A NEWSLETTER BY NATIONWIDE CHILDREN'S HOSPITAL FAMILY ADVISORY COUNCIL

How to Protect Your Baby While They Sleep

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Did you know Franklin County and Ohio have some of the worst infant mortality rates in the United States? The infant mortality rate is the number of deaths of infants less than 1 year of age per 1,000 live births. The United States infant mortality rate ranks amongst the poorest among industrialized

nations of the world ranking number 26 in the most recent rankings with a rate of 6.1/1,000 live births. The state of Ohio ranks among the worst in the United States ranking 39/50 with an infant mortality rate of 6.85/1,000 live births in 2014, the most recent year with death data. The 6.85/1,000 live births translates into three babies under 1 year of age dying each week in Ohio or three classrooms of children that will never get to go to school!

The news is no better when analyzing local data for Franklin County where we have an infant mortality rate of 8.3/1,000 live births. More concerning is the disparity between Caucasian and African-American numbers where an African-American infant has a two times greater risk of dying before its first birthday than a Caucasian infant.



The number one cause of infant deaths in the United States, Ohio and Franklin County between one month and 1 year of age are sudden unexpected infant deaths or SUIDS. There are three causes for SUIDS which are sudden infant death syndrome (SIDS),

accidental asphyxiation/suffocation and strangulation in bed as well as unknown causes. The numbers of SIDS deaths have decreased over the years, but unfortunately the accidental suffocation, strangulation and asphyxiation in bed have increased in recent years, probably due to better reporting and investigation after a baby dies as well as the increase in parents sleeping with their babies.

A baby's death cannot be classified as a SIDS death unless there has been a death scene investigation, interview with the caregiver at the time of death, autopsy and thorough review of the baby's medical record. SIDS is what we call a diagnosis of exclusion, which means when there is no identifiable cause, it becomes a SIDS death.

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We still don't know the cause of SIDS, which makes these deaths hard to prevent, but we can prevent the accidental suffocation, strangulation and asphyxiation in bed deaths.

So how do you protect your baby while they are sleeping? First and foremost, you need to follow the Academy of Pediatrics ABCs of sleep for your baby from birth to 1 year of age. The ABC's of sleep stands for the baby to be Alone, on their Back and in their own Crib until 1 year of age. The recommendations also promote breastfeeding, infants being placed on firm surface with a fitted sheet, room sharing and not bed sharing, keeping soft objects and loose bedding out of cribs, keeping the head of the bed flat, as well as pacifier use.

Nationwide Children's Hospital has joined forces with other hospitals and agencies in Franklin County to be part of an initiative called Celebrate One, to ensure that all babies born in Franklin County make it to their 1st birthday. You can do your part in decreasing our high infant mortality rate, by assuring that your baby is always placed in a safe sleep environment, as well as babies of your friends and family members.

For more information on safe sleep, visit NationwideChildrens.org/Safe-Sleep.

Food Focus: Local Dining Options

Samantha Sharpe, Family Advisory Council Member

Nationwide Children's Hospital has a wide variety of food options located within the hospital, with Subway and KoCo's in the Food Court, a vast array of food stations in the Cafeteria, and grab-and-go treats in both gift shops and coffee shops. In addition to these on-site eateries, there are a variety of local restaurants to consider when planning your next main campus meal. Here are some suggestions for whatever mood strikes!

1. The Crest Gastropub - 621 Parsons Avenue (behind CVS); Brunch, lunch and dinner menu focused on excellent service, locally-grown and locally-sourced food and innovative, seasonal menus all with a

commitment to our environment and community. Many vegetarian, vegan and gluten-free options with a wide variety of tap beverages and a fantastic small plate happy hour. Anyone with an employee or parent badge will receive a discount on their bill.

- 2. Alchemy Juice Bar + Café 625 Parsons Avenue (behind CVS); Fresh, wholesome, innovative food and drinks that nourish both the mind and body. Incredible selection of packaged fresh salads and sides, made fresh sandwiches and the best smoothies in town! Try the Snickerdoodle smoothie for a sweet treat or the Breakfast II Smoothie for a caffeine pick-me-up.
- **3. Upper Cup Coffee House** 79 Parsons Avenue; House-roasted espressos and creative pours are the focus of this brick-walled café located just north of the hospital. Craving an iced chai or café mocha? This coffee shop is worth the visit!
- **4. Happy Dragon** 277 East Livingston Avenue; (614) 224-1468. A local staple for Chinese food! A huge menu (and portion sizes) defines this delicious destination. Enjoy choosing from the lengthy selection of Hunan, Sichuan and Cantonese dishes with free delivery to Nationwide Children's with orders over \$25.
- **5. Plank's Pizza** 743 Parsons Avenue; (614) 443-6251. A neighborhood institution featuring an eclectic comfort food menu, beer and sports on the multiple TVs. All pizzas have a bit of a surprise: sweet dough! Delivery available 11 a.m. to 11 p.m.



