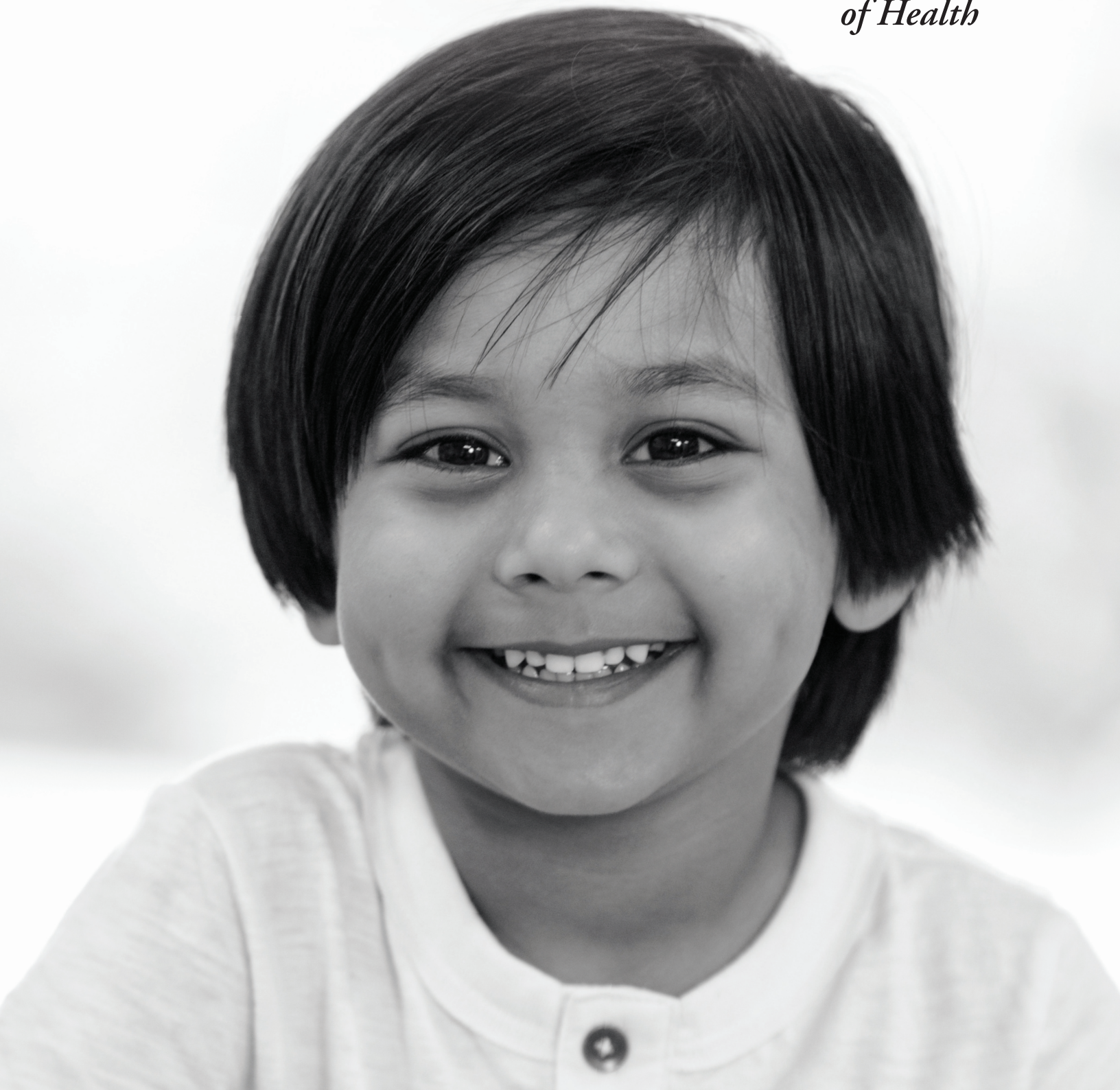


..... Everything Matters In

Patient Care

*Social Determinants
of Health*



*The staff at Nationwide
Children's Hospital is
dedicated to improving
the social determinants
of health for children.*



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Pictured left: As we dive into the definition of health in this issue, you'll learn it means not only not being sick, but actually being well.

Improving the Social Determinants of Health for Children



Linda Stoverock
DNP, RN, NEA-BC,
Senior Vice President,
Patient Care Services,
Chief Nursing Officer

This issue of *Everything Matters in Patient Care* reports on some of the many ways Nationwide Children's is dedicated to improving the overall social determinants and population health of children. Our organization recognizes that not all children receive the necessary resources to help them reach their full potential and that health equity must be a key component of programs to improve population health.

What is health equity? According to the American Public Health Association, health equity means that everyone has an opportunity to reach his or her highest level of health. Health equity recognizes that not all children have the same advantage to reach their full potential and that goals to provide these extra resources are important in improving health. As Steve Allen, MD, said, "Zip code should not determine the health of a child." In order to truly impact care across all zip codes, Nationwide Children's must partner with other community groups and leverage resources to help infants and children reach their potential.

National and state data tell us that there are more infant mortalities in some zip codes than others. It is important to understand the health inequities that contribute to these mortalities.

Asking pertinent questions such as, "Do women have the necessary resources for healthy pregnancies?" is a start. It is important to provide evidence-based programs that reduce infant mortality, such as providing pre- and post-natal care, access to good nutrition, promoting breast feeding, educating about safe sleep, and providing well-child visits. Families within our own and other zip codes may have added barriers such as transportation or living in a "food desert" that creates immediate disadvantages for children in getting a healthy start.

Access to health insurance is another important factor in regards to population health. According to the Kaiser Family Foundation, 74% of all uninsured families in 2015 had at least one full-time worker. Reasons for this disparity are that employers do not always offer health insurance or, if they do, the premiums are too expensive for the employee. Programs that leverage this for all families help all children have a head start in life.

These are only a few elements of population health. Read more in this issue to learn about our programs, and ways you can make a difference for best outcomes for everyone, not just those children who reach our doors.

***"Zip code should not determine
the health of a child."***

— Steve Allen, MD

Social Determinants of Health and Why Everything Truly Matters

Deena Chisolm, PhD, Vice President of Health Services Research

Director, Center for Population Health and Equity Research

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“Health isn’t just not being sick, it is actually being well.”

