

# 2016 Community Health Needs Assessment Implementation Plan

Your child. Our promise.

Nemours<sup>®</sup> Children's Hospital

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## 2016 Community Health Needs Assessment Implementation Plan

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# About Nemours



## About Nemours

Nemours Children’s Health System is dedicated to one promise: To treat each child as if they were our own, doing everything within our power to help each child grow up healthy and reach their full potential. As one of the nation’s largest pediatric health systems, we integrate innovative patient care, research, education, prevention and advocacy to support the children and families in our care and the communities beyond our walls.

In addition to our physical locations, including two freestanding children’s hospitals and more than 60 primary, specialty and urgent care offices in six states, families, educators and health care professionals across the country rely on Nemours’ pediatric expertise. Nemours is not defined by structures or places, but by an incredible group of people, united by a common set of principles and connected by one purpose: *Your child. Our promise.*



We are dedicated to helping families receive “exactly the care they need and want, how and when they need and want it” — improving quality and outcomes, reducing cost and keeping care as local as possible. Clinical integration across our regional networks, enabled by a sophisticated electronic medical record system, increasingly supports the highest levels of patient care at the location of the families’ choosing — at home, in the doctor’s office or at an affiliated community hospital. Nemours CareConnect, the nation’s first pediatric telehealth service, offers families 24/7, immediate access to a face-to-face online consultation with a Nemours board-certified pediatrician via mobile device, tablet or computer.

Our children’s health system contributes to the greater body of child health knowledge in many ways: International “hot topic” conferences and free continuing medical education (CME) units for health professionals; outreach to community physicians and hospitals; and online information and in-person support for health care professionals and families. Nemours helps train the next generation of pediatric specialists through its affiliations with six major medical schools, and annually hosts nearly 1,500 residents, medical students and physician fellows. In 2016, Nemours submitted the Institutional Accreditation for NCH to the ACGME (Accreditation Council for Graduate Medical Education), the first step towards acquiring a pediatric residency program. Nemours will welcome the first residency class at NCH in 2018. Development of the Nemours GME program further demonstrates Nemours commitment to innovation, scholarship and training the next generation of pediatric specialists.

Leveraging our children’s health media, education and prevention resources continues to add value for families, providers and communities — even in areas where Nemours does not have a physical presence. Nemours KidsHealth.org launched more than 20 years ago and changed the way families access trustworthy information about children’s health. Today, KidsHealth is the world’s most visited website for children’s health information by parents, teens and kids and has comforted and entertained more than 2.3 billion visitors.

Nemours also improves the health of children across the country by impacting national policies and practices based upon our expertise and experience. As a trusted resource, Nemours works closely with hundreds of key strategic partners that serve children to advance integrated models of community-based prevention and clinical care, to expand multi-sector childhood obesity prevention, and to deliver superior quality and outcomes in children’s health.

## Nemours in Florida

Nemours Children’s Hospital is home to experienced teams and world-class experts accustomed to working together to care for kids, newborns to age 18. The Emergency Department (ED) at Nemours Children’s Hospital is equipped to handle all kinds of pediatric emergencies. Unlike a general emergency room, our Emergency Department is dedicated exclusively to the care of children from newborns to age 18. Nemours is home to many specialized pediatric programs, some of which offer care never before available in their respective regions. When a specialist is necessary, our pediatricians have immediate access to renowned experts in more than 30 pediatric specialties including:

**Nemours Cardiac Center** in Florida opened in 2016, expanding our existing expert cardiology services to include integrated care for kids with all types of heart disease.

Nemours **pediatric interventional radiologists** are at the forefront of imaging and image-guided therapies, offering innovative ways to diagnose and treat conditions in a minimally invasive way. Of the 100 fellowship-trained pediatric interventional radiologists in the United States, Nemours employs three in Central Florida.

Our **neuromuscular program** offers the area’s only Muscular Dystrophy Association-approved clinic, and Nemours Children’s Hospital is one of only four locations in the world conducting the first targeted drug trial for spinal muscular atrophy.

**Nemours orthopedic specialists** develop treatments to help children with bone, muscle and joint conditions become more independent.

Our **Vascular Anomalies Program** provides expert evaluation and treatment for children with vascular (blood or lymph vessel) conditions such as hemangiomas and arteriovenous malformations.


**Nemours Center for Cancer and Blood Disorders (NCCBD)** isn’t a single “place,” but a multisite pediatric oncology and hematology program made up of four core locations, three of which are in Florida (all are members of the Children’s Oncology Group).

Nemours Children’s Health System in Florida reaches from Pensacola to Vero Beach and beyond. In addition to Nemours Children’s Hospital, we are affiliated with hospitals across the state where Nemours specialists provide services. Outpatient specialty care is available at Nemours Children’s Specialty Care locations across Florida as well as at outpatient offices located inside Nemours Children’s Hospital in Orlando’s Lake Nona Medical City. Nemours’ primary and specialty care network in Florida is a statewide physician practice with more than 30 locations including campuses in Orlando, Jacksonville and Pensacola, with providers including pediatricians, physician assistants and advanced nurse practitioners who have extensive training and experience. Our Urgent Care is ready for kids (from newborns up to age 21) with problems that can’t wait for office hours. Our six urgent care locations are open every day of the year providing evening (5–11 p.m.) and weekend (1–11 p.m.) acute care.

*“It has been my firm conviction throughout life that it is the duty of everyone in the world to do what is within his power to alleviate human suffering.”*

—Alfred I. duPont, Nemours’ Founder



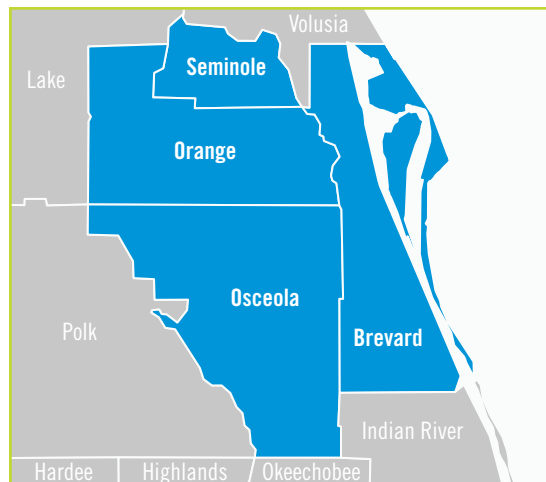


Community Health  
Needs Assessment (CHNA)

## Community Health Needs Assessment (CHNA)

During 2016, Nemours embarked on a journey to identify the child and adolescent health needs of the communities near Nemours Children’s Hospital (NCH) in Central Florida. Nemours engaged Professional Research Consultants, Inc. to assist in determining the health status, behaviors and needs of children and adolescents in our immediate service area which has been defined as households with children in Brevard, Orange, Osceola and Seminole counties in Florida.