Don't want to go out but still want delicious food? Consider using UberEATS, GrubHub or Skip The Dishes. There are many, many local restaurants featured, too many to list! All of these food delivery services will come to the C Lobby of the hospital, near Crossroads Registration in the middle of the hospital. There is a valet parking and patient drop off area with a "courier parking" sign to meet your driver.

Regardless of your choice, enjoy your meal!

ED vs. Urgent Care

In February, Nationwide Children's opened a freestanding Emergency Department in Lewis Center. With two EDs now and a variety of Urgent Cares, it can be hard to know just where to go! Here are some tips.

Treatment for the following conditions is provided at Nationwide Children's Hospital Main Campus **Emergency Department and the Lewis Center Emergency Department:**

- Broken bones
- Burns
- Difficulty breathing/respiratory distress
- Fever (especially in infants eight weeks of age or younger)
- Seizure
- Severe pain



The Lewis Center Emergency Department is staffed and prepared to treat and stabilize any emergency situation. However, if the patient is stable, in the following situations it would be best to be seen at the Main Campus Emergency Department where specialists and inpatient resources are more readily available:

- patients who will most likely need admission to the hospital;
- major trauma/injuries;
- injuries following a motor vehicle accident, being struck by a vehicle or fall from a height;
- concerns for illness or injury from abuse or assault.

Urgent Cares offer treatment for illnesses and injuries that need immediate attention, but do not need to be seen in the Emergency Department. Treatment for the following conditions is provided at a Nationwide Children's Urgent Care Center:

- Allergic reactions
- Asthma/difficulty breathing
- Small broken bones (service not provided at Main Campus Urgent Care)
- Minor/small burns
- Minor/small cuts (service not provided at Main Campus Urgent Care)
- Fever
- Rashes
- Sore throat
- Vomiting and diarrhea

Nationwide Children's Urgent Care facilities work with the Emergency Departments to ensure each child receives the best care in the appropriate location.

To learn more, visit NationwideChildrens.org/ed-urgent-care.

Partners in Care, Partners in Hope 2016 **Award Recipient**

Dr. Mohamed Abdelbaki is the 2016 recipient of the Partners in Care, Partners in Hope Award of Excellence in Family Centered Care. Tim and Jennifer Allerding nominated "Dr. Mo" for the care he provided to not just their son, but to the whole family.



Tim, Jennifer and their son, Kaden, presented Dr. Mo (center) with the 2016 award.

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Jennifer Allerding stated, "I am so grateful for all Dr. Mo has done for our family. He has an attention to detail beyond most doctors. He is knowledgeable, works collaboratively with us and the team, he makes us laugh, he is honest about possibilities, and also provides a demeanor that is calming and reassuring. I have trusted this man with my most prized possession, my son's life."

The nomination letter showed all the core concepts of family centered care: dignity and respect, information sharing, participation and collaboration.

Each year, the award recipient is given a handcrafted award made by a local artist with a connection to Nationwide Children's. This year's artist was Mehri Davis.

The award selection committee had several standout nominations this year, and a very difficult choice had to be made. You can find the nominees for this year's award listed on the Partners in Care, Partners in Hope page of NationwideChildrens.org. You will also find the Allerding family's full nomination letter posted there.

Deadline for the 2017 nominations is December 1.

Opening this May: Livingston Ambulatory Center

To better serve our families, several clinics are moving this spring to our new Livingston Ambulatory Center, 380 Butterfly Gardens Drive, on our expanded main campus.

Attend an Open House on Thursday, May 4 from 3 to 7 p.m. to preview the new facility and enjoy refreshments!



This building will be home to many of our busiest clinics, such as:

- Adolescent Medicine
- Behavioral Health
- Center for Healthy Weight and Nutrition
- Dental Clinic
- Primary Care

A new parking garage, the Yellow Parking Garage (420 Butterfly Gardens Drive), is adjacent to the Livingston Ambulatory Center and is near Livingston Avenue and Grant Avenue. Valet services are also available at the front door.

We are expanding our Express Check-in program into the new building to simplify and expedite the check-in process. Upon entering the building, families will go directly to the level their clinic is on and check in there. Express Check-In kiosks will be available for those who have been contacted by Nationwide Children's to be preregistered or have been seen at Nationwide Children's Hospital in the past 30 days.

Visit NationwideChildren's.org/LAC for more information and a full listing of clinics in the building.

MyChart Is Better Than Ever!

More than a dozen new features were added to MyChart in 2016! In addition, functionality has been enhanced for many of the current features on desktop and mobile. Now, more than ever, MyChart is a must-have tool to help manage your family's care. Here are five ways MyChart can make your life easier.

- 1) Securely and confidentially communicate with your child's care team. Your care team can message you too a great way to exchange information without having to coordinate schedules.
- View and print your child's eye prescriptions to order glasses or contacts.

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- 3) Keep track of past and upcoming appointments.
- 4) Need a copy of your child's school excuse or gym absence letter? Print a copy of provider letters at your convenience.
- 5) Review test and lab results quicker than waiting for a phone call.

Learn more about MyChart at MyChart.NationwideChildrens.org.

How Canine Companions Can Help!

