

Everything Matters In

Patient Care

*Best Outcomes
at Nationwide
Children's
Hospital*

Daisy Award

Kelly Lilienthal, RN, BSN

The quarterly Nationwide Children's Hospital Daisy Award was presented to Kelly Lilienthal, RN, BSN, of C4B. 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.



Says Kelly's nominator, a parent of a patient: "I gave birth to my twin daughters 16 weeks early. They weighed one pound each. Altogether, their hospital stay was a total of 147 days in NICU. ... Around week three or four we met Kelly when she began caring for my daughters. My husband and I both noticed right away that Kelly was a great nurse. She was very experienced and paid attention to simple yet important details most would overlook. ... She took care of our daughters about three nights a week for the remainder of their hospital stay and, on the nights she didn't work, we looked forward to when she would come back. NICU babies and NICU parents are lucky to have Kelly as their nurse. And I hope there are hundreds of more nurses out there like her because every patient deserves to have a Kelly."

To learn more about our Daisy winners, and read their full nomination, visit NationwideChildrens.org/Daisy-Award

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The Nationwide Children's Hospital mission remains unchanged. We're committed to best outcomes and health equity for all children.

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Photography: Brad Smith and Bill Tijerina | **Art Direction/Design:** John Ordaz

Happy Spring!



Lee Ann Wallace
MBA, BSN, RN, NEA-BC
Senior Vice President,
Patient Care Services,
Chief Nursing Officer

It is most definitely not spring as I am writing this. There are high winds, cold temperatures and snow accumulations! Despite the current weather, we have much to celebrate. In 2023 we recovered from the viral surge and workforce challenges while refocusing our efforts on *Leading the Journey to Best Outcomes*. It was also a year that saw spectacular successes in our quality and safety performance. We finished the year with our lowest Central Line Associated Bloodstream Infections (CLABSI) rate, with a 20% reduction from 2022 and an 11% reduction from 2019. Our best year ever!

Eight clinical units received a 1,000 Zero Award for going 1,000 central line days without an infection. Pressure injuries were our second-best year ever, with a 60% reduction in higher severity injuries. We also continue to see impactful reductions in unplanned extubations in our smallest NICU patients, with a 9% reduction in 2023, and an overall 45% reduction since 2021, making it our best year ever in this category. Our Adverse Drug Event teams saw a center line shift and are achieving near Six Sigma-level performance in preventing medication errors.

These are just a few of many examples of how our team's relentless pursuit of excellence is making a difference for our patients and families! These successes are only possible because of our front line staff, their line of sight to quality and safety, and our one team culture. These are some of the foundational elements of our 2021-2026 organizational strategic plan. As we move from winter to spring, from snow to sunshine, let me take a moment to say thank you to each of you who make a difference for our patients and families every day.

Equitable Access and Patient Safety Considerations in Gene Therapy Treatment with Neuromuscular Patients

Shannon Chagat, MSN, FNP-C, Department of Neurology

Megan Waldrop, MD, Assistant Professor of Pediatrics and Neurology, Principal Investigator Center for Gene Therapy,
Co-Director Neuromuscular, MDA and SMA Clinics





Five-year-old Gideon Griffiths and other children like him who were born with a rare and severe genetic disorder involving progressive muscle degeneration and mobility loss have a brighter future now. In June 2023, after decades of research and testing in the Center for Gene Therapy at Nationwide Children's Hospital, the FDA issued an accelerated approval for a gene therapy treatment for Gideon and others with Duchenne muscular dystrophy (DMD).

Jerry Mendell M.D. with Gideon and his mom. (pictured left)

Two of the most common inherited genetic neuromuscular disorders are Spinal Muscular Atrophy (SMA) and Duchenne Muscular Dystrophy (DMD), and both are treated at Nationwide Children's Hospital with adeno-associated virus (AAV) gene therapies. These groundbreaking therapies were, in part, developed in the Center for Gene Therapy, a division of the Abigail Wexner Research Institute at Nationwide Children's Hospital, and led by Jerry Mendell, MD, as primary investigator for both trials. The neuromuscular clinical team at Nationwide Children's was determined to ensure that once FDA approval was obtained, these therapies could be provided to all qualifying patients. Our team applied similar principles to the planning for both therapies to ensure that we were able to provide an equitable and fair process for all eligible patients.

Zolgensma® (onasemnogene abeparvovec-xioi) was the first neuromuscular AAV gene replacement therapy to obtain FDA approval for use in patients under the age of 2 years with SMA. SMA is a condition of progressive motor neuron degeneration that causes weakness. The most severe form of SMA presents during infancy and death occurs between the ages of 8 to 24 months without intervention. Due to the rapid progression of this disease, patients must be identified as soon as possible for treatment with Zolgensma. Although treatment is effective when children have symptoms, treatment works best when given before symptoms start, and thanks to parent advocacy efforts, the state of Ohio quickly incorporated SMA into its recommended newborn screening. This program allows for most SMA patients born in Ohio to be identified during their first week of life.

Elevidys (delandistrogene moxeparvovec-rokl) was the second neuromuscular AAV gene therapy to obtain FDA approval and is indicated for patients from 4 to 6 years of age with a diagnosis of Duchenne Muscular Dystrophy (DMD). DMD is the most common fatal genetic disorder diagnosed in childhood and primarily impacts males. It is a progressive neuromuscular disorder of skeletal and cardiac muscles that leads to death in the second or third decade of life. FDA approval of Elevidys in summer 2023 ignited excitement amongst the DMD community, offering additional hope for improved patient outcomes.

Preparing to administer these therapies safely and effectively to our patients became a top priority even before FDA approval. To ensure all necessary processes and procedures were in place, we created a multidisciplinary team that met weekly to develop the screening process for patients and the post-treatment safety monitoring parameters. This collaboration led to standardization of the necessary lab work and testing that must be completed by each patient. Additionally, our team established subspecialty contacts at Nationwide Children's to be available for consultation if any patient experienced treatment-related complications. Completing this planning before commercial approval allowed us to initiate treatment quickly after FDA approval.

This speed was very impactful for our SMA patients where timing is a critical factor to optimize treatment response.

After FDA approval, our team worked with each patient who would benefit from treatment to personalize care. We first needed to establish whether the patient could safely proceed to infusion day. To do this, our team coordinated arrival to Nationwide Children's for screening labs and follow-up clinic visits to discuss treatment plans. Patients and their families are counseled on the results of the screening and given additional guidance about preparation for infusion day. Additionally, to optimize communication and enhance care, our team continued with weekly multidisciplinary meetings to discuss individual patients and their safety monitoring pre- and post-treatment review.