The assessment was comprised of both qualitative and quantitative data including a customized child and adolescent health survey, focus groups, public health data, vital statistical data and other benchmark data on the health of children in Central Florida. To ensure the ever-changing needs of the community are continuously captured, the CHNA is conducted every three years using the same methodology. The 2016 administration of the CHNA resulted in the following areas of opportunity representing the significant health needs of children and adolescents in the community.



### Areas of Opportunity

- Access to Health Services
- Prenatal, Infant & Child Health
- Injury & Safety
- Nutrition, Physical Activity & Weight
- Asthma & Other Respiratory Conditions
- Mental Health
- Vision, Hearing & Speech
- Potentially Disabling Conditions
- Diabetes
- Oral Health
- Sexual Health

After reviewing this Community Health Needs Assessment report, Nemours’ Central Florida leadership team met to evaluate and prioritize the top health needs for children in the community. Data for the community were examined, and attendees were asked to evaluate each significant health issue (see Areas of Opportunity above) along the following criteria:

**Magnitude** — the number of children affected, as well as differences from state/national data or Healthy People 2020 objectives

**Seriousness** — the degree to which a health issue leads to death, disability or loss of quality of life

**Impact** — the degree to which it affects/exacerbates other health issues

**Feasibility** — the ability to reasonably impact the issue, given available resources

**Consequences of Inaction** — the risk of exacerbating the problem by not addressing at the earliest opportunity

This process yielded the following top priorities for Nemours to address in improving the health of the community’s children:

- Access to Health Services
- Prenatal, Infant & Child Health
- Injury & Safety

Our immediate focus will be on these top three priorities identified through the evaluation process. However, Nemours believes that we have a responsibility to our communities to address all health concerns identified by this study. Through direct services, or partnership with other health care or community leaders in the area, we are committed to addressing the health and wellness needs identified for children in Central Florida.



Access to  
Health Services





## Access to Health Services

According to the needs assessment, 6.9 percent of children in the Total Service Area (TSA) lack health care insurance coverage, comparable to the national benchmark. However, this percentage increases significantly among children living just above the federal poverty level (11.4 percent). Of those parents with children who have health care coverage, 12.2 percent report that their child was without coverage at some point in the past year.

In addition to insurance instability, the three greatest barriers to access to health care reported in the study were **lack of appointment availability**, **inconvenient office hours** and **finding a physician**. More than one-third of parents in the TSA reported difficulty or delay in obtaining health care services for their child (36.3 percent), less favorable than the national benchmark (29.4 percent). Families in Osceola County reported the most difficulty getting an appointment and finding a physician. In addition, in Orange County, families reported the highest prevalence of difficulties due to culture or language difficulties.

Approximately 37.2 percent of parents in the TSA reported that their child needed to see a specialist at some point in the past year. Among these respondents, 45 percent of these parents had “major” or “moderate” problems obtaining the necessary care for their child. In addition, 17.5 percent reported that it took 30 or more days to get an appointment.

A total of 13.7 percent of parents in the TSA reported taking their child to a hospital emergency room more than once in the past year. Of those respondents, nearly half reported that the visit was for something that could have been treated in a doctor’s office.

In addition, 13.6 percent of the TSA perceived that mental health (depression, suicide) is the number one health issue affecting adolescents ages 12 to 17. Of those respondents who perceived mental health as the number one issue, 70 percent believe that mental health resources and services are insufficient in their communities.

### Initiative

To provide coordinated, comprehensive and culturally appropriate care to children and families of Central Florida in a way they can understand

### Goals

- A. Create programs and initiatives to increase access to specialty care.
- B. Expand and maintain satellite operations to extend specialty care into the community.
- C. Provide and expand unique service offerings and subspecialty care that are not otherwise accessible in the Central Florida community.

### Metrics

- 1. # of patients seen at Nemours Children’s Primary Care locations
- 2. # of patients seen at Nemours Children’s Urgent Care locations
- 3. # of patients seen at Nemours’ satellite operations
- 4. # of patients enrolled and seen with Nemours CareConnect
- 5. # of schools using Nemours CareConnect

Nemours is dedicated to providing and improving pediatric health care at all levels of care – from minor injuries to the most complex conditions through coordinated patient-centered medical services, biomedical research, education, prevention and advocacy – ensuring patients experience care that is safer, more reliable, more responsive, more integrated and more available. NCH has earned The Joint Commission’s Gold Seal of Approval for accreditation by demonstrating compliance with their national standards for health care quality and safety in hospitals. As we continue to fulfill our mission and vision in Central Florida, we are enthused to bring the highest quality of care to the community we serve by offering a large number of pediatric specialties and subspecialties including:

- allergy
- anesthesiology
- audiology
- behavioral health
- cardiac surgery
- cardiology
- endocrinology
- gastroenterology
- general surgery
- genetics
- hematology/oncology
- immunology
- infectious disease
- interventional radiology
- neonatology
- nephrology
- neurology
- neurosurgery
- ophthalmology
- orthopedics
- otolaryngology
- pain management
- physical medicine and rehabilitation
- pulmonology
- radiology
- rheumatology
- urology

## New Models of Care and New Technology

In response to the evolving health care landscape, Nemours recognizes the need for improving health care quality, as well as increasing access and equality for all children in Central Florida. One method of improving access is through application of innovative models or technologies that better coordinate care and information sharing for all patients. Within the TSA, Nemours is involved in a number of efforts to address these issues and expand access throughout that area, including:

### Support Patient-Centered Medical Homes

Recent Patient-Centered Medical Home (PCMH) success stories show reduced emergency department use, decreased hospital admission rates and improved quality outcomes in their patients. This model provides patients with enhanced access to care, the ability to develop and sustain quality relationships with their provider and health care team as well as building relationships with specialists to expand care in the community. It also allows Nemours’ practices to become proactive in the care of their patient population, and the ability to shift the care from emergency care to prevention and health promotion.