As providers in the health care system, we think a lot about things like “keeping people healthy” or “restoring people to good health” but how often do we really think about what “health” really is and how we reach it? The World Health Organization defines health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.” More simply put, health isn’t just not being sick, it is actually being well. When we think about health this way, it is easy to understand that the health care system is only a small part of the health equation. In fact, it has been estimated that health care only explains about 20% of the health of the population, while health behaviors and social and economic factors drive 30% and 40%, respectively. This means that we cannot achieve the best health for the population by just providing exceptional health care. We have to think hard about what happens before and after people interact with the health care system and even what happens to people who never seek or receive care.

The term *social determinants of health* (SDH) has been used to describe the combination of social and physical experiences and exposures that affect us in the places where we live, work, learn and play. The Center for Disease Control defines social factors as things like access to educational, economic and job opportunities, transportation options, public safety, and availability of resources to meet daily needs like safe housing and local food. Physical factors include the environment such as buildings, sidewalks, bike lanes and roads, toxic substances and pollution, parks and green spaces. Taken together, the differential distribution of these factors can create an uneven playing field for health, where a person’s zip code tells us more about their likely health problems than their genetic code.

More recently, terms like *social drivers of health* and *social opportunities for health* have been proposed for use instead of social determinates of health to reflect the understanding that these social factors don’t *determine* the health of any individual in the population. They instead create environments that make good health difficult for everyone. As such, SDH require solutions that both address systemic problems and, at the same time, support each person’s ability to maximize their health within their current situation. This goal of enhancing each person’s ability to achieve optimal health is often referred to as reaching for *Health Equity*. That is our ultimate goal but we still have room for improvement.

Ohio ranks in the bottom half of states for child poverty, high school graduation, adult incarceration, unemployment, and many other measures.

The Health Value Dashboard, published by the Health Policy Institute of Ohio, brings together data from multiple sources to examine Ohio’s rank and relative to other states on health and SDH. It also highlights gaps in outcomes between groups for some of Ohio’s most at-risk populations. Overall, Ohio ranks 46th in health value, defined as the health outcomes that are achieved for the amount of money that we invest. According to this report, Ohio ranks in the bottom half of states for child poverty, high school graduation, adult incarceration, unemployment, and many other measures. These SDH challenges are experienced most acutely in the state’s racial and ethnic minority, rural, and disabled populations.



For example, if we were able to close the Black-White racial poverty gap in the state, more than 100,000 fewer Black children would be living in poverty. Most strikingly, here in Ohio, residents in a suburban Cleveland census tract can expect to live 89 years while in census tract on the west side of urban Columbus, the average resident can only expect 60 years of life. That is a difference of nearly 30 years. Both of these neighborhoods have excellent health care systems nearby, but these data show that excellent health care is not enough. The places we live and the hardships, hassles, stressors and opportunity limiting conditions associated with those places matter.

As part of the Nationwide Children's Hospital strategic plan's commitment to wellness and population health, a multidisciplinary team has developed an approach to assess each Nationwide Children's patient's specific social needs while they are in the clinical setting. To date, we have screened more than 30,000 thousand patients for food insecurity, housing instability, transportation needs and utility needs. Each patient with an identified need is provided with information on local resources where they can get assistance and those with urgent needs receive additional direct support from a social worker if they desire it.

Residents in a suburban Cleveland census tract can expect to live

89 years
while in census tract on the west side of urban Columbus, the average resident can only expect **60 years.**



Nationwide Children's approach to SDH also extends beyond our clinical care settings, to our quality improvement activities, our community wellness

initiatives, our health policy engagement, our quality improvement and our research. This includes:



Assessing our processes of care and ensuring that we provide culturally and linguistically appropriate, patient and family-centered whole-child care.



Assessing the needs of the communities we serve and building collaborative approaches for neighborhood development.



Assessing the health and social landscape and working with policy makers, government agencies, schools, businesses, faith communities and others design systems that address the whole child and whole family.



Researching how factors like health literacy, substance use, food access, health care disparities and community development projects effect outcomes like infant mortality, obesity, health care costs and quality of life.

Our unique position as a trusted provider of care and member of the community allows Nationwide Children's to be part of not just the health care solution but the health outcomes solution for the children and families

we touch. However, the health care sector cannot achieve *Best Outcomes* alone. Community solutions require community engagement. When it comes to social factors we can certainly say that everything matters.

Optimizing Patients' Transition Home

Addie Brown, PharmD, PGY1 Community Care Pharmacy Practice Resident

A hospitalization is a stressful time for both the sick child and family members. Frequently, families face several significant life changes simultaneously: new diagnoses, medications, recommended lifestyle modifications and expenses. All of these factors can contribute to patient or caregiver apprehension when discharged and transitioned home. In addition, numerous social determinants may play a role in patients' health, including where they live, access to community pharmacies, what language they primarily speak and their financial situation.

Studies have shown that 28% of medications are never picked up from a community pharmacy once a patient is discharged from the hospital, and up to 60% of patients may have medication errors at discharge.

Both situations have potential to result in readmissions, preventable medication-related adverse events and increased financial burden to patients and the health care system. Accordingly, the Pharmacy Department at Nationwide Children's Hospital established the Transitions of Care service in 2005 with a goal of easing the transition for patients from around-the-clock care and close supervision by highly-trained healthcare providers back into the community.

While admitted, pharmacists play a key-role in the multi-disciplinary approach for comprehensive medical care, by assisting providers with medication selection, dosing, checking for drug interactions, and much more. Once the health care team determines a child is ready for discharge, home-going prescriptions must be sent to a pharmacy. Nationwide Children's has three outpatient pharmacies: Blue, Orange and Yellow.

The Blue Pharmacy, located within the main hospital, dispenses hundreds of medications each day, with many for patients being discharged. Pediatric-trained pharmacists working in the outpatient pharmacies directly communicate with inpatient pharmacists, providers and nurses to resolve medication-related problems prior to discharge. In addition, they have the ability to access pertinent hospitalization information, dispense compounded and pediatric-specific medications, and collaborate with financial counselors.