Jennifer Bobbitt, Family Advisory Council Member

In December of 2012, our family of five found ourselves in a very unfamiliar place. Our youngest child, Andrew, had just turned 13 and less than two weeks later, he suffered a major hemorrhagic stroke as the result of a brain aneurysm. He went from a very healthy, active 13-year-old teenager, to a child requiring multiple brain surgeries. He lost the ability to walk, talk, read, write and his left side was immobile.

While at Nationwide Children's Hospital, we were introduced to Canine Companions for Independence (CCI) through the Service Dog that worked at the hospital. Ansley, the Service Dog, was owned by one of the speech therapists and soon became one of Andrew's favorite visitors during his hospital stay.



After two months in the hospital and multiple brain surgeries, we brought Andrew home. After two years of therapies, we signed up for a service dog and two years later we brought Winken home to assist Andrew. We trained as a skilled companion team. This means that Andrew and I both went through the two weeks of intensive training, and as the facilitator, I am responsible for the care of the dog and encouraging a strong bond between Andrew and Winken.

At 17, Andrew has made great strides - he learned to walk, talk, read and write again, and he will graduate from high school in 2018. He plans on attending college with Winken by his side. You may have heard the phrase "right hand man" used to indicate that someone is invaluable to you. Well, Winken is Andrew's "left hand dog." Andrew is unable to use his left hand and Winken steps in when an extra hand is needed. She helps him to maintain his carefree, independent spirit.

Tasks CCI Service Dogs are trained to do include:

- Retrieve and deliver dropped items
- Tug to open a door or drawer
- Pull a laundry basket or help with a sock or jacket
- Push with their nose to shut a drawer
- Open a door with an automatic push plate
- Pull a lightweight manual wheelchair over a short distance
- Turn lights on and off

Another way Winken helps Andrew is that she can be integrated into his therapies. Walking, hand eye coordination (playing ball), and speech therapy (addressing the dog and giving commands) are all repetitive behaviors that aide in his ongoing recovery.

A Service Dog can also boost confidence and increase feelings of self-sufficiency and responsibility in someone who has had their life changed through a disability.

Caring for another living being and being the recipient of much affection and attention creates a strong bond and increased responsibility. Having a dog helps keep you on a schedule as they require food, exercise, training and play time.

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CCI trains 4 types of dogs:

- 1) **Service Dogs** assist adults with physical disabilities by performing daily tasks
- 2) **Hearing Dogs** alert the deaf and hard of hearing to important sounds
- 3) **Facility Dogs** work with a professional in a visitation, education or healthcare setting.
- 4) **Skilled Companions** enhance independence for children and adults with physical, cognitive and developmental disabilities.

Most of the Service Dogs placed through CCI are Goldadors; a Golden Retriever and Labrador mix. For the first year and a half they are placed with a puppy raiser who works on basic skills and socialization with the dog. The puppy raisers generously give their time and resources to get the dogs ready for the next leg of their journey. For the next six months, the dog lives in the CCI facility and undergoes extensive training before being selected to participate in the two-week training classes with potential owners. The dogs are provided to eligible recipients free of charge, and the entire program is maintained through charitable donations of time, talents and resources.

To be eligible for the CCI program you need to submit an application request via their website, cci.org. Once your application is approved, you will have a full application to complete along with medical and professional reference forms. The next step is a selection review followed by an invitation to the Team Training class. The entire application to placement process can take up to two years.

Through the process of recovery the past four years and in helping Andrew adjust to a changed life, we have discovered the adventure is not one you can go on alone. The assistance and encouragement comes in many forms - medical, spiritual, community and in Andrew's case, through the assistance of a four legged partner to provide a hand and added joy to the journey.

Primary Care for Kids with Disabilities

Dr. Garey Noritz, Complex Healthcare

The cornerstone of pediatric health care is the services that are provided in primary care offices by pediatricians, family practitioners, nurse practitioners or physician assistants (collectively Primary Care Providers, or PCPs). Primary care services include immunizations, surveillance for health problems, screening for developmental disorders and parental guidance on a range of topics from nutrition to safety to behavior. The current system of primary care is often called a "medical home." The American Academy of Pediatrics describes the medical home as accessible, familycentered, continuous, comprehensive, coordinated, compassionate and culturally effective. This design of primary care grew out of the way that pediatricians provided care to children with special health care needs in years past.

It is ironic then that children with special needs are less likely to receive primary care services. One reason for this is care has become extremely specialized such that care is often provided at large academic centers like Nationwide Children's Hospital, which might be far from a child's home. It can be hard for primary care pediatricians to coordinate care that takes place in the hospital, especially as many children will see multiple specialists, as well as therapists, dieticians, psychologists, etc. Families may also not realize how important primary care services are for their children with special needs.

But this care is extremely important. Children with special needs are children first. While a specialist such as a neurologist is an expert in the brain and nervous system, her training and ability to provide holistic primary care is limited. The family's relationship with the PCP, which is characterized by accessibility and continuity of care, often provides a much-needed source of stability and support. The PCP will always be on the lookout for ways to keep your child healthy, and to make sure a special need does not overshadow the specialness of a child.