One major barrier to access was the cost for patients and families. Due to the high price of these therapies, obtaining approval from health insurance can be a difficult task. To successfully advocate for treatment, we utilized a group consisting of our neuromuscular physicians, nurse practitioners, nurses, a clinical pharmacist who specializes in gene therapy and a genetic counselor. Our team developed strategies to address insurance barriers and then collaborated with care coordinators to ensure continuity following

approval. This multidisciplinary collaboration of experts in the field worked hard to ensure we could get these therapies to all patients who would benefit from treatment.

Once a patient can proceed to gene therapy treatment, care coordination moves to the forefront. The day of treatment starts an intensive schedule of weekly lab draws and office visits. Patients are on an immunosuppressive dose of prednisone and therefore are at considerable risk for illness. Limiting patients' exposure to viral illness is an important component of their safety in the pre- and post-treatment periods. We ask families to limit interactions with others during this time. If possible, we request that their circle of contacts be limited to those living in the home with the patient. This can be a difficult request for families, especially if they are navigating jobs outside of the home, childcare, older siblings in school and other responsibilities. This period



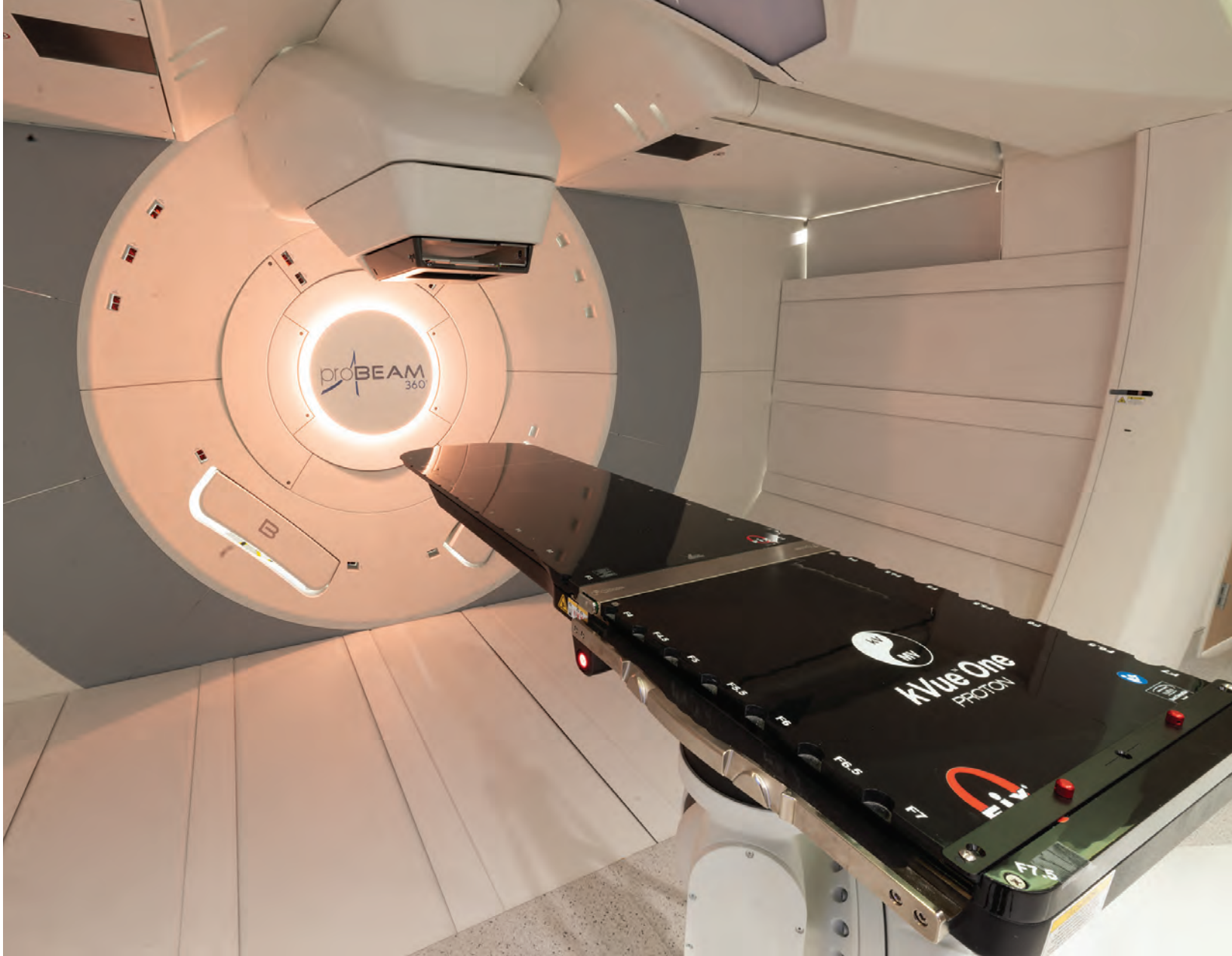
begins a couple of weeks prior and lasts a minimum of eight weeks post-treatment but can extend well beyond that depending on the patient's safety surveillance lab results. One of the reasons this post-monitoring period is so important for patient safety is due to the risk of complications associated with AAV gene therapy. These complications can include thrombotic microangiopathy, an acute liver injury that can lead to liver failure and patient death, decreased platelet levels, immune-mediated myositis or myocarditis. Post-infusion viral infection can extend the period the patient is on immunosuppressive therapy and increase their risk for complications. Once the patient's prednisone is weaned to a dose that is no longer immunosuppressive, our team provides guidance on return to activities, school, etc.

The post-monitoring period following therapy can be a stressor for families as they monitor for symptoms after infusion and worry about each week's lab results. This can also be a period of logistic complexity as they navigate the complex care plan for their child. Our neuromuscular team, especially our nursing, social work and administrative

team members, help with this care coordination and family support. Gene therapy has specific safety monitoring requirements after infusion. Because there are not many hospitals that can safely administer these therapies, families can travel from other states for treatment. If families don't live a manageable daily driving distance to Nationwide Children's, we do ask them to relocate to central Ohio for a minimum of four weeks post-treatment and secure their consent before moving forward with treatment.

Considering these logistics and potential barriers, we worked to ensure equitable access. Since these therapies can provide life-changing improvements and stability to life-limiting diagnoses, it is imperative that all eligible patients have equal access to these treatments. For all potential gene therapy patients, we extensively discuss the safety monitoring with families before treatment, utilizing teach-back and open-ended questions. This counseling helps identify barriers for our families that could lead to non-adherence. We develop customized plans for each family to optimize safe monitoring for symptoms post-infusion. For some families, this means weekly reminder calls before appointments and lab visits; for others, this means organizing transportation support and Ronald McDonald House stays. We utilize resources at Nationwide Children's to assist families, including Partners For Kids and our department social worker. Our team is fortunate to have a designated Partners For Kids assigned team supporting our department. They have been instrumental in helping navigate solutions to barriers that prevent patients from fulfilling their safety visits post-infusion. A holistic approach, combining both medical and social needs of the patient, contributes to improved compliance for our patients' post-gene therapy course. One of the more important lessons our team has learned while administering gene therapy is the need to be flexible and recognize our plan of care for each patient post-treatment needs to be personalized to the patients and their families.