The Transitions of Care service, located within the Blue Pharmacy, delivers medications to the bedside and provides individualized, comprehensive medication education to families. The pharmacy-led service, currently completes more than 170 deliveries each month and is run by one full-time pharmacist with the assistance of pharmacy residents and student pharmacists. Upon delivering the medications to the bedside, the pediatric-trained pharmacist counsels the patient and/or family on each medication, including indication, administration, frequency, timing of doses, duration and adverse effects. Additional services include technique demonstration with devices, providing medication schedules and educational handouts, and utilizing translators and interpreters. Completion of the transaction and counseling at the bedside facilitates an environment where families can ask questions about medications without interruption. This service ensures patients' have their medications in-hand upon discharge, eliminates potential gaps in therapy and ultimately saves the family a trip to the pharmacy.

In addition to striving for exceptional care during inpatient hospitalizations, Nationwide Children's also attempts to optimize acute- and long-term health outcomes following patient discharge. The services provided by the Transitions of Care program are designed to improve the discharge process. This aligns with and seeks to uphold Nationwide Children's mission that no child should be refused the highest quality health care and necessary education despite limited ability to pay for services.

On A Mission: Increasing Graduation and College Acceptance Rates for Local First-Generation College Students

Natosha Willis, PhD, Project Director for Upward Bound Math & Science

In October 2017, the U.S. Department of Education awarded Nationwide Children's Hospital with a five-year grant to support the implementation of the prestigious Upward Bound Math & Science (UBMS) program on the campus of Nationwide Children's. The program is housed in Nationwide Children's Community Wellness department, within the Healthy Neighborhoods Healthy Families (HNHF) initiative. The focus of the HNHF initiative is revitalizing Columbus' South Side through programs and partnerships that support the health and well-being of children and families in five key areas that include: Affordable Housing, Education, Health and Wellness, Safe and Accessible Neighborhoods, and Workforce Development. Within the Education prong, HNHF supports programs to improve educational outcomes for children and youth in the community.

Kelly Kelleher, MD, serves as Principal Investigator for the UBMS grant. Under his leadership, the HNHF team applied for UBMS funding to support HNHF's effort to increase high school graduation rates in its target zip codes. An extensive number of studies have confirmed that higher levels of educational attainment correlate with better health. The literature suggest that individuals with advanced schooling may have more ability to advocate for themselves within the health care system.

The mission and goal of UBMS directly aligns with the HNHF initiative. UBMS is a component of the larger TRIO programs. Federal TRIO programs emerged out of the Economic Opportunity Act of 1964 in response to the administration's War on Poverty. These programs focus on increasing access to higher education for economically disadvantaged students. UBMS was created in 1990 to address the need for specific instruction in the fields of math and science and to encourage youth to pursue the emerging, innovative STEM fields.

The Nationwide Children's UBMS program serves high school students from low-income households and whose parents have not earned a college degree. Participants live in the 43205, 43206 and 43207 zip codes and/or attend Marion-Franklin or South High school. There is a (rigorous) application process, as students must complete an application and two essay questions and, also, students must submit transcripts, grades, and recommendations. Once materials are submitted and reviewed, students and their families are called in for an interview. UBMS serves 60 9th through 12th grade students each year until they graduate and pursue post-secondary opportunities. There are six required objectives for UBMS, including academic performance, secondary school retention and graduation, postsecondary enrollment, and postsecondary completion.

The Nationwide Children's UBMS program officially launched programming in January 2018. Throughout the academic year, the program offers mentoring, tutoring, Saturday experiential learning sessions, academic counseling, cultural events, career networking events, college exam preparation, and other activities. The UBMS team designs and implements programming to meet the needs of the participants, as they are the focus. During the summer, students participate in a six-week learning academy that incorporates courses, dorm-living, and a national college tour. This summer, students were provided with the opportunity to work with the PAST (Partnering Anthropology with Science and Technology) Foundation as they learn about Arduino computing platforms. Additionally, students will research and learn about assistive devices and their uses in the education and healthcare settings. As a culminating project, students will present their information, poster style, at the first ever UBMS Research Symposium.

The UBMS summer work-study program provides juniors and seniors an opportunity to intern with a

department at Nationwide Children's. Students submit applications, interview with potential departments, and attend hospital orientation. Students work alongside hospital staff for five-weeks, helping to develop programming and projects as well as day-to-day tasks. Through the work-study program, students are able to explore various careers and add to their work skills.

The Nationwide Children's UBMS program just graduated its first senior class, with all ten seniors graduating, on time, from high school. With all accepted into at least one college or university, the bar has been set for classes to come as to what a UBMS graduate exemplifies. Most seniors received scholarship

money from their selected postsecondary schools, and many have earned summer employment opportunities with Nationwide Children's or other partner-employers.

An overarching goal for Nationwide Children's is that the UBMS program create more intentional pathways for potential first-generation college graduates who are interested in healthcare careers. With exposure to the amazing faculty, researchers, physicians, and staff at Nationwide Children's, UBMS participants are provided with life-altering opportunities to explore their interests and the unknown. This exposure is representative of HNHF's efforts through programs like UBMS to create a more equitable and diverse South Side.



Understanding Immunosuppressant Adherence in the Pediatric Hematopoietic Stem Cell Transplant Population

Micah A. Skeens, PhD, RN, CPNP-PC, Nurse Scientist, Department of Nursing Research

Rates of adherence to recommended treatment have been reported at approximately 50% overall in pediatric patients.

These rates are typically lower in chronic disease. The most important determinants of non-adherence are complexity and duration of treatment regimens. Patients undergoing difficult pediatric hematopoietic stem cell transplants (HSCT) that require complex medication regimens are at high risk for medication non-adherence.

The three known HSCT studies reported adherence rates from 57% to 94.7% during the acute phase (first 100 days post-transplant). None of these studies examine adherence to immunosuppressant therapy alone. Our study aimed to describe adherence to tacrolimus during the acute phase in outpatient pediatric HSCT patients.

We conducted a retrospective descriptive study of 357 clinic visits (n=57 patients) between 2009 to 2016. Direct (tacrolimus levels) and indirect (subjective reporting) measures were evaluated.

Fifty-one percent of visits did not document adherence. Our study found an overall non-therapeutic rate of 59.6% using direct serum assay method. Patients with at least one non-therapeutic level were in the outpatient period longer than those with therapeutic levels ($p = .002$). There was no statistical association between gender, graft versus host disease or readmissions. Patients 1 to 5 years old were the group most often non-therapeutic.