### Nemours Children’s Primary Care, Longwood

Nemours Children’s Primary Care, Longwood is the first of our practices to become certified as a PCMH by the American Academy of Pediatrics (AAP). The PCMH is a model of primary care that combines patient-centered access, team-based care, population health management, care coordination and quality improvement to enhance care delivery. Research shows that medical homes can lead to higher quality and lower costs and can improve experiences of care for both patients and providers. The practice was one of the first participants in a rigorous statewide demonstration project that have been granted this designation by the AAP. Nemours is expanding the PCMH model to its primary care practices in the region.



## Nemours CareConnect

Nemours launched CareConnect (Nemours' direct-to-consumer telemedicine program) in November 2015, which allows families to hold a video visit with a Nemours pediatrician through a smart phone, tablet or home computer. The service is available 24/7, anywhere in Florida. Nemours is available when families need answers. Whether it's the middle of the night or during regular office hours, Nemours board-certified specialists are available at the push of a button.

Nemours also uses CareConnect in collaboration with 31 provider organizations including six hospital affiliates in Florida. When working with a partner hospital, Nemours pediatric subspecialists are able to remotely access a patient's medical record and directly consult with their provider to determine the safest, most appropriate care. Using this model, Nemours pediatric experts are able to influence delivery of children's health care outside of our system, ensuring that all children have access to the best pediatric expertise, and allowing families to remain in their local communities for treatment.

Nemours is also exploring the use of CareConnect to consult with school nurses in Central Florida; school nurses provide essential care to children, many of whom have complex medical conditions that require careful management and care coordination. Morning Star Catholic School, a Diocese of Orlando school serving students with special needs, is the first school in Florida to use CareConnect. The service allows the school nurse to directly connect with a Nemours board-certified pediatrician through video technology. The video visits are intended for minor injuries and acute health issues, such as fevers, vomiting rashes as well as chronic disease management. Families are contacted by the school prior to a video visit and are welcome to join in on the appointment via their mobile devices, tablets or computers. More than 50 percent of the students at Morning Star have been enrolled in the program. Nemours plans to expand this CareConnect service to additional school clinics in the Central Florida area.

## Growing to Increase Access

Among the TSA, 9.4 percent of total families surveyed reported lack of transportation as a barrier to health care access. In response to this challenge, Nemours continues to expand a robust distribution network by opening new primary care, urgent care and specialty care offices throughout the region.

## Nemours Children's Primary Care

To meet a need of primary and preventive care in the community, Nemours is growing a network of highly qualified pediatricians in Central Florida, called Nemours Children's Primary Care. To date, Nemours has expanded its network to 14 pediatric primary care practices in Central Florida in Clermont, Orlando-Waterford Lakes, Sanford, Kissimmee, Orlando-Windermere, Vero Beach, Longwood, Ormond Beach, Windermere-Horizon West, Maitland, Oviedo, Winter Haven, Orlando-Lake Nona, and Palm Bay. Our primary care pediatricians and staff provide general pediatric and preventive health services, including care for routine illness and everyday bumps and bruises, vaccinations and wellness checkups. From the tiniest newborns to youth up to age 18, Nemours is helping every child grow up healthy and reach their full potential.

In addition to primary care, Nemours also offers special expertise and services, including:

- asthma/allergy care and education
- behavioral evaluations (ADD/ADHD)
- obesity prevention and healthy choices

In order to address the concern from parents regarding inconvenient office hours, Nemours Children’s Primary Care has extended office hours on Saturday’s from 8:00 a.m. to noon. These hours are offered specifically for “sick care” so families do not have to resort to an ER visit. Currently, there are three Nemours Children’s Primary Care practices offering Saturday hours: Longwood, Windermere and TLC (Waterford Lakes). When families call any of the other primary care practices, they are re-directed to one of these “home” practices offering extended hours.

### Nemours Children’s Urgent Care

Of the CHNA respondents who took their child to the Emergency Room in the last year, over half reported that the visit was for something that could have been treated in a physician’s office. For this reason, Nemours has expanded our urgent care operations to six locations throughout the TSA. Nemours Children’s Urgent Care offers immediate, advanced pediatric care to kids and young adults — from newborns to 21 years of age — and is available evenings, weekends and holidays. The pediatricians who practice at Nemours Children’s Urgent Care are board-certified in pediatrics, with specialized experience in emergency medicine and urgent care. Their passion is caring for children, and their commitment is to support primary care physicians by providing urgent medical services outside regular office hours. Nemours Children’s Urgent Care brings Nemours expertise closer to home for Central Florida kids through locations in Kissimmee, Melbourne, Orlando (Dr. Phillips, Orlando), Waterford Lakes, Sanford and Lake Nona.

### Nemours Children’s Specialty Care

To meet access needs of children and families in our community, Nemours operates outpatient pediatric clinics providing specialty pediatric care for families in Central Florida in Orlando-Downtown, Kissimmee, Lake Mary, Lakeland, Titusville, Orlando-Lake Nona and Melbourne. Nemours rotates a multitude of specialists throughout our specialty care network offering appointments in cardiology, neurology, pulmonology, GI, urology, endocrinology and many others. Nemours plans to open additional satellite operations throughout the TSA in 2017.