Providing care to patients with SMA and DMD can be challenging due to the severity of these illnesses and the complexity of the care required. It is incredible watching these children achieve milestones and development skills that they would not have obtained before treatment. We also see stability in patients that we would otherwise note progressive decline without treatment. We have young patients running down our clinic hallways excitedly telling us about their activities since we saw them last in clinic! With each clinic visit, it is more and more inspiring to watch patients thrive after treatment. This new era of treatments for neuromuscular disease is full of hope and optimism for patients and certainly a big step toward better outcomes for our patient population.



Everything Matters in Proton Therapy

Timothy P. Cripe, MD, PhD, Division Chief, Pediatric Hematology/Oncology/BMT

Mindy J. Bibart, DNP, RN, CPHON, NEA-BC, CPPS, CSSBB,
Director of Patient Services, Pediatric Hematology/Oncology/BMT

WHAT IS RADIATION THERAPY?

Radiation is used primarily to treat patients with cancer. Because it is so effective, radiation remains a mainstay of cancer therapy, even for children. Radiation is used in patients with almost every type of solid tumor and is even used in some cases in patients with leukemia to treat areas that chemotherapy doesn't reach very well like the brain and spine. Most radiation therapy used for the past century around the world is based on X-rays, which pass all the way through the body. While those rays damage the tumor, unfortunately, they also damage normal organs surrounding the tumor. In addition to the short-term side effects such as skin rash or inflammation of mucosal surfaces and other internal organs, radiation based on X-rays often causes long-term effects such as growth defects, endocrine organ damage, cognitive (brain) damage and even other types of cancer later in life.



WHAT IS PROTON RADIATION THERAPY?

Protons are tiny particles at the center of every atom, one of the so-called “sub-atomic” particles. The most basic atom is hydrogen, which consists of a positively-charged single proton, surrounded by a negatively-charged single electron, which forms a neutral (no charge) atom. The electron can be stripped from a hydrogen atom, leaving a positively charged proton. The Proton Therapy Center uses a 90-ton cyclotron, which is only about eight feet in diameter, to propel protons by electromagnets in concentric circles faster and faster until they reach about two-thirds the speed of light. Then the beam is directed by electromagnets down the back hall into the three treatment rooms (gantries). The fast-moving particles can then be directed with extreme precision into a patient’s tumor and mapped to its three-dimensional shape. The energy (radiation) in the particles gets deposited in the tumor, killing the tumor cells. Thus, there is little to no radiation of the normal tissues beyond the tumor, markedly reducing radiation exposure to the surrounding normal organs.

WHY IS PROTON THERAPY ADVANTAGEOUS?

Less radiation to normal organs should result not only in fewer short-term side effects but also less damage to organs and fewer long-term side effects, including fewer future cases of cancer. Because many of those side effects such as stunting growth and damaging the development of the brain and other organs are most pronounced in children, proton therapy is particularly advantageous for pediatric cancer patients. Also, the so-called secondary cancers often take decades to develop, again making proton therapy particularly beneficial for children, as we hope they will experience a normal cancer-free lifespan.

IS PROTON THERAPY USED FOR EVERY PATIENT GETTING RADIATION?

Proton therapy is not for everyone. Whether or not proton therapy is the best treatment will be determined in consultation with the radiation oncologist. For some patients, conventional X-ray radiation therapy will still be used because either proton therapy will not be advantageous or is not feasible. For example, if the tumor cannot be mapped precisely because its borders don’t show up clearly on imaging (CT or MRI) or the tumor constantly moves such as on the lung or heart, then proton therapy may not be as effective as conventional therapy. Proton therapy might miss some of the tumor as it moves in and out of the treatment field. Patients who get total body radiation as part of their bone marrow transplant to treat leukemia will continue to get conventional radiation.

WHY DO PATIENTS RECEIVE RADIATION THERAPY AT OSU?

Nationwide Children’s Hospital and The Ohio State University James Cancer Hospital (OSU-JCH) have a long-standing partnership in caring for pediatric cancer patients who require radiation as part of their treatment. Nationwide Children’s does not provide radiation oncology services on campus because pediatric cancer is a rare group of diseases, and our patient population is not large enough to support a radiation program. Our patients usually receive that portion of their care at OSU-JCH. This collaboration has blossomed throughout the planning of the new proton center. Both organizations viewed this exciting new program as an important opportunity to enhance the pediatric experience for patients receiving radiation therapy. Multidisciplinary teams, with support from process improvement specialists, evaluated all phases of care, from referral through billing, to ensure that pediatric patients have the same great experience in both organizations.

WHAT DOES PROTON THERAPY MEAN FOR THE PATIENT EXPERIENCE?

The patient experience during proton therapy will largely be similar to their experience with conventional radiation. Before the opening of the Proton Therapy Center, patients traveled to OSU-JCH for therapy. Now, patients will go to the new facility on The Ohio State University West Campus (where parking should be easier!). Therapy will still be administered every weekday for the same number of days as conventional therapy, in most cases six weeks, depending on the total radiation dose. Young patients will still need to undergo anesthesia each time.

WHAT EXPERIENCES ARE SPECIALLY DESIGNED FOR PEDIATRIC PATIENTS?

The new West Campus facility was specially designed with many features specific to pediatric care. Pediatric patients and their families have a private waiting room with toys and distraction activities while they wait for their procedures. Pediatric patients will also benefit from a separate ambulance entrance and streamlined patient flow designs. The radiation team at OSU-JCH has always provided a patient-focused experience, allowing kids to choose what music they listen to or what movies to watch during their procedure. These child-friendly interventions will continue at the new campus.

DO CLINICIANS AT OSU-JCH HAVE PEDIATRIC-SPECIFIC CLINICAL TRAINING?

Pediatric patients undergoing radiation therapy at OSU-JCH are in great hands. In addition to the world-class radiation oncology providers directing care, many members of the multidisciplinary team underwent additional training to care for pediatric patients. All Nationwide Children’s patients

treated at OSU-JCH are seen by nurses with pediatric experience who are in close communication with the patient’s primary oncology team at Nationwide Children’s. These nurses receive Nationwide Children’s facilitated education and competency evaluation for central line care and are familiar with pediatric cancer treatment protocols. Additionally, the OSU team recently hired a child life specialist to help provide child-friendly education and to support patients as they cope with their treatment. For young patients who require sedation during their procedures, Nationwide Children’s faculty anesthesiologists perform their sedation and pediatric trained PACU nurses are with them during recovery.