This is the first known study to examine adherence to tacrolimus in the acute phase post-transplant. Although our indirect adherence rate of 96% was high, our overall adherence rate of 58% using direct measure is similar to previously reported data. More than half of the patients (53%) were non-therapeutic *more than* 20% of the time and 34.4% of the patients were non-therapeutic *more than* 40% of the time.

This study highlights the necessity for adherence awareness, assessment and documentation in clinical practice. Further studies are needed to determine facilitators and barriers, best measurement methods, correlations to outcomes, as well as interventions to improve adherence. Good adherence is fundamental to safe, cost-efficient transplant with optimal long-term outcomes. Research to improve adherence is crucial.

A Wellness Strategic Plan Focus: Identify Opportunities to Support a Family's Connection to Needed Resources

Jeanette Foster, MSW, LISW-S, Director, Social Work & Language Access Services
Millie Dolce, PhD, MSW, LSW, Program Evaluator Analyst - Wellness Initiatives



To illustrate social determinants of health, let's review a case study about "Nancy." She is 29 years old and the single parent of three small children. She has family in the area, although similar to her, they are working multiple jobs in order to meet the basic needs of their families. At Ohio's minimum wage of \$8.55/hour, her annual salary of approximately \$25,000/year entails her working 60 hours a week.

Nancy works endless hours to provide for her family. She both lives and works in Groveport near Main Street. She has no car because she cannot afford it. Her rent is \$743/month. The three kids have been seen by a variety of providers at Nationwide Children's Hospital and are generally well, however one child has asthma and another requires follow up with Neonatal Developmental clinic.

It is challenging for Nancy to get to appointments at the hospital. She cannot afford to take time off from work and she doesn't want to abuse her time off in case of a medical emergency with the children. She has a COTA monthly pass for herself and the two children over twelve years of age. This costs her \$186/month when she can afford to buy them. If she cannot afford the monthly pass, each trip to Nationwide Children's for appointments costs her \$15.75 for the family. It also takes them an hour and 21 minutes each way in travel time alone.



Let's review her situation:



\$25,000 per year in income
(working 60 hours a week in 2 separate jobs)



\$8,916 in rent



\$2,900 in utilities
(does not include cable/internet but does include mobile phone)



\$1,440 in child care/sitters
though this is much less than it had been



\$8,832 in groceries



Leaving \$2,912 for all other expenses for the year
– transportation, school related expenses, personal care, apparel, household supplies, birthdays, holidays, fun, etc.

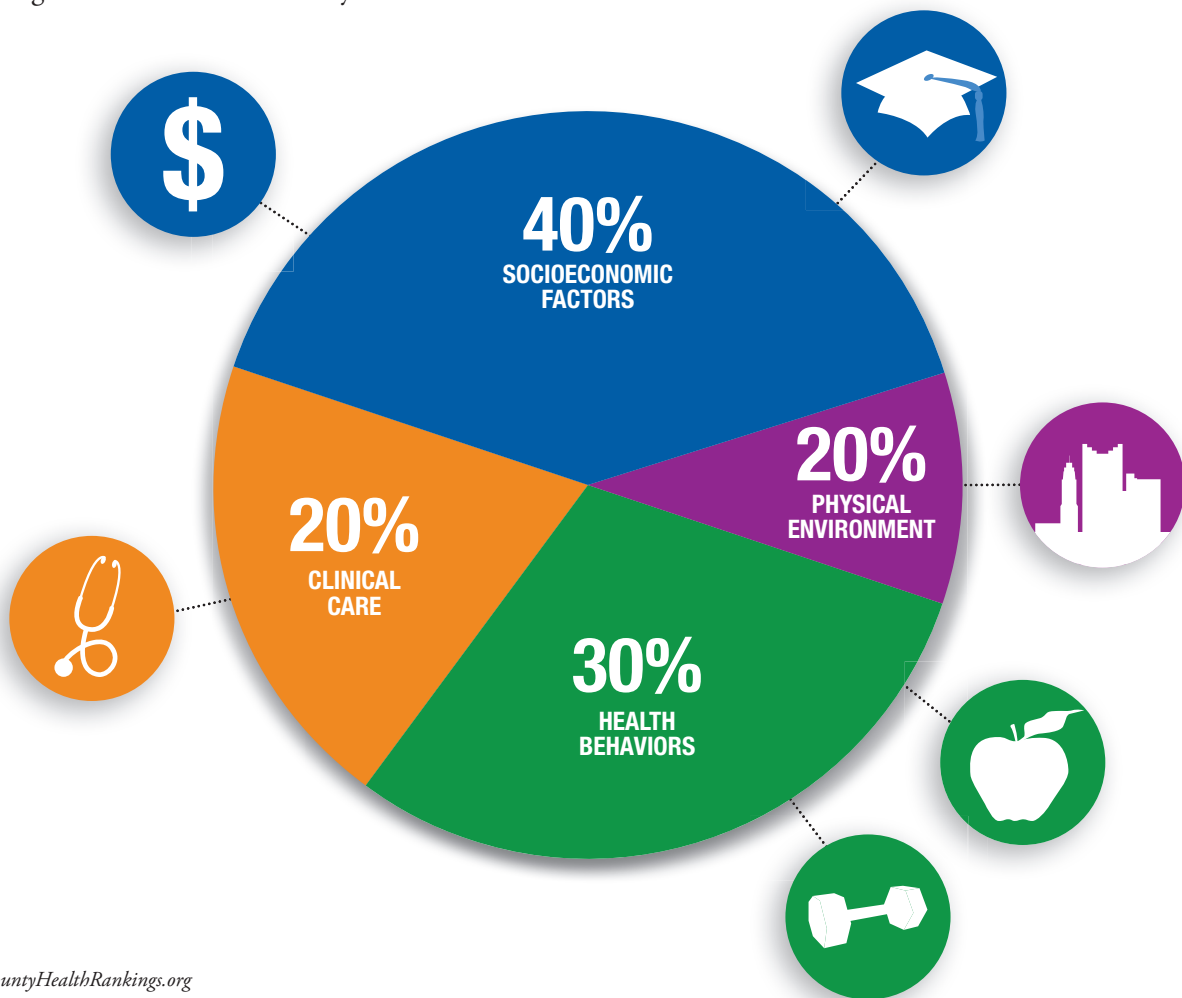
Imagine that the tiniest thing goes wrong – or “right” – and there is an unexpected expense. The math just doesn’t work. No matter how hard Nancy tries to make it work it simply won’t and she will need to begin to make tough decisions.