### Nemours Hospital Partners

To further demonstrate Nemours’ organizational commitment to provide access to world-class pediatric health care for all children and families in Central Florida, Nemours partners with affiliated community hospitals throughout the region and beyond to provide pediatric subspecialty care close to home. Nemours provides a variety of support for these partners including hospital-based services, subspecialty consults and, in some cases, outpatient clinics. Partners include:

- Heart of Florida Regional Medical Center in Haines City, Florida
- Indian River Medical Center in Vero Beach, Florida
- Osceola Regional Medical Center in Kissimmee, Florida
- Oviedo Medical Center in Oviedo, Florida
- Wuesthoff Regional Medical Center in Rockledge, Florida
- Parrish Medical Center in Titusville, Florida
- Lakeland Regional Health in Lakeland, Florida



## Nemours Programs

### Pediatric Critical Care Transport

NCH offers 24/7 neonatal and pediatric intensive care transport. Nemours' transport program plays a vital role in getting infants and children to and from Nemours Children's Hospital, providing a mobile intensive care unit environment so critical care can begin immediately. Our ground transport includes a fully equipped pediatric intensive care ambulance plus a Nemours-owned, custom-designed mobile intensive care unit (the size of a fire truck) that features space to care for two newborn or pediatric patients at once. Nemours' transport vehicle allows us to be there for children and families throughout the region, at moments when they need us the most.

### Ronald McDonald House

Because of the complex nature of pediatric services, children and families come from throughout the region, across the country and around the world to receive services at NCH. Since 2012, Nemours has provided families from all 50 states and 61 countries with medical care for children with rare and unique conditions. For families to have access to these relatively rare medical resources, they require a place to stay while their child is receiving care. Ronald McDonald House (RMDH) provides a "home away from home" for families of seriously or chronically ill or injured children receiving treatment at area hospitals by offering nurturing and supportive environments where families can stay together and find comfort.

Through Nemours' partnership with RMDH, families have access to a location to rest and regroup, allowing parents and guardians to stay near their children. Facilities at RMDH include 15 guest rooms, laundry rooms, showers and kitchenettes with free coffee and vending machines, computers with high speed internet, and many other amenities. A statement from the American Academy of Pediatrics (AAP) emphasizes the positive effects of family presence during a child's hospital stay. Both children and parents experienced decreased levels of stress, children were able to be discharged earlier and recovery time was reduced.

### Nemours' Financial Assistance Plan and Nemours' Uninsured Discount Program

Since opening our doors, Nemours has remained committed to providing our patients and families with the care that they need and want, when they need and want it. This commitment includes those who may have difficulty affording needed care. In 2016, Nemours provided more than \$6.4 million in charity care services so that children needing care could receive it without financial barriers. Through our commitment to our patients, Nemours will continue to provide this assistance to those in need each year.

### Inpatient Rehabilitation Unit

Nemours Children's Hospital's Inpatient Rehab Unit is currently a six-bed unit, with room to grow to nine beds. It is the first pediatric inpatient rehab unit at a freestanding children's hospital in Florida. The unit admits patients from three months to 17 years of age. The rehab unit offers intensive physical, speech and occupational therapy, as well as 24-hour inpatient medical and nursing care.

## Language/Interpreter Services

One of the primary barriers to access reported in Orange County is health literacy and cultural competence. Nemours believes that one of the most important aspects of delivering family-centered care is making sure families are informed, in a language they understand, about what is happening with their child's health at every step.

To help families be the very best advocates for their child's care, Nemours provides a variety of language and interpreter services, including:

- **Spanish:** Our compassionate, face-to-face Spanish language interpreters are on-site at the hospital Monday through Friday. We also provide families with printed educational materials translated into Spanish.
- **Other languages:** When a referring doctor lets us know that an interpreter will be required for a patient, we will either arrange to have a face-to-face interpreter on campus or over the telephone for their visit.
- **Phone interpreter service:** Nemours' phone interpreter service is available in almost every language – 24 hours a day, seven days per week for both inpatients (staying at the hospital) and outpatients (coming in for an appointment or procedure then going home).
- **American Sign Language (ASL):** Nemours also meets the communication needs for deaf children and families, providing an American Sign Language interpreter when needed.

## Community Initiatives

### Osceola Community Health Services

The Nemours Division of General Academic Pediatrics is partnering with the Department of Health in Osceola County to provide primary care to children of low-income families through their Federally Qualified Health Center (FQHC). Recognizing that asthma and other chronic diseases impact so many children in Osceola, Nemours is exploring extending subspecialty care such as pulmonology and infectious disease to this FQHC as well.

### Shepherd's Hope

Nemours partners with Shepherd's Hope, a not-for-profit in Central Florida that operates free medical clinics for low-income families, to provide volunteer providers for back-to-school physicals in the summer. In 2016, over 25 Nemours providers volunteered and completed over 300 physicals. During the clinics, patients are seen for free by the doctors, nurses and other volunteers who donate their time to serve uninsured, low-income families in need of medical care. Through this work, many Nemours physicians have been inspired to continue volunteering at the medical clinics regularly.

### Central Florida School Districts – School Nurse Training

In addition to partnering with Central Florida schools for CareConnect consult services, Nemours providers offer specialized training classes for school nurses, health aides and clinic assistants throughout the TSA. Nemours believes that school nurses play an integral role in a child's care team and require ongoing training to facilitate care for their students. Nemours providers have conducted training seminars on many topics including diabetes, sickle cell, infectious disease, trach care, asthma, allergies, injuries, common cardiac diseases and rheumatology. In 2016, NCH was awarded District Business Partner of the Year from Osceola County School District for providing unique learning and training opportunities for school nurses in the district.





# Prenatal, Infant & Child Health

## Prenatal, Infant & Child Health

The infant mortality rate in the TSA is 6.3 per 1,000 live births, slightly higher than both the Florida average (6.1) and national average (5.9); Orange County has the highest rate of 6.7 per 1,000 live births. In the non-Hispanic Black population, the rate increases to 11.5 per 1,000 live births. The predominant cause of death between 2005 to 2014 for children under one year of age was perinatal conditions (certain conditions occurring in the perinatal period, usually low birth weight, preterm birth, and complications of pregnancy, labor and delivery).

Between 2012 and 2014, the TSA reported an annual average of 31.6 child deaths (age one to four) per 100,000. Among these children, ages one to four, accidents and congenital conditions are the number one and two leading causes of death, respectively.

### Initiative

Increase education and awareness of prenatal and infant health issues among families and health care providers in Central Florida

### Goals

- A. Provide **Prenatal Education** to moms, families and providers that promotes healthy pregnancies and safe deliveries.
- B. Create **Infant Health Programs and Outreach** that provide services, education and support to families and providers.