WHAT IS FLASH THERAPY?

The new Proton Therapy Center equipment is so advanced that six weeks of therapy is delivered in under one second. The rapid delivery of all that energy is termed FLASH therapy. FLASH therapy is not yet approved for use in humans, but it shows great promise in animal studies. When there is enough evidence that it is likely to be safe and effective in humans, FLASH will then be tested in clinical trials. Someday, we hope FLASH therapy will enable patients to be treated with just a single visit to the Proton Therapy Center.

Moral Distress: An Invisible Occupational Hazard

Alice K. Bass, MSN, APRN-CNP, CPNP-PC, FPCN Nursing Professional Practice Specialist, Center for Nursing Excellence

At Nationwide Children's Hospital, we always strive for *Best Outcomes* for our patients and families. Achieving this requires a coordinated one team approach to patient care and involves staff members of all disciplines and departments. Some days, the path to *Best Outcomes* is easy, and the work is straightforward. Other days are harder, however, and we may find ourselves or our colleagues in emotionally challenging situations where we struggle with what is being asked of us in our roles or what “feels right.”


Moral distress is a complex issue that occurs when a person understands the correct action to take but is restricted from acting on it due to elements that are often out of their control. Constraining factors may be:

External factors: Barriers outside the individual, including institutional, systemic or situational constraints. Examples include poor communication, policy or staffing.

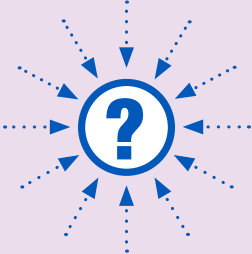
Internal factors: Obstacles that exist within the individual, such as anxiety, fear, spiritual conflicts or lack of self-confidence.

When you cannot convert your moral choices into action, an emotional conflict arises and threatens those core values; this can lead to feelings of powerlessness and suffering for patient care staff. Moral distress is often confused for an ethical dilemma, but the latter only exists when there are more than one ethically justifiable actions that do not have a clear solution.


Symptoms of moral distress may differ between individuals and include feelings of failure, resentment, guilt, sadness, anger, isolation or hopelessness. Staff may contemplate leaving their positions or even their careers. If you or a colleague expresses similar feelings, consider taking these steps as recommended by the American Academy of Critical Care Nurses (AACN):




IDENTIFY what you are experiencing; distinguish between feelings of moral distress, compassion fatigue and burnout.



FAMILIARIZE yourself with common symptoms and gauge the severity of your distress.



GATHER facts and identify potential causes (internal or external).



TAKE ACTION and speak up within your unit or through your chain of command.

Repeated episodes of moral distress can lead to longer lasting moral injury. This can negatively impact overall job satisfaction and longevity in a health care field, a field that requires compassion, trust and resilience. As we strive for *Best Outcomes* for staff at Nationwide Children’s, recognizing and addressing moral distress when it occurs is of high importance. If you suspect moral injury, look to your support systems and seek resources that exist within Nationwide Children’s, including Employee Wellness and the YOU Matter Program for additional tools and references.

Breast/Chestfeeding the Substance Exposed Neonate: Nationwide Children’s Hospital Journey to Increasing Breast/Chestfeeding Rates

Gail A. Bagwell, DNP, APRN, CNS, FAAN,
Education Nurse Specialist, Neonatal Network

Amy Thomas, BSN, RN, IBCL,
Lactation Educator, Neonatal Network



Breast/chestfeeding is considered the ideal nutrition for all neonates. The World Health Organization (WHO) states that breast/chestfeeding is one of the most effective ways to ensure survival and health of a child. With the continuing substance abuse problem in the United States and Ohio, especially for women of childbearing age, the question of whether we should be encouraging them to breast/chestfeed their neonates is often asked.

Maternal opiate use disorder (MOUD) and neonatal abstinence syndrome/neonatal opioid withdrawal syndrome (NAS/NOWS) have become a national epidemic. In the United States in 2021, the National Survey on Drug Use and Health showed that among pregnant women 15 to 44 years of age, 7.7% of those surveyed admitted to using illicit substances in the past month, which is an increase from 5.8% in 2019. In Ohio, current numbers of women affected by a substance use disorder are not available, but the NAS/NOWS incidence is available. In 2022, the most recent data showed that there were 1,300 babies with a NAS discharge diagnosis or about 1% of the 128,284 births in Ohio. This is a significant improvement from 2018 when there were almost 2,000 babies with a NAS diagnosis in Ohio. While the numbers in Ohio are not huge, it is still a concern as a fetus exposed to any illicit substances in utero has the potential to withdraw from these substances after birth. When fetuses are exposed in utero to opioids or other substances, 55-95% will demonstrate signs of withdrawal.

Opioid use in pregnancy is not a new phenomenon in the United States. There is documentation of women addicted to morphine in the late 1800s and early 1900s. More recently there was a heroin epidemic in the 1950s and 1960s that brought attention and concern of the effects of the drug on the developing fetus. This led to a recommendation in 1969 for pregnant women to be treated with methadone to help decrease the side effects of heroin on the fetus.

With more recognition of the effects of drugs on the fetus/newborn and recognizing signs of withdrawal, tools have been developed to assess, and treatments discovered to reduce, the signs of withdrawal. The mainstay of NAS/NOWS treatment has been mostly pharmacological — treating the infant with a similar drug they were exposed to in utero, but in the last decade, more emphasis has been placed on non-pharmacological management of the infant, especially as we learn more about the long-term neurodevelopmental effects of some medications used to treat the neonates.

This is a mass improvement from 2018 when there were almost 2,000 babies with a NAS diagnosis in Ohio. While the numbers in Ohio are not huge, it is still a concern as a fetus exposed to any illicit substances in utero has the potential to withdraw from these substances after birth.



One non-pharmacological intervention that is proven to help the neonate is breast/chestfeeding when a parent providing milk is in a treatment program for their MOUD. Multiple studies have been done looking at the amount of methadone and buprenorphine transferred to human milk as well as how much the infant actually absorbs. Both methadone and buprenorphine are transferred to the human milk in lesser amounts, but the amount that is actually absorbed by the neonate is minuscule, thus making it safe for the parent in a treatment program to provide milk for their baby either by a direct method or by bottle. As a result of this research, the American Academy of Pediatrics in 2001, American College of Obstetricians and Gynecologists in 2012 and the Academy of Breastfeeding Medicine in 2009 published position papers encouraging breastfeeding for women in treatment programs that are HIV negative and have strong social support.

