked beyond our conversations based on the past and asked 'what if'. With one question, she opened avenues to be explored and tossed a little hope into that unknown sea."

To learn more about our Daisy winners, and read their full nomination, visit [NationwideChildrens.org/Daisy-Award](https://www.nationwidechildrens.org/Daisy-Award)

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