### Metrics

- 1. # of patients seen at Nemours Center for Fetal Care
- 2. # of families attending the Baby Basics Classes
- 3. # of attendees at the NAS Summit

## Prenatal Education

### Nemours Children’s Primary Care Mommy-to-Be Classes

Nemours Children’s Primary Care physicians offer a meet-and-greet, Baby Basics Class, for pregnant families, providing prenatal education and infant education to prepare moms- and dads-to-be for the days leading up to and following birth.

### KidsHealth.org – Pregnancy and Newborn Center

Nemours provides online resources to help families better understand how to stay healthy and safe during pregnancy, prepare for parenthood, childbirth, newborn care and health conditions. All content is reviewed regularly for accuracy and balance by Nemours pediatricians and subject-matter experts. The site is free to use, requires no registration and is free of advertising.

### NICU Discharge Education

Nemours focuses on practices that allow children and families to live healthier lives. Our goal is to provide health information and encourage wellness development for all children, including child safety. Prior to discharge from the NICU, Nemours providers educate families on safe sleep practices, car seat safety, shaken baby syndrome and infant CPR. Nemours providers teach parents proper CPR technique and provide hands-on training with simulation mannequins. For more training, parents are provided an Infant CPR Kit which contains video instruction and an inflatable mannequin for the family to practice at home. The infant CPR Kits were donated to NCH by the AHA (American Heart Association).

## Improving Outcomes & Safety for Mothers & Infants

### Nemours Fetal Care Center

Nemours is dedicated to serving children and their families at every stage of life. The Fetal Care Center at NCH provides expert maternal-fetal and perinatal care to Central Florida mothers-to-be facing high-risk pregnancies or problems with their unborn child. Although Nemours doesn't deliver babies, we co-manage care with mom's doctors and coordinate services focused on baby's health before, during and after birth. The Fetal Care Center is designed with pregnant patients' health in mind and provides a dedicated clinic space, prompt scheduling, and referrals to pediatric specialists that are arranged and tracked by the Fetal Care Center.

### Milk Bank of Florida

Breast milk is the preferred feeding for all infants and offers benefits not found in any substitute. It provides "passive immunity" for the baby, protecting the baby from a wide variety of bacterial and viral illnesses. Breastfeeding also can lead to better cognitive development, as well as physical and emotional benefits due to skin-to-skin contact. Because early nutrition is a significant contributor to healthy child development, NCH provides a storage location to support milk banks as well as a neonatal practitioner and international board-certified lactation consultant. To support breastfeeding and infant health, Nemours hosts a weeklong certified lactation counselor training course once a year, providing education, certification and resources to providers and breastfeeding advocates.

### Neonatal Resuscitation Program

NCH provides classroom instruction in the Neonatal Resuscitation Program (NRP)<sup>™</sup>. NRP is an educational program based on the American Academy of Pediatrics and the American Heart Association guidelines for cardiopulmonary resuscitation and emergency cardiovascular care for newborns at time of delivery. NRP introduces concepts and basic skills of neonatal resuscitation. Successful completion of the online written course is required before participants attend the classroom portion of the NRP course. The course is open to all health care providers in the Central Florida community for a nominal fee.

### S.T.A.B.L.E. (Sugar, Temperature, Airway, Blood pressure, Lab work, and Emotional support)

NCH offers classroom instruction for the modular instructional program known as S.T.A.B.L.E. S.T.A.B.L.E. is a neonatal education program for health care providers focusing on the post-resuscitation and pre-transport stabilization care of sick infants. The course is available to all health care providers and ancillary personnel for a nominal fee.

### March of Dimes of Central Florida

The March of Dimes in Central Florida is a long-time partner of Nemours, supporting the hospital through generous donations and support. Throughout the years, Nemours Associates have become heavily involved in March of Dimes' events and fundraisers with collaborative efforts resulting in significant dollars raised to support research, educational opportunities and support services for parents, caregivers and families. Donations from the March of Dimes also supports the education of medical and nursing staff in the latest developments and findings regarding neonatal and perinatal diagnosis, treatment and plans of care for high-risk newborns.



### **NICU Cuddler Program**

Nemours understands the importance of bonding and skin-to-skin contact with any newborn, especially those in the NICU. However, we also understand that not all parents are able to stay at the hospital for extended periods of time, whether a parent needs to leave for work or other obligations. For this reason, volunteers with the Nemours NICU Cuddler Program are specially trained to provide love and affection to babies and families in the NICU at Nemours Children's Hospital. These volunteers are trained on the proper techniques for holding and rocking in order to soothe and comfort our tiniest patients. The Nemours NICU Cuddler Program is especially important to soothe babies with neonatal abstinence syndrome (NAS), who may be experiencing elevated stress and discomfort.

### **Neonatal Abstinence Syndrome (NAS) Summit**

NAS is a group of problems that occur in a newborn who was exposed to addictive opiate drugs while in the mother's womb. Babies with NAS are more likely than other babies to be born with low birth weight, have breathing and feeding problems and seizures. Nemours Children's Health System, the Department of Health in Brevard County and the Space Coast Health Foundation are working together to prevent and improve care for this issue both in the health care setting and at home. The NAS Summit is designed to enable various disciplines and centers to come together to educate, network and brainstorm ways to communicate and improve care for infants with NAS and their families.

# Injury & Safety



## Injury & Safety

While the majority of children in the TSA were not seriously injured in the last year, 13.3 percent sustained injuries serious enough to require medical treatment. Of these respondents, more than two-thirds (67.3 percent) reported that their child was seriously injured once in the past year, 22.9 percent of respondents reported two incidents and 9.8 percent said their child needed medical treatment for an injury three or more times in the past 12 months. When asked what the child was doing when the injury occurred, parents mentioned activities such as organized sports, playing, and falling or tripping. The prevalence of serious injury among children in the TSA is highest among boys, teens, and White and Hispanic children.

The number one leading cause of death among children ages one to 19 years is accidents, primarily drowning in children ages one to four and motor vehicle accidents in children age 15 to 19. Approximately 91.8 percent of respondents reported that their child “always” wears a seatbelt (or appropriate car seat for younger children), a significant decrease in seatbelt usage from 2013. The lowest usage was reported among children under four years of age at just 84.4 percent.