Traditionally infants experiencing NAS/NOWS have not been breastfed. There are multiple reasons why breastfeeding does not occur. Some factors include but are not limited to health care providers' lack of knowledge on the pharmacokinetics of how medicine transfers to human milk resulting in a fear of large amounts of drugs crossing into the human milk, the lack of trust in the parent providing milk who is in treatment programs to not abuse drugs, the parent providing milk being discouraged to

breastfeed and the parent providing the milk not always being available to breastfeed their infants.

As stated earlier, numerous studies have been done that show the amount of transfer of methadone or buprenorphine from the parent providing the milk to the neonate is minimal, thus making it safe to breast/chestfeed. In addition, studies have been done comparing breast/chestfeeding to formula-fed neonates with NAS/NOWS. The studies found that those neonates that were

closeness of the neonate to the parent providing the milk, making the neonate feel secure, warm and comforted. Breast/chestfeeding also benefits the parent providing the milk as it helps them to bond with their infant, maintain adherence to their drug treatment program and increase their QALY similar to their neonate.

But despite the national recommendations, breast/chestfeeding in this population remains low. Health care provider biases and hospital policies often discourage the

Breast/chestfeeding also benefits the parent providing the milk as it helps them to bond with their infant, maintain adherence to their drug treatment program and increase their QALY similar to their neonate. But despite the national recommendations, breast/chestfeeding in this population remains low.

breast/chestfed had improved outcomes such as decreased length of stay in the hospital, decreased pharmacologic interventions, a decrease in the severity of the signs of withdrawal and an increase in the quality of adjusted life years (QALY) making this non-pharmacologic intervention an integral part of caring for neonates diagnosed with NAS/NOWS. Since the amount of methadone/buprenorphine in the human milk is low, the thought of the improved outcomes is related to the

parent from providing their milk, even when they have a desire to do so. This was the situation at Nationwide Children's Hospital prior to 2014 when our hospital policy stated that any parent providing milk whose neonate had a diagnosis of NAS/NOWS would have to have their milk tested prior to the infant receiving the milk. Although unintentional, this was brought to our attention as a form of profiling.

THESE INITIATIVES
HELPED TO
INCREASE THE
BREASTFEEDING
RATES FROM:

6%
in
34.4%
in main campus NICUs

26.25%
in our delivery NICUs for an overall
28.5%
rate for the neonatal network



In 2013, an interdisciplinary group of health care providers in the Neonatal Network met to review and revise the *Human Milk: Drugs of Abuse, Opioids, and Other Harmful Substances at Nationwide Children's*. This was part of the journey the Neonatal Network embarked upon to increase breastfeeding in the neonatal intensive care unit (NICU) for all neonates, including those with NAS/NOWS whose parents who provided milk were in a treatment program.

In revising the policy *Human Milk: Drugs of Abuse, Opioids, and Other Harmful Substances*, the milk toxicology testing was eliminated except in cases where a practitioner believes that the neonate's signs could be from potential drugs in the milk provided by the parent. The policy now requires that all parents who want to provide milk to their baby, regardless of their neonates' diagnosis, will have a thorough history taken regarding what prescription, non-prescription, herbal and illicit drugs they are taking, have a review for any history of drug use, a review of recent toxicology testing assessing for recent positive toxicology test, as well as being counseled on the need to provide safe milk to their babies. In addition to the

policy revision, education was provided to the NICU health care providers on the pharmacokinetics of drugs in breast milk. These initiatives helped to increase the breastfeeding rates from 6% to 34.4 % in the main campus NICUs and 26.25% in our delivery NICUs for an overall rate of 28.5% for the neonatal network. While we were able to increase our breast/chestfeeding rates in the NAS/NOWS population, we unfortunately have not maintained it with the most recent data from 2022 showing a 20.3% human milk provision during the hospital stay and 19.4% providing human milk at discharge.

Breast/chestfeeding in neonates with NAS/NOWS is more than nutrition. It is a treatment modality that is proven to improve outcomes related to the NAS/NOWS and provide lifelong benefits from being breast/chestfed. As health care providers, it is essential that we support the parents providing milk in substance abuse treatment programs to breast/chestfeed their infants without bias, so they have the best outcomes.

YOU Matter

Celebrating
10
years!

Well-being Consultations with YOU Matter

Kristy deVries, MSW LISWS, YOU Matter Program Manager

For 10 years, the YOU Matter program at Nationwide Children's Hospital has focused on the emotional and mental well-being of staff. Hospitals can be high-pressure environments, and the past four years have multiplied that stress. The state of the world around us has caused increased tension and distress among workers. The YOU Matter Staff Support Program provides resources and peer support to Nationwide Children's employees to reduce stress that is related to both work and non-work situations, with a special focus on staff who have been injured while working. Because of the focused work that Nationwide Children's staff perform, it can be difficult to link with a YOU Matter Staff Support Clinician.

As a result, a new intervention, the Individual Well-being Consultation was implemented in 2023. The Individual Well-being Consultation was developed to increase access to emotional and mental well-being resources by connecting staff to a master degreed, licensed social worker or counselor. This program provides an opportunity for Nationwide Children's staff to meet with a YOU Matter clinician to discuss personal stress levels by using the Stress First Aid Continuum and to receive concrete recommendations and strategies to increase overall well-being. Practices may include utilizing breathing techniques to reduce anxiety, learning to monitor thinking to challenge thought patterns or learning how to have a bridge-building conversation to increase effective communication. Employees utilizing the program can meet once or up to three times with the YOU Matter clinician. This is not intended to be intensive therapy where a full psychosocial assessment and treatment plan

are completed. Occasionally, the YOU Matter clinician will recommend linkage with an outpatient therapist. The Individual Well-being Consultation is easy to schedule using the Nationwide Children's Hospital intranet. Search Individual Well-being Consultation on ANCHOR. In a similar way to scheduling a haircut, employees will go to the site, identify the time and day they'd like to meet and the YOU Matter clinician they prefer. The YOU Matter clinician will then send an Outlook calendar invite with a Teams link for the meeting.

Since its start in March 2023, the YOU Matter Program has provided 176 Individual Well-being Consultations. Work-related stressors were the main reason staff made appointments, followed by home stressors, grief and requests for resources.

For more information, please reach out to the YOU Matter Program at YOUmatterProgram@NationwideChildrens.org.

This program provides an opportunity for Nationwide Children's staff to meet with a YOU Matter Clinician to discuss personal stress levels by using the Stress First Aid Continuum and to receive concrete recommendations and strategies to increase overall well-being.