Nancy’s situation, unfortunately, is not unusual. And understanding Nancy’s situation can be challenging. It requires vulnerability and strength on the part of parents to admit to and risk sharing with us that they have no food at home, are getting evicted, have been laid off from a job, or have been missing appointments because they have been too overwhelmed to even think about and navigate this daunting task. When our patients come for medical or behavioral health care, they often bring so many additional concerns with them. They come with their lived experience, their strengths and a sense of resiliency.

Social Determinants of Health (SDH) have a large influence on health outcomes. Identifying these needs and linking patients to appropriate resources has potential to positively impact health outcomes. Since June 2018, Nationwide Children’s has been implementing a SDH screening tool to identify families’ health-related social needs and make referrals to community resources (through a resource handout) that can help meet these needs. The overall goal is to improve health care outcomes for the child. As a plank in the strategic plan under population health, the SDH tool attempts to create a standardized process for Nationwide Children’s to screen all patients once a year for issues with housing, food insecurity, transportation and utility needs. The screen will be implemented during a phased roll out over the next three years.

Social Determinants of Health (SDH) are the conditions in the places where people live, learn, work and play

An estimated 80% of health outcomes are influenced by social determinants of health



Source: CountyHealthRankings.org

As of May 18, 2019, 30,054 families have been screened and of those screened, 5,485 have identified needs. Approximately 11% of the needs have been related to housing, 35% food insecurity, 31% transportation and 24% utilities. Among other interventions, our social workers and care management clinicians have assisted families with care coordination, resource linkages, and solution focus problem-solving.

It is important to get family feedback on the SDH screen and screening process. During the summer of 2018, a team based in the Center for Population Health and Equity Research surveyed families at two primary care clinics about their experiences and preferences of the screen. Overall, families seemed to welcome the screening process for SDH during their child's appointment. In addition, families thought that it was both helpful and appropriate for medical staff to ask about their social needs during their visit. Families with a

SDH need preferred someone to help them navigate potential resources as opposed to just receiving the resource handout. The SDH planning team plans to incorporate this and future family feedback to continue to improve and assist families in navigating appropriate resources both at Nationwide Children's and in the community

Now let's get back to Nancy and her kids. As a result of the screening and connection to organizations in the community who could assess her situation, Nancy qualified for \$642/month in help with food, subsidies for child care which reduced her expenses to approximately \$80/month, and some assistance with transportation to medical appointments for the children (who are all Medicaid eligible).

These interventions saved Nancy approximately \$8,000 per year which may allow her to be able to make and sustain choices for her family that promote their health and well-being.

Families thought that it was both helpful and appropriate for medical staff to ask about their social needs during their visit.





The Expensive Cost of Living in Poverty

DeShauna N. Lee, JD, Inclusion and Culture Manager, Human Resources
Diversity, Inclusion and Cultural Competency



Complex.
Stressed.
Overwhelmed.
Disorder.
Gratitude.

Complex. Stressed. Overwhelmed. Disorder. Gratitude. These are just a few feelings expressed by employees who participated in the Poverty Simulation offered at Nationwide Children's Hospital. This experiential opportunity is used as an empathy-building tool, and is incorporated into Nationwide Children's monthly diversity curriculum to sensitize employees to the realities of generational and situational poverty and community involvement.

In this two-and-a-half hour, CE approved simulation, participants and community resource volunteers are the two groups represented. A maximum of 80 employees/participants from across the hospital's footprint are instructed to suspend their current realities before entering the room and are asked to fully embrace the identity of one of the 26 real-life family profiles. Some of the families are homeless; others are grandparents trying to obtain custody

of their grandchildren. There are others who are suffering from a mental illness, but lack assistance to attend hospital visits and or obtain medication.

The second group, community resource volunteers, are a crucial element to creating an experience that mirrors the real-life struggles of those living in poverty. The 18 to 22 volunteers serve as representatives from the community such as payday loan officers, employers or social services and interact with participants as they attempt to navigate community resources with limited income.

The simulation replicates a month in the life of a family living in poverty broken down into 15-minute segments. The ultimate mission of each week is simple - to survive! Employees are asked to complete a list of tasks such as attend appointments, pay for childcare, go to work, avoid shut-off notices and housing evictions all while maintaining their household and other personal obligations. After, employees are asked to share their experience.

Commonly, the concept of poverty is described as the shortage of materials - the lack of food, water, shelter, resources, time, finances etc. Yet, during the debrief, the poverty experience is often reflected in psychological terms - feelings of loss of control, frustration, powerlessness and respect are commonly described amongst employees. Additionally, employees witness first-hand that there is more to “good health” than just health care, and they are reminded that health care is only one factor that contributes to one’s holistic well-being. With this in mind, employees are challenged to broaden their

understanding and to explore health where it starts: in the places where our patients live, learn and play.

As noted by Mullainathan and Shafir (2014), “The over-committed can miss a few deadlines. Dieters can take a break from their diet. The busy can take vacations. However, one cannot take a vacation from poverty.”

The poverty simulation challenges our own prejudice. We become so routine in our daily habits that we isolate ourselves from others outside our own race, religion, cultural community or economic class. This occurs in the workplace as well. How often do we truly interact with others outside our department/unit? While unintentional, this type of behavior and isolation feeds systems of poverty since it limits our perspective, fuels bias, and diminishes engagement and shared resources. To be seen as “other” is like being the non-agent, non-subject matter and the non-being - in other words, irrelevant to others.

A substantial number of patients/families are experiencing economic distress, and those who have limited understanding of the challenges of poverty may hold misconceptions regarding the patient’s commitment to their health care needs. This lack of exposure is likely to hinder the employees’ potential for competent intervention, display of cultural humility during patient interaction, and would draw greater socioeconomic disparities preventing us from reaching *Best Outcomes*. Additionally, we must be mindful that some challenges highlighted in the simulation may be real-life for someone we work with every day. Thus, expanding the scope of empathy is not only needed for our patients, but for our co-workers as well.