### Initiative

Increase awareness of and participation in community safety and injury initiatives and programs.

### Goals

- A. Provide **Safety/Injury Education** to patients and families.
- B. Create targeted **Safety/Injury Initiatives** to serve the needs of the community.

### Metrics

1. # of attendees at our School Health Conference
2. # of players served through USTA Player Development Program

## Education and Training Initiatives

### Car Seat Safety Program

In addition to Nemours’ NICU discharge education program, NCH provides car seat safety resources for all children leaving the hospital. If a family does not have an appropriate car seat to safely transport the patient, NCH will provide one at the time of discharge. In addition, Nemours Certified Car Seat Installation Technicians review best practices for car seat safety and provide detailed instruction on how to install a car seat into the family’s vehicle.

### Hands-Only™ CPR Training Initiative & World Heart Day

Hands-Only™ CPR is cardiopulmonary resuscitation without mouth-to-mouth breaths. It is recommended for use by people who see a teen or adult suddenly collapse in an out-of-hospital setting, such as at home, at work or in a park. In the event of a cardiac emergency, people are more likely to perform Hands-Only™ CPR and ultimately save a life. The Nemours Cardiac Center is working together with the American Heart Association, Central Florida school districts, fire departments and other community organizations to promote and conduct Hands-Only™ CPR Training throughout Central Florida.



On World Heart Day, September 29, 2016, people across Orange County took advantage of free, Hands-Only™ CPR training. World Heart Day was founded in 2000 to inform people around the globe that heart disease and stroke are the world's leading causes of death, claiming 17.3 million lives each year. More than 28,000 people participated in the CPR training sessions, including 200 participants who trained at NCH.

Along with Nemours Children's Hospital, the following organizations offered the training sessions:

- Orange County High Schools
- Orlando International Airport
- University of Central Florida
- DoubleTree Suites by Hilton
- Catalyst Community Church
- Children's Safety Village
- Lake Whippoorwill KOA
- SeaWorld
- Ocoee Fire Station #25

### Nemours' School Nurse Health Conference

In August, Nemours hosts an Annual School Nurse Health Conference dedicated to school nurses and other school health professionals from across Central Florida. The program includes training for typical pediatric care in a school setting such as management of injuries, allergies, asthma, diabetes, substance abuse, mental health and response to medical emergencies. The conference will include hands-on training through the Nemours Children's Hospital simulation lab and small group discussions on topics relevant to school health.

### YMCA Safety Around Water Program

NCH supports the YMCA's Annual *Safety Around Water* event, a four-day introductory swim program for youth ages four to 12 years. During the event, nearly 5,000 children receive water safety education and character development lessons in a safe, structured environment. YMCA Swim Academy instructors instill a love of the water while helping kids and parents build safety skills and knowledge. The program is free, open to the public and is offered at 20 YMCA locations across Central Florida. Nemours is also collaborating with the YMCA for Florida's Healthy Kids Day on Saturday, April 29.

## Sports Medicine – Prevention and Treatment

### United States Tennis Association (USTA) Collaboration for Sports & Injury

Some of the nation's top youth tennis players optimize their performance through sports medicine programs designed by the Andrews Institute for Orthopaedics & Sports Medicine and Nemours Children's Health System. The two organizations have come together to serve as the Official Medical Services Providers for the USTA National Campus, the Home of American Tennis.

Nemours and Andrews Institute provide a team physician, program director, sports nutritionist and athletic trainers for the USTA National Campus in Orlando's Lake Nona Medical City. These specialists offer pediatric-focused injury prevention, rehabilitation and therapy along with athletic performance programs focused on optimizing a young athlete's performance.

## Concussion Treatment and Prevention Program

Concussion is a public health concern that affects at least 10 percent of children who participate in youth and school athletics. Nemours' chief of neurosurgery created a comprehensive concussion program that is saturating the Central Florida catchment area. The program includes partnerships with the Central Florida Football and Cheer Association and the Amateur Athletic Union (AAU) to provide concussion education to children, parents, coaches and providers across Orange, Osceola and Seminole counties. Additional outreach and education through various media outlets includes appearing on local NBC, CBS and ABC news affiliates, presenting at the AAU National Conference, speaking to the National Association of Nurse Practitioners, and CME talks for community physicians around concussion prevention and treatment. Our team has also created a Concussion Tool Kit for primary care providers which includes information about concussion, how to detect signs and symptoms, flow sheets with strategies for clinical management, and tear sheets for providers to disseminate information to parents (Parent Guide, Academic Accommodations, and Return to Play).

## School Partnerships

NCH currently provides sports physicals and a sports medicine physician for football games for Lake Nona High School and is currently looking to expand this service to additional schools in Central Florida. In addition, Nemours providers support education training for teachers, coaches and school staff for sports-related topics such as common cardiac conditions.

## Special Olympics Young Athletes Program

Nemours Children's Hospital sponsors *The Young Athlete Program* for groups in Central Florida – Orange, Osceola, Polk, Lake, Brevard and Seminole counties. *The Young Athlete Program* offers children with special needs an opportunity to learn the basic skills needed for sport activities. Provided at no cost, this program is offered at schools, play groups or for any group of at least six children with special needs. The goal of *The Young Athlete Program* is to increase awareness and educate the community about the benefits of early physical activity for children with special needs.