Promoting Best Outcomes by Infection Prevention in Children Undergoing Solid Organ Transplantation

Sanya Thomas, MD, FAAP, Assistant Professor of Pediatrics at OSU and
Physician Faculty of Host Defense within Pediatric Infectious Diseases

Children who undergo solid organ transplantation, such as liver, lung, kidney or heart, are actively immunosuppressed to minimize the risk of allograft (donor organ) rejection. In doing so, parts of the immune system, particularly T cells, are functionally or quantitatively reduced making the child more susceptible to infections. As such, it is important to take measures to prevent or decrease exposure to infectious agents in the environment. These measures include safe living practices, anti-infective prophylaxis and staying up-to-date on immunizations.

Immunizations, as laid out by the Advisory Committee on Immunization Practices (ACIP), are recommended for all transplant recipients. Infections prevented by vaccines include those caused by bacteria, such as *Bordetella pertussis*, *Haemophilus influenzae* type b and *Streptococcus pneumoniae*, and viruses including hepatitis, influenza and respiratory syncytial virus. The immune response to vaccines is optimal when vaccines are administered prior to initiation of

immunosuppression. To take advantage of this pre-transplant period, immunizations are often administered on an accelerated schedule as recommended by the Infectious Diseases team during the pre-transplant evaluation. Maintaining adequate immune response against vaccine-preventable illnesses is important to reduce the risk of infection-associated complications including possible injury to the allograft. To that

end, patients who aren't fully immunized prior to their transplant should continue to receive the required vaccines once immunosuppression is reduced. Live vaccines typically are not given post-transplant due to the theoretical risk for vaccine strain infection, with exceptions made by the transplant team in select scenarios. For viral and fungal infections against which we do not have vaccines, anti-infective prophylaxis provides another active infection prevention measure.

Anti-infective prophylaxis is commonly instituted to prevent viral and fungal infections in the post-transplant period. Prophylaxis against Herpesviridae is used in children with known exposure to herpes simplex virus, varicella zoster

virus or cytomegalovirus as these viruses tend to become latent in the child after exposure and can re-activate during states of immunosuppression.

Of the fungal organisms, candidal infections such as thrush require fluconazole or nystatin. However, prophylaxis against mold infections is also required in lung transplant recipients as these children undergo a much higher degree of immunosuppression compared to other solid organ transplants and exposure to mold is typically acquired through inhalation, increasing their risk for mold infections of the pulmonary tract. *Pneumocystis jiroveci* pneumonia (PJP) is yet another fungal organism that is ubiquitous and can cause fungal pneumonia in T cell deficient states and is associated with a high rate of mortality and morbidity due to respiratory decompensation. Although its incidence is low, given the burden of illness, all transplant recipients receive prophylaxis against PJP. While these active measures may be effective, preventing infections by minimizing exposures to organisms by following safe living practices is equally important.

Safe living includes lifestyle changes and increased attention to hygiene practices. Depending on the child's and household members' hobbies and home environment, the recommendations vary. Some recommendations may be minor adjustments while others can be more challenging to adopt. Hands are the most common vectors of transmission of organisms and thus, hand hygiene should be strictly followed. Similarly, avoidance of individuals with respiratory symptoms or use of masks in large gatherings or crowded spaces is important to limit the chances of acquiring respiratory infections. To reduce the risk of cross-contamination of foods by organisms that may be present in raw meats or fish, avoid exposure of vegetables or fruits to fresh poultry or seafood by cooking these in different spaces or at separate times after cleaning the workspace. Additionally, transplant recipients should not ingest any unpasteurized dairy, undercooked meats, raw fish or wild (game) meat. During outdoor activities including hiking sunscreen and mosquito repellent should be applied and long-sleeved cotton clothes worn. This lessens the chances of acquiring mosquito-borne or tick-borne infections or sunburn. Bonfires or fireplaces that actively burn wood should be avoided so that fungal spores released into the air are not accidentally inhaled by the immunosuppressed child. Gardening, farming, dirt-biking, construction and

renovation are strongly discouraged as these activities disperse dirt and soil and increase the likelihood of inhalation of fungal particles. Swimming in ponds, rivers and lakes is also strongly discouraged; however, swimming in a chlorinated pool may eventually be allowed with caution. To drink, only bottled or filtered water should be used, especially in houses that receive well water. These precautions should be followed pre-transplant to minimize the chance of an infection before transplant that may delay the transplant. Other infections may incubate for a longer period and only present in the post-transplant period, seriously complicating the post-transplant management.

Infections in the post-transplant period, particularly viral infections, require a decrease in immunosuppression and can be particularly challenging. When immunosuppression is decreased, the child's immune system can become more sensitized to the allograft and over time may theoretically increase the risk for allograft rejection. This is particularly challenging in the first three months post-transplant, where a decrease in immunosuppression is not ideal and should be avoided by strict adherence to infection prevention measures. Any infection post-transplant typically requires hospitalization for monitoring and management which inevitably disrupts the child's and the family's life and daily routines. These prevention measures are paramount to optimize the longevity of the allograft but more importantly, the overall health and quality of life of the child who has undergone transplant.

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Leading the Journey to Best Outcomes Before Birth: Fetal Surgery for Spina Bifida

Adolfo Etchegaray, MD and Mickey Johnson, MHA, RN

Engaging in early and consistent prenatal care significantly enhances the chances of delivering a healthy baby. Ongoing advancements in imaging technologies enable the continuous monitoring of pregnancy progression and fetal development, allowing for timely interventions when necessary. Fetal ultrasound serves as the main imaging method, providing crucial information for health care professionals. This includes details about viability, pregnancy stage, fetal count, presence of anomalies, fetal size, amniotic fluid levels and placental location, among other critical insights. Routine prenatal care integrates fetal ultrasound and other assessment tools to systematically screen for abnormalities that may pose risks to both the pregnant individual and the fetus, ensuring a comprehensive and proactive approach to maternal and fetal well-being.

Imagine yourself as Brittany, halfway through pregnancy and attending a routine obstetrics appointment. You are getting ready for a highly anticipated fetal anatomy ultrasound so you can see images of your baby and receive reassurance that the pregnancy is progressing without complications. During the scan, it becomes apparent that there is something wrong. The provider obtains extra images to verify the findings. You are informed the ultrasound may indicate the fetus has spina bifida and you will be referred to the Fetal Center at Nationwide Children's Hospital. At Nationwide Children's you will receive advanced diagnostics to confirm the findings and collaborate with you to determine next steps.

Spina bifida is a congenital condition characterized by the incomplete closure of the neural tube during fetal development. This incomplete closure can result in a gap in the spine, exposing the spinal cord and nerves. The severity of spina bifida can vary, leading to complications such as hydrocephalus, motor and sensory impairments, bladder and bowel issues, and in severe cases, paralysis.