Registration for Poverty Simulation Training can be found and completed in the Learning Center on ANCHOR.

Evidence-based Monitoring of Clinical Symptoms on T4D Infusion Clinic

Merry Gilbert, RN

The T4D Infusion Clinic at Nationwide Children's provides intravenous (IV) diagnostic and therapeutic services for several thousand ambulatory pediatric patients annually. The clinic performs diagnostic stimulation testing services for Endocrinology patients, enzyme replacement for patients with metabolic disorders and medication administration services, involving high risk biologic and chemotherapeutic IV medications, for non-oncology patients. These high risk medications have the potential for severe sensitivities and adverse anaphylactic reactions can also occur.

As monoclonal antibody (MAB) therapies were being introduced, the clinic was on the forefront, providing this therapy to pediatric patients with gastrointestinal disease. In 1998, infliximab or Remicade®, was first introduced for the treatment of inflammatory bowel disease (IBD). The nursing administration instructions from the drug maker stated to take the total volume of the prepared medication and infuse over three hours; three hundred milliliters would infuse at 100 ml per hour. The patient's initial infusion went well. The subsequent infusions, a month or two later, usually did not go well. Patients developed antibodies to the drug proteins and would adversely react to the medication. Within the first two minutes of the second, third or fourth infusion, facial flushing was noted, followed by coughing and complaints of difficulty breathing. The Registered Nurses (RN) in the clinic noted that vital signs did not deviate from baseline. By reacting to the patient's symptoms and not the vital signs, the RNs were able to prevent further deterioration. Stopping the infusion, treating the patient with antihistamines, steroids and antipyretics would stop antigen/antibody reaction, so the patient could complete the medication infusion, at a much slower rate of administration.

The RNs noticed that there was an interval pattern that could predict the patient's intolerance to an IV medication. Patients seemed more vulnerable to

experiencing a sensitivity or an adverse event, the longer the interval, between the infusion treatments. For many patients, these second, third or fourth infusions would trigger the insensitivity. Patients with these infusions were roomed close to the nurse's station so that they could be watched for facial flushing. Once flushing occurred, the infusion was stopped and the provider was notified. Often the patient did not immediately realize what was happening since the experienced nursing staff were able to identify the reaction so quickly, based on their clinical symptoms.

These observations led nursing leadership to review the administration protocol for infliximab with the Gastroenterology providers and the lead scientist from the drug company, Centocor (now Janssen Biotech, Inc.), maker of infliximab. Based on these clinical observations, a medication administration protocol was developed. Patients were advised to be pretreated with diphenhydramine and acetaminophen 30 minutes prior to the infusion. The rate of administration was adjusted so that the patient would receive the medication more slowly. The rate of administration started out at 10 ml/hour, doubling the rate every 15 minutes as tolerated by the patient to a maximum rate of 150 ml/hr. To limit the time for the patient's body to develop antibodies to the drug's protein, the medication would initially be given with three infusions over a six week induction period. The maintenance interval was every 8 weeks, post induction. These changes, based on the clinic's observations and those of other institutions, greatly lowered the rate of adverse reactions.

From the experience with infliximab, the staff learned in the clinic that they were able to predict an adverse event by observing the patient face to face and for sudden onset of facial flushing. For most medications, facial flushing is the first sign of intolerance. Flushing is followed by slight coughing, complaints of clearing their throat or complaints of a tickle in their throat that was not there prior to the

initiation of the medication. Requests for additional blankets in an otherwise warm environment, can also be a symptom precursor to the onset of rigors. These rigors are often symptoms of an adverse response to an immunoglobulin infusion, or a blood transfusion. Surprisingly, during the patient assessment the vital signs did not vary and vital signs did not predict that an adverse reaction was imminent. Oftentimes, the vital signs remained stable even as the reaction or sensitivity was unfolding. Blood pressure would rise, only in response to the patient experiencing dysphoria. With reassurance to the patient and remaining calm, the RNs realized that they could prevent the blood pressure from rising. The patient's visual, physical symptoms were the cues to medication intolerance.

Nursing monitoring guidelines, as outlined by the Nationwide Children's Pharmacy drug cards, required that a full set of vital signs be performed every 15 minutes as the rate of the medication administration was increased. These vital sign numbers were thought to be a predictor of patient tolerance or intolerance to the medication. Other high risk biologic medications had no monitoring parameters advised when the medication administration rate remained constant, from beginning to end. These monitoring inconsistencies prompted a discussion among the RN staff as to the value of vital sign numbers in predicting an adverse reaction or insensitivity to the medication. Since this area is an ambulatory clinic, they do not have access to telemetry and perform vital signs manually. Because of these requirements the leadership decided to hire a Medical Assistant to help with this time consuming task of taking vital signs every 15 minutes, on multiple patients.

Infliximab and laronidase are examples of medications where infusion rate changes occur every 15 minutes. As per Nationwide Children's drug cards, a set of vital signs must be performed at every rate change. Toddlers receiving Laronidase, for example, detest getting their blood pressures taken on a frequent basis. They receive a pretreatment of diphenhydramine, which makes them sleepy. Disturbing their slumber can result in a blood pressure that is above normal range. The children become angry and are extremely agitated. The RNs did not intervene when there was an increased blood pressure in this patient's type of agitated state. When sleeping quietly with an easy respiratory effort, these children are

not experiencing an adverse event. But rather evaluating the patient as a whole and not just using the numbers from vital signs which have no value in this situation.

The question was raised if other institutions were noticing that vital signs were not a good predictor of an impending adverse event.

Using the principles of Evidence based Practice (EBP) model, a PICOT question was formed:

PICOT	
P	Inpatients receiving IVIG, Infliximab, & Rituximab
I	Does a full set of vital signs every 15 minute
C	Compared with direct observation
O	Predict impending infusion reactions
T	During the course of the infusion therapy

A review of published literature was performed which confirmed the observations; vital signs are not a predictor of an impending adverse event during the infusion of high risk medications. The authors noted that vital signs do not significantly deviate from baseline during the reaction. Blood pressure can rise, only in response to the patient experiencing dysphoria.

Nationwide Children's Pharmacy was in the process of transitioning the drug cards, to Lexi-Comp®. Lexi-Comp is a drug information data base that incorporates the organizations drug monitoring policy with national standards and ensures that information is kept up to date. Nationwide Children's customized our nursing monitoring requirement to reflect this EBP. These changes and evidence were reported to the Pharmacy and Therapeutics Committee who voted to approve the changes in patient monitoring based on this evidence.