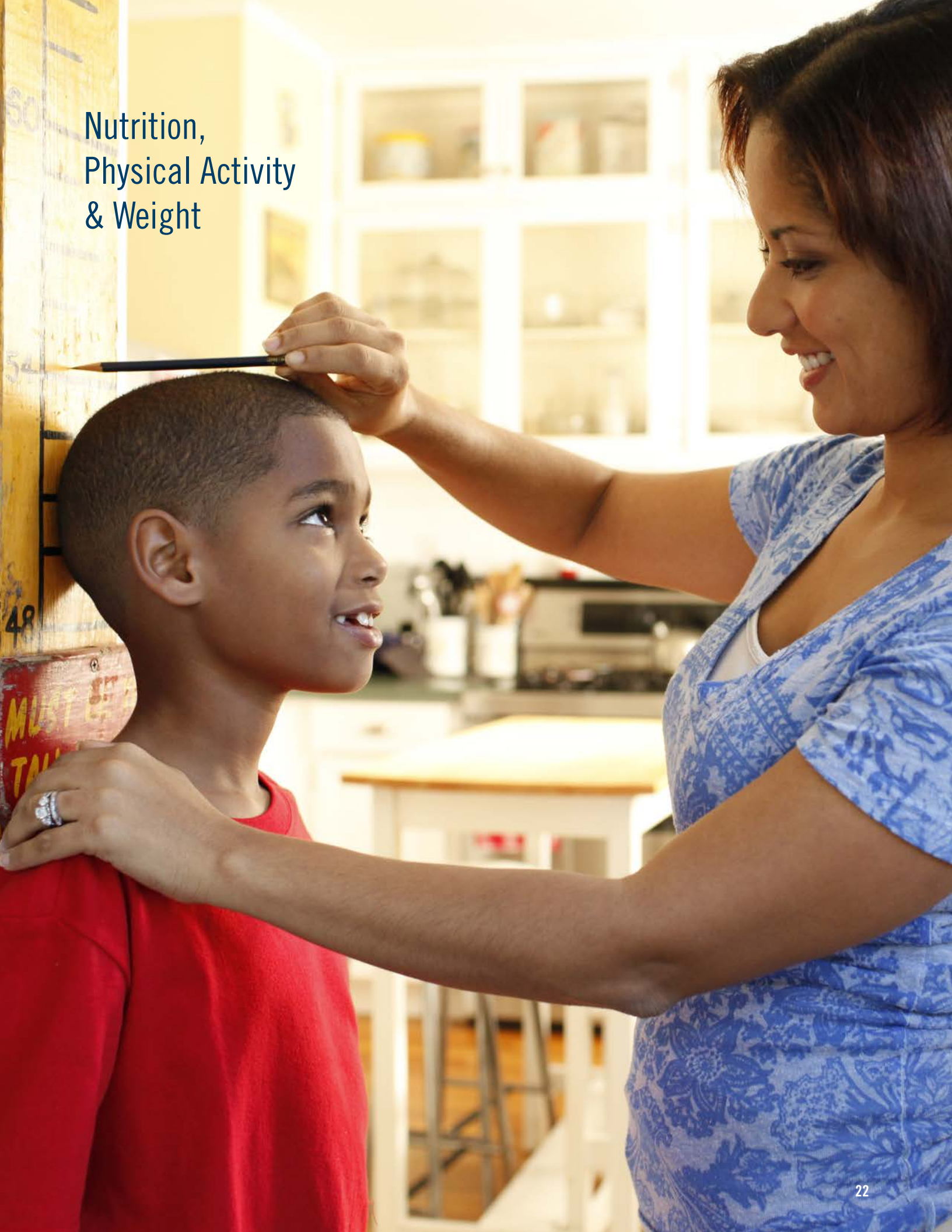
Nemours is an avid supporter of this program and the Special Olympics Organization. In collaboration with these groups, Nemours hosted The Special Olympics Young Athletes program, a free play program for children with disabilities between the ages of two and seven. These children, along with their siblings, were invited to participate in developmentally appropriate play activities designed to foster physical, cognitive and social development as well as to introduce them to the world of sports. The program was hosted at NCH for 12 weeks in 2016.

## Educational Resources for Young Athletes

At Nemours, our team of experts understand that young athletes are not simply smaller versions of adult athletes. We also understand the importance of preventing sports medicine injuries before they happen. For this reason, Nemours provides free printable resources for coaching staff, parents and athletes on many topics including:

- Concussion Prevention & Detection
- Female Athlete Triad
- Heat-Related Illness
- Knee Safety: Preventing ACL Injuries
- Overuse Injuries
- Preventing Dehydration
- Preventing Sports Injuries

Nutrition,  
Physical Activity  
& Weight





## SECONDARY HEALTH CONCERN

## Nutrition, Physical Activity & Weight

Obesity and Nutrition was identified by families in the TSA as the number one perceived health issue for children and teens. The prevalence of overweight and obese children in the total TSA is more than the national average, a significant increase from 14.4 percent in 2013 to 19.3 percent in 2016. Obesity was reported highest among boys, children between the ages of five and 12, children in low income households and Hispanic and white children.

### Programs and Education

#### Healthy Choices Clinic

The Nemours Healthy Choice Clinic, an outpatient pediatric weight management program, provides multidisciplinary care to over 300 children in the Central Florida community who are clinically obese, or overweight with related risk factors. The multidisciplinary team, including physicians, nurses, health coach, registered dietitians, exercise specialists and mental health counselors, works with patients and families to adopt long-term, sustainable lifestyle changes that can lead to significant improvements in children's health and well-being. To increase access to the Healthy Choices Clinic, Nemours now offers this service at satellite clinics in Downtown Orlando and Brevard County.

In order to further extend our clinical expertise and provide convenient access to obesity and nutrition counseling, our researchers have developed a pilot program using telehealth technology. Nemours Health Coaches connect with families through the Nemours CareConnect application to provide goal setting and behavioral counseling to patients in the comfort of their own home. Nemours supports the patient-centered medical home model by providing the patient's primary care physicians with clinical decision support tools and access to the patient's encounter with the health coach.

#### KidsHealth.org: Health Education for Patients and Families

Nemours Children's Health Media/KidsHealth maintains a website with more than 10,000 articles, animations, movies, fact sheets, recipes and more, in English and Spanish, around a wide range of medical, emotional, behavioral, safety and developmental topics. The site has dedicated areas with age-appropriate content created specifically for parents, kids and teens. All content is reviewed and systematically updated for accuracy and balance by Nemours pediatricians and experts in the subject matter. The site is free to use, requires no registration and is free of advertising.

### Florida Prevention Initiative (FPI)

#### Wide Dissemination and Targeted Saturation of Community Prevention Programs

Nemours Children's Health System has a tradition of working beyond the walls of our facilities and in the community where families live, work and play. We provide a continuum of care from outpatient and inpatient services, to community outreach and child health advocacy. The Nemours Florida Prevention Initiative (FPI) fills a strategic role in our integrated health system through health promotion and disease prevention activities, reaching not just the children who use our medical services, but also those who are part of our community, currently focusing on obesity prevention in early childhood.