Fetal surgery has significantly changed the prospects for children with spina bifida. Traditionally, spina bifida was treated after birth through surgical procedures to close the opening in the spine and treat hydrocephalus. However, advancements in medical technology and surgical techniques have allowed for prenatal intervention. Fetal surgery for spina bifida involves repairing the spinal defect while the baby is still in the womb. This early intervention has shown improved outcomes for affected children. By addressing the spinal opening before birth, fetal surgery aims to minimize the exposure of the spinal cord to amniotic fluid, which can contribute to damage. Studies have indicated that fetal surgery for spina bifida can lead to better neurological function and reduce the need for shunts to manage fluid accumulation in the brain, a common complication associated with this condition.

The Fetal Center at Nationwide Children's is a one-stop destination program that seamlessly coordinates diagnosis and multispecialty care, including surgical fetal intervention and delivery when indicated for patients diagnosed with a fetal anomaly. Upon referral, Brittany was assigned to a fetal nurse coordinator who served as the primary point of contact and navigator for her care journey. Brittany underwent fetal repair through a minuscule uterine incision and was discharged five days later, remaining in close surveillance by the fetal team. The pregnancy proceeded without complications, and subsequent imaging displayed promising results, indicating a reversal of previously observed anatomical changes in the fetus. This resulted in a successful delivery 12 weeks later, at 37 weeks of pregnancy. Brittany and her daughter stayed at the Nationwide Children's Fetal Unit together and were discharged home together after a short stay. Brittany's daughter is thriving in development and has not required any further surgical interventions.

Brittany's journey embodies the Fetal Center team's inspiration, emphasizing the pivotal role of early treatment in achieving optimal outcomes.

Going WILD!

A Nursing Education Journey to Best Outcomes

Liam Hix, MSN, RN, PMH-BC, Nurse Education Specialist and J.R. Sike, BSN, RN, Nurse Educator

In planning for the March 2020 opening of Nationwide Children’s Hospital Big Lots Behavioral Health Pavilion, leaders and educators within the service line were tasked with a daunting challenge: onboard hundreds of new nursing staff members, train them to care for a specialized patient population and plan for countless “what-if” scenarios for which they needed to be prepared. Through the combined efforts of Behavioral Health Education and Behavioral Health Nursing Education, this task was achieved and the path was set for how the nursing education team would continue the development of their respective staff.

Unfortunately, during the pandemic, the team of inpatient nurse educators dwindled to just one, leaving many of the educational needs of the nursing staff on hold. During this time, limited resources curbed the momentum for growing and developing nursing staff to the top of their practice. This led to a splintered strategic vision, minimal accountability and reactive education. Unsurprisingly, staff turnover was high.

Fast forward to the summer of 2022, as the Behavioral Health Nursing Education group began to grow again, starting with the unification of the inpatient and outpatient teams. With the support of the Behavioral Health Pavilion’s leadership, the first priority was overhauling our onboarding and orientation process to best support our staff.

THIS LED TO THE CREATION OF NEW INTERVENTIONS, INCLUDING:

01

Welcome Week, a two-day introduction to the foundations of psychiatric nursing which was approved for 10 continuing education units

02

Individualized orientation plans and assigned educators

03

Standardized “check-ins” starting two weeks before the new hire’s start date, and continuing during their first year of employment

Based on staff feedback, it was clear there was a need for this caliber of education and more. Word soon spread among both the new and experienced nursing staff, and we began receiving requests for additional education to better prepare them to work with our growing patient census and unexpectedly high acuity. After deliberation, we began to plan our Behavioral Health Nursing Education Days.

"This was honestly the best job orientation I've been a part of. It was clear, informative but not excruciatingly long and redundant. I feel comfortable starting my first day on the floor tomorrow."

☐☐ = Annual Skills and Orientation Days Staff Quotes



Though staff had experienced education days previously, they had now gone almost two years without any annualized development events. We feared pushback from the staff, who had lost touch with their Nursing Education team and realized we would need to reconnect with them creatively. We set our sights on creating inclusive, relevant and fun Education Days that would set the standard for future staff development. Choosing a jungle safari theme, we held the Education Days on BH8B, an empty inpatient unit in the Behavioral Health Pavilion. This enabled us to create a high-fidelity learning environment. Many staff had expressed frustration about completing required learning outside of their regular work hours, so we incorporated many yearly “check-offs” to meet these obligations all at once. In addition, we collaborated with other

groups including YOU Matter, the Simulation Program, Point of Care Testing Services, psychiatry and psychology providers, and the Diabetes/Insulin Inpatient Service Consult team. We offered a conference-style approach, providing posters and different presentations staff could choose to attend. Finally, we created an escape room to challenge staff to work as teams, communicate calmly under pressure and race against the clock while completing a full room check for contraband!



"The camaraderie of the team we worked with was great. Good communication and good energy all around."

After wrapping up Education Days, the team came together to review staff feedback, leadership perspective and the educators' conclusions. What we found was reassuring: staff had an amazing time learning with their peers and were actively looking forward to more. The education team immediately began brainstorming our next events: Charge RN Workshops, Preceptor Development and Certification Support, all specifically designed for Behavioral Health. With these continued efforts, we have been able to further connect with staff and provide them with the development opportunities they have requested and deserve. As a team, we have greatly enjoyed the process of planning and executing these projects, as we recognize the impact they have on our staff's confidence in delivering high-quality care. While we plan for our next Education Day and beyond, we are eager to develop new and exciting ways to assist our staff in providing higher levels of care to our Behavioral Health population!



"The fact that nothing was too long, and we learned many multiple things. Loved the lectures."



"All of the info was actually relatable and needed for my position at the BHP."



"The overall theme and how the educators created the theme to make the day enjoyable for everyone!"



"Having gone through Welcome Week in October, it is evident that the changes made will positively impact employees."