Infusion reactions are recognizable by clinical symptoms rather than by deviation from baseline vital signs. Patients can be taught to recognize and report any unusual symptoms that may be indicative of an impending reaction. Nursing resources, which had been previously devoted to time consuming vital signs, are able to be efficiently reallocated, increasing patient satisfaction, privacy, and likely decrease health care costs.

Knowledge and Attitudes Toward Trans* and Gender-Nonconforming Patients

Christine Humphrey, DNP, MBA, RN, Program Manager, H11B and Dialysis Unit

Between
.3-5%
of individuals in
the United States
identify as trans*

Standards of care for transgender and gender-nonconforming individuals were initially published by the World Professional Association for Transgender Health (WPATH) in 1980. However, this population remains misunderstood and ill-served. The term transgender, synonymous with the term trans*, is utilized by individuals whose gender and assigned sex at birth differ from one another, compared to cisgender persons whose gender and assigned sex are aligned. In recent years, gender clinics have noted an increase in the number of gender-nonconforming youth. According to the Journal of Family Practice in 2016, between 0.3% and 5% of individuals in the United States (US) identify as trans*. At the young age of two years, children are able to label themselves as boy or girl and at four to five years of age, gender becomes part of a child's identity. It has also been identified that age 10 to 14 years old is a crucial period for gender identification. Medical staff may be unclear of the criteria for a child to be considered transgender. Just because a child identified with the opposite sex once, does not mean they are trans*. A child is identified as transgender by health care providers after consideration of three key factors: consistence, persistence and insistence. To be identified as trans*, the youth will consistently identify with a different gender across all situations, persistently identify with a different gender over a period of time, and will be insistent in identifying firm belief in their gender identity.

Working at Nationwide Children's Hospital, everyone is in a unique position to positively influence this population

since staff may interact with trans* youth at their most critical times. Conscious and unconscious biases impede the advancement of knowledge and attitudes needed to promote best outcomes for trans* patients. Trans* patients have many of the same health care concerns as cisgender individuals. However, unique needs for this population arise from compounded issues of prejudice and bias. Hospital staff in any capacity must be confident and competent in their abilities to care for trans* patients. Improved cultural competence is one component that is impactful and essential to the improvement of knowledge and attitudes. Cultural competence encompasses awareness of personal beliefs, biases and attitudes, knowledge and understanding of various cultural groups, and the ability to ensure culturally sensitive assessments and interventions.

In caring for transgender and gender-nonconforming patients, it is imperative for staff to provide gender affirming treatment to achieve best outcomes. This does not always mean hormones and transition. More often, gender affirming treatment means treating patients with respect and meeting them where they are. Do not laugh or gossip about a patient's appearance or behavior and do not use stereotypes when providing care for this population. Gender affirming care can improve global functioning for the transgender population. This type of care reduces depressive symptoms, anxiety, body dissatisfaction, suicide attempts and self-harm to scores equivalent or less than the general population.

As health care workers and ancillary staff, it can be easy to make assumptions or jump to



conclusions which create massive obstacles to an effective relationship. Assumptions imply you must look or act a certain way based on your gender. When interacting with patients and families across the continuum, always ask questions and do not make assumptions. Never assume you know a person's gender identity or sexual orientation based on how they look or sound; never assume you know how a person wants to describe themselves or their partners. When encountering a new patient, try to steer clear of words that assume a certain gender identity or sexual orientation. For example, avoid using pronouns or words like sir, ma'am, Mrs., Ms., or Mr. This will help from accidentally insulting the patient or family.

Respecting preferred name and pronoun use is vital in establishing a trusting and respectful relationship. For the trans* population, birth name is often called "dead name" and carries a negative connotation. Always ask about and use preferred name and pronouns. Staff may find insurance, medical record and legal paperwork contradict each other, especially if there

is an ongoing legal process for name change. Staff in the Patient Accounting department work with other divisions to ensure the bill is being submitted appropriately so services are covered. There is no concern, in terms of legality, for hospitals using preferred names and pronouns. In fact, staff are encouraged and expected to use preferred names and pronouns. It is imperative to listen, understand and mirror terms that patients use to describe themselves. Keep in mind that some patients may not like to use terms to describe their orientation and gender identity.

From day-to-day, we must all have a mutual accountability when caring for the trans* and gender-nonconforming population. This will create an environment of accountability and respect which requires everyone working together. Being each other's "wing person" means politely correcting colleagues if they make a mistake or insensitive comments. Working as one we team we have the ability to provide best outcomes for the trans* and gender-nonconforming population.

Health Disparities for Individuals with Disabilities: What Can We Do?

Amy Pequignot, Education Coordinator, International Scholars Program
Chair, CapABLE, Disability Related Employee Resource Group, Education Department



Social determinants of health are conditions in the environments in which people are born, live, learn, work, play, worship and age that affect a wide range of health, functioning and quality-of-life outcomes and risks. Social determinants of health can also be described as social, economic and political systems that can intersect and overlap, and contribute to disparities in health care and access to education, employment and of other aspects of a life.

Having an understanding of social determinants of health can provide a foundation and framework for

understanding health disparities that are faced by people with disabilities. Compared to individuals without disabilities, individuals with disabilities are more likely to experience challenges in the factors that determine or influence health. If health starts in our homes, schools, workplaces, neighborhoods and communities, consider the barriers people with disabilities have to housing, education, employment, transportation and community involvement, and the multiplying effect these barriers have on poor health outcomes. Why is it so important to understand health disparities in this population? Consider these facts.

61 million

Americans have a disability that affects major life activities, according to a report in CDC's Morbidity and Mortality Weekly Report.

1 in 4

U.S. CDC figures show 1 in 4 U.S. adults now live with a disability, with cognitive disability most common in younger adults and mobility disabilities most common for others.

7 million

In 2017 to 2018, the number of students ages 3 to 21 who received special education services under the Individuals with Disabilities Education Act (IDEA) was 7 million, or 14% of all public school students.

\$400 billion

Annual health care expenditures associated with disability are estimated at \$400 billion.

largest minority group

People with disabilities are the largest minority group any person can join at any time, and due to injuries and old age, eventually do!