FPI's current focus on birth to five years is based on the recognition that habits are readily malleable in the early years. Early learning confers value on acquired skills, and early prevention beats the cost of later remediation. With almost 16,000 young children in Central Florida impacted by FPI training for child care providers and through focused initiatives to saturate targeted communities, the program is moving towards a tipping point in which Nemours' healthy eating and physical activity messaging is widely recognized, adopted and sustained.

### Wellness Policies in Early Care and Education (ECE)

Nemours FPI aims to improve environments, policies and practices to support healthy behaviors in early childhood education (child care) settings through the development of customized wellness policies. Our approach includes working with ECE professionals through technical support to increase their knowledge of nutrition, physical activity, recommendations for regulating screen time and best practices to help create healthier environments that support children's development of positive associations with healthy eating and activity. Nemours aims to increase access to active play, healthy food and healthy beverages, as well as support breastfeeding and staff wellness.

### Leveraging Community Partnerships to Disseminate Messaging

Nemours FPI is a key partner in Central Florida's ECE arena, serving on various boards, committees and task forces with the shared goal of children's health. With feedback from community partners, ECE programs and families, we have developed science-based, educational materials around healthy living to share in the community and in our clinical practices. Nemours works with community partners to spread consistent health messaging across the TSA and empower children and families to practice healthy behaviors where they live, learn and play. Developing a united effort and co-branding our community resources with local school districts and county health departments has been of great benefit to the Central Florida community.

Nemours' Community Resources include:

- 5-2-1-Almost None – brochure with magnet and posters
- Nemours Healthy Plate and Place Mat
- Healthy Lifestyle Prescriptions Pads
- Staying in the Game: A Care Guide for Adolescent Athletes
- Sleep and Your Child: A Guide for Families
- Eating Healthy on a Budget
- Sometimes/Anytime Food & Activities Game Cards
- Nemours Child Care Wellness Policy Workbook and Customized Posters
- A Simple Guide to Packing Healthy Meals
- Activity Cubes to promote movement in the classroom

### Early Care and Education Learning Collaborative

The ECELC is a collaborative effort of Nemours and the Centers for Disease Control and Prevention (CDC) to implement an intervention aligned with the *Preventing Childhood Obesity in Early Care and Education Programs* (2nd edition), *Selected Standards from Caring for Our Children* (3rd edition) and *Let's Move! Child Care* to increase support for breastfeeding and improve the healthy eating, physical activity and screen time practices, policies and environments in early care and education (ECE) settings. The ECELC, currently in its fifth year, has been implemented in eight new states – Florida, Alabama, New Jersey, Missouri, Kentucky, Indiana, Virginia and California (L.A. County). The program was previously implemented in Arizona and Kansas. The collaborative uses an empowerment model designed to support the growth of leadership, collaboration and efficacy of ECE providers as they learn, change, grow and become champions for children's health, development and learning.

## Other Community Initiatives

### Development of Culinary Medicine Elective at UCF College of Medicine

The University of Central Florida College of Medicine, in collaboration with Nemours, has developed a Culinary Medicine elective that will combine medical nutrition, dietetic and culinary concepts that students will use to more effectively counsel patients on lifestyle skills. The elective will allow for hands-on experiences in professional kitchens, under the supervision of professional chefs and registered dietitians to improve medical students' knowledge and skills in counseling patients about healthy lifestyles, nutrition and cooking. Effective counseling will help patients achieve and maintain optimum health. The Culinary Medicine elective seeks to demonstrate the powerful triad of physician, dietitian and chef in health promotion and disease prevention. Nemours physician, Rob Karch, MD, was instrumental in developing this elective's curriculum and hosts hands-on experiences at the NCH Teaching Kitchen.



# Asthma & Other Respiratory Conditions



## SECONDARY HEALTH CONCERN

## Asthma & Other Respiratory Conditions

More than 25 million people have asthma in the United States. At Nemours, we treat nearly 30,000 children with asthma each year. In fact, it's the number one reason children chronically miss school with flare-ups and the most common cause of pediatric emergency room visits due to a chronic illness.

Among school-aged children with asthma in the TSA, 62.8 percent missed school on one or more days in the past year because of asthma-related problems. Of those children, 20 percent missed five or more school days due to issues with asthma in the past year. This data is considerably higher than the national benchmark. Further, 55 percent of TSA parents with asthmatic children reported that they missed at least one day of work in the past year due to their child's problems with asthma. Of those parents, 10 percent missed four or more workdays in the past year, which is notably higher than the national average.

### Asthma Management and Education

Education and prevention are critical components to the daily management of asthma. Nemours specialists, respiratory therapists, primary care physicians, parents and teachers must work together as an integrated care team to develop a plan to avoid triggers and prevent and anticipate flare-ups. Nemours is dedicated to providing the proper education and training to parents, educators and staff to keep children in the classroom and out of the emergency room.

### Orange County Head Start

Through Nemours' partnership with the Orange County Head Start program, Nemours respiratory therapists provide critical asthma education for early child care providers. Moving forward, Nemours and Orange County Head Start plan to expand this program to include asthma education for administrators and to develop asthma action plans with teachers and parents. The goal of an asthma action plan is to reduce or prevent flare-ups and emergency department visits through day-to-day management. Following a written asthma action plan can help children do normal everyday activities without having asthma symptoms.

### Orange County Public Schools

Nemours is currently developing partnerships to provide asthma education for elementary school nurses in Orange County.

### Asthma Educator Institute

Nemours is committed to offering top-notch preventive care and education, to help children who have to be hospitalized for asthma reduce or eliminate the need to be re-admitted to the hospital again for the same problems within a certain time frame. Our asthma care team — pulmonologists, allergists, pediatricians, nurse practitioners, respiratory therapists and nurses — adheres to evidence-based national standards for asthma management. For this reason, NCH holds an annual two-day asthma education training for physicians, nurses, respiratory therapists and other asthma personnel.

## Programs and Initiatives

### Cystic Fibrosis Clinic