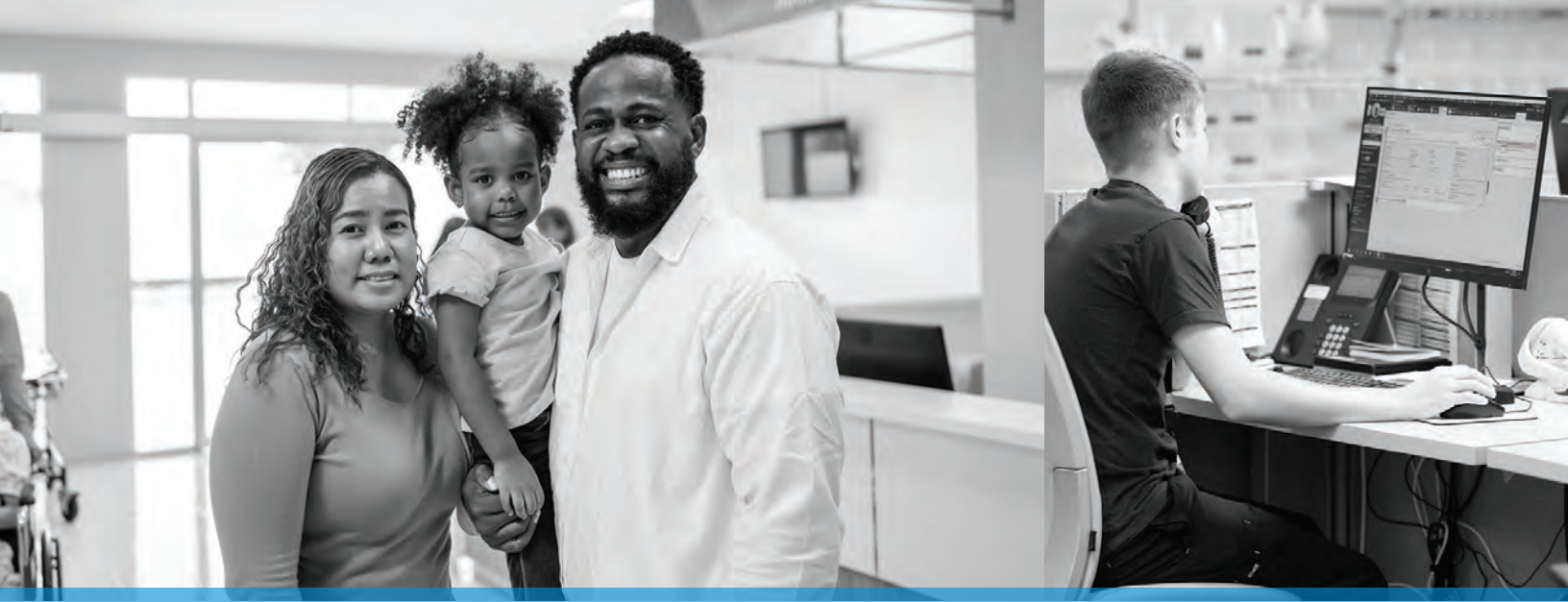


Best Outcomes in Pharmacy Practice: Facilitating a Safe Transition from Hospital to Home

Weslie Donia, PharmD, BCPPS, Patient Care Pharmacist, Pharmacy

As patients transition through the health care system, they are vulnerable to medication errors that may lead to adverse drug events. It is estimated that up to 60% of all medication errors occur during transitions of care (TOC). The pediatric population is especially susceptible to errors due to complex medication regimens, unique dosing formulations and the need for knowledgeable caregivers. Both The Joint Commission and World Health Organization emphasize implementing structured medication management strategies, specifically during TOC, to optimize patient safety, limit prescribing errors and ultimately support best patient outcomes. Highlighted in these recommendations include the major role a pharmacist can play on a multidisciplinary team by providing medication reconciliation, identifying medication discrepancies and providing discharge counseling to patients and caregivers. Literature supports the implementation of pharmacist-driven TOC programs by showing reduction in medication errors at discharge, improvement in adherence/understanding of medication regimens and reducing hospital readmission rates in high-risk patient populations.

Navigating the hospital setting can prove to be overwhelming for many patients and their caregivers, especially during transitions in and out of the health care system. It is imperative that the interdisciplinary team collaborate to empower, educate and provide resources to ensure a successful and safe discharge.



In recent years, the Pharmacy department at Nationwide Children’s Hospital has implemented a bedside medication delivery service that incorporates pharmacist-led discharge counseling. Pharmacists involved in TOC document an intervention on 61% of their patients, which has resulted in more than 2,000 total interventions in the past year. Examples of common interventions include switching dosage forms to optimize administration, adjusting duration of therapy to follow evidence-based guidelines and identifying medications that will be covered by insurance. Pharmacists can also create accurate medication lists, daily schedules and calendars that can be written in the patient’s preferred language. Focused education for each prescription allows patients and caregivers to understand the purpose and identify potential side effects. Patients and caregivers have direct access to a pharmacist to ask questions, voice concerns and collaborate to create a medication regimen that works best in their daily life.

Navigating the hospital setting can prove to be overwhelming for many patients and their caregivers, especially during transitions in and out of the health care system. It is imperative that the interdisciplinary team collaborate to empower, educate and provide resources to ensure a successful and safe discharge. Pharmacists at Nationwide Children’s have made significant strides over the last few years in providing patients and families the support they need as they get ready to go home. As a result of these interventions, patients and caregivers can gain the skills to successfully adhere to a manageable medication regimen in any setting.



Surgical Smoke-Free Environment

Pamela Chism, MSN, RN, CPN, Nurse Director, Westerville Surgery Center

In 2019, a Westerville Surgery Center operating room nurse attended the Association of periOperative Registered Nurses (AORN) conference. She brought back with her excitement regarding smoke evacuation and how this eliminates the risk of inhaling surgical smoke in the operating room (OR). To begin implementing this technology, the clinical leader scheduled educational in-services with manufacturers committed to improving the OR environment. Surgical smoke is a byproduct generated when the surgeon uses electrocautery and other devices to cauterize vessels and tissues. In the *Journal of Perioperative Care and Operating Room Management*, Dr. Kay Ball and Richard Glider describe over 100 hazardous substances found in surgical smoke and workplace safety concerns due to prolonged exposure to these substances.

Jonathan M. Grischkan, MD, MS, FACS, FAAP, Department of Pediatric Otolaryngology at Nationwide Children's Hospital, agreed to be the surgeon champion for the surgical smoke evacuation project. In partnership with nursing leadership at the Westerville Surgery Center, Dr. Grischkan helped choose the most effective smoke-evacuating tool. The smoke-evacuating cautery system selected by the team was ergonomically superior making it the best choice for the team. Strong working relationships

between the surgery center nurses and the surgeons along with the team’s overall adaptability to this change led to successful implementation.

At Nationwide Children’s, we are leading the *Journey to Best Outcomes* by focusing on evidence-based practice and safety for both our patients and our employees. Last summer, Ohio passed Senate Bill 86 which established that ambulatory surgical facilities would adopt and implement policies related to surgical smoke evacuation, including the use of a smoke evacuation system. Thanks to the efforts of this multidisciplinary team, the Westerville Surgery Center and other surgical locations at Nationwide Children’s were prepared to meet this new standard. All three surgery locations have started using smoke evacuation products to ensure a smoke-free environment.

With the assistance of Wendy Whitaker, BSN, RN, operating room clinical leader, the Westerville Surgery Center received the AORN Go Clear Award for our commitment to becoming smoke-free. Hannah Campbell, CSM, shared that, “Nationwide Children’s Hospital Westerville Surgery Center is officially recognized as a Center of Excellence in Surgical Safety.