"At some point in their lives, most people will either have a disability or know someone who has a one," said Coleen Boyle, Ph.D., director of CDC's National Center on Birth Defects and Developmental Disabilities. "Learning more about people with disabilities in the United States can help us better understand and meet their health needs."

Knowledge about the health status needs of people with disabilities is essential for addressing these and other health disparities. People with disabilities comprise a significant portion of the communities that health professionals serve. They are our co-workers, neighbors, family members, friends and community members. Anyone can become disabled at any time and the risk of acquiring a disability can increase as people age, as does the possibility of severe disability and the need for assistance.

- People with disabilities are less likely to receive recommended preventive health care services, such as routine teeth cleanings and cancer screenings.
- People with disabilities are at a high risk for poor health outcomes such as hypertension, falls-related injuries, and mood disorders such as depression.
- People with disabilities are at a greater risk for chronic diseases such as obesity and cardiovascular disease.
- According to the 2018 National Council on Disability report, The Current State of Health Care for People With Disabilities, the absence of professional training on disability competency issues for health care practitioners is one of the most significant barriers that prevent people with disabilities from receiving appropriate and effective health care.

So what can we do to promote the health of people living with disabilities? The answer is the same for the many challenges faced by this population: inclusion.

- When collecting data on disparities and inequity in health care, **include disability status** in addition to REL (race, ethnicity and language). By including disability status, health professionals will be able to use existing data sets to compare the health outcomes and health disparities of people with disabilities across multiple data systems.
- **Include people with disabilities in planning and design** of not only the health care facilities, but also communication methods, products, health literacy programs, community outreach initiatives and inclusive training opportunities.
- **Endorse The Core Competencies of Disability for Health Care Education.** Including disability content and standards in health care education will prepare future providers to deliver appropriate, person-centered, quality health care to people with disabilities across the lifespan.
- **Become an active member of CapABLE**, the disability related employee resource group at Nationwide Children's Hospital.

The mission of CapABLE is to foster an environment of understanding, acceptance, inclusion and continued support for our employees who have a disability, the coworkers of individuals with a disability, the employees who provide care for a loved one with a disability, and our employees who treat and serve patients with disabilities. Members serve as advocates for employees who are disabled, support for coworkers and departments who have employees who are disabled, champions for employees who care for an individual with a disability, and training and resources for employees with patients who have a disability.

For additional information and to learn more about what we are doing to address the disparities in health care for people with disabilities, please contact CapABLEerg@NationwideChildrens.org.



NATIONWIDE CHILDREN'S





Four Time Magnet Designation is a Win-Win for Patients and Hospital

Sherri Watts, MSN, RN, Magnet Program Director

Known as the gold standard for nursing excellence, the American Nurses Credentialing Center (ANCC) Magnet Recognition® is bestowed upon the entire organization. In June 2019, Nationwide Children's Hospital was honored to become the first free-standing pediatric hospital in Ohio to receive a fourth consecutive Magnet designation.

To ensure the ANCC standards of nursing excellence remain current, valuable, and challenging for health care organizations, the ANCC Magnet Application Manual is revised every four years. In Magnet-recognized health care organizations, this every four year renewal cycle is referred to as a journey; each exemplifying special characteristics.

The initial Nationwide Children's Magnet journey is remembered for the small team's ambition and pride for becoming the first freestanding pediatric hospital in Ohio to receive Magnet designation in 2005. This journey's original Magnet document is the only paper manuscript on file. The second Magnet journey was championed by Cheryl Boyd, PhD, who successfully coordinated a document and site visit for the 2009 designation. The third designation was received in 2014 and will always be remembered as having a 4,000 page document, numerous supplemental requests and spirited ANCC appraisers who acknowledged our interprofessional shared governance model. A stark opposite was the most recent journey, which will represent the first electronic document submission of less than 300 narrative pages which scored in the excellence range and took us straight to site visit. Within six weeks, a newly formed Nationwide Children's site visit team scheduled and prepared the hospital for a comprehensive site visit.

For three days in April 2019, time stood still while three ANCC appraisers arrived to validate, verify, and amplify the Magnet document findings of nursing excellence in all patient care settings, nurse roles and nursing practices. The well-orchestrated visit encompassed 30 group interview sessions, including, but not limited to; the Executive Leadership Team, Nurse Managers, Quality Committee, Ethics Committee, Community Members, Nurse Residents, Nurse Educators, Family Advisory Committee and multiple other key stakeholder teams. In addition, there were 30 inpatient unit tours which included four offsite Neonatal Intensive Care Units, the Simulation Center and Transport Team. Furthermore, the ANCC appraisers visited a total of 23 ambulatory patient care settings. It was important to ensure the ANCC appraisers understood that nursing excellence at Nationwide Children's was supported by a large interprofessional collaborative team who enculturated our mission to provide the highest quality patient care. This is achieved through our Zero Hero principles, evidence-based practices and innovative environments.

We were privileged to learn the ANCC appraisers also sensed the compassion that goes into every patient and family interaction, the respect for our One Team values, and the endless opportunities that exists for our employees. Their final report summarizing findings from our Magnet document, as well as, observations and feedback received during the site visit, warranted the Commission on Magnet to confer Nationwide Children's with an Exemplar of excellence for our interprofessional collaborative practices and care coordination. As one of the largest children's hospitals, with more than 1.5 million patient visits in 2018, it is an honor to receive this recognition proving our mission to provide the best care for all children remains.

Nationwide Children's Hospital
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Daisy Award

Laura Brewer, RN

The 25th Annual Nationwide Children's Hospital Daisy Award was presented to Laura Brewer, RN of the C4A NICU. 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.

Laura received the Daisy Award because of her care of a patient who came to Nationwide Children's from across the country. "[The patient] was an extremely challenging patient, as he required constant, intensive care during periods of agitation that at times lasted a full shift," says her nominator. "Despite the multitude of challenges, Laura was somehow able to remain not only an exemplary nurse with high level critical thinking skills, but also became a beacon of hope, positivity and connection to



the outside world for his parents. Laura's impact on nursing care and compassion is clear and always present now on C4A, as nurses have learned from her how highly skilled nursing with chronic, long term patients and families also includes therapeutic relationships, deep empathy and sometimes a sense of humor."

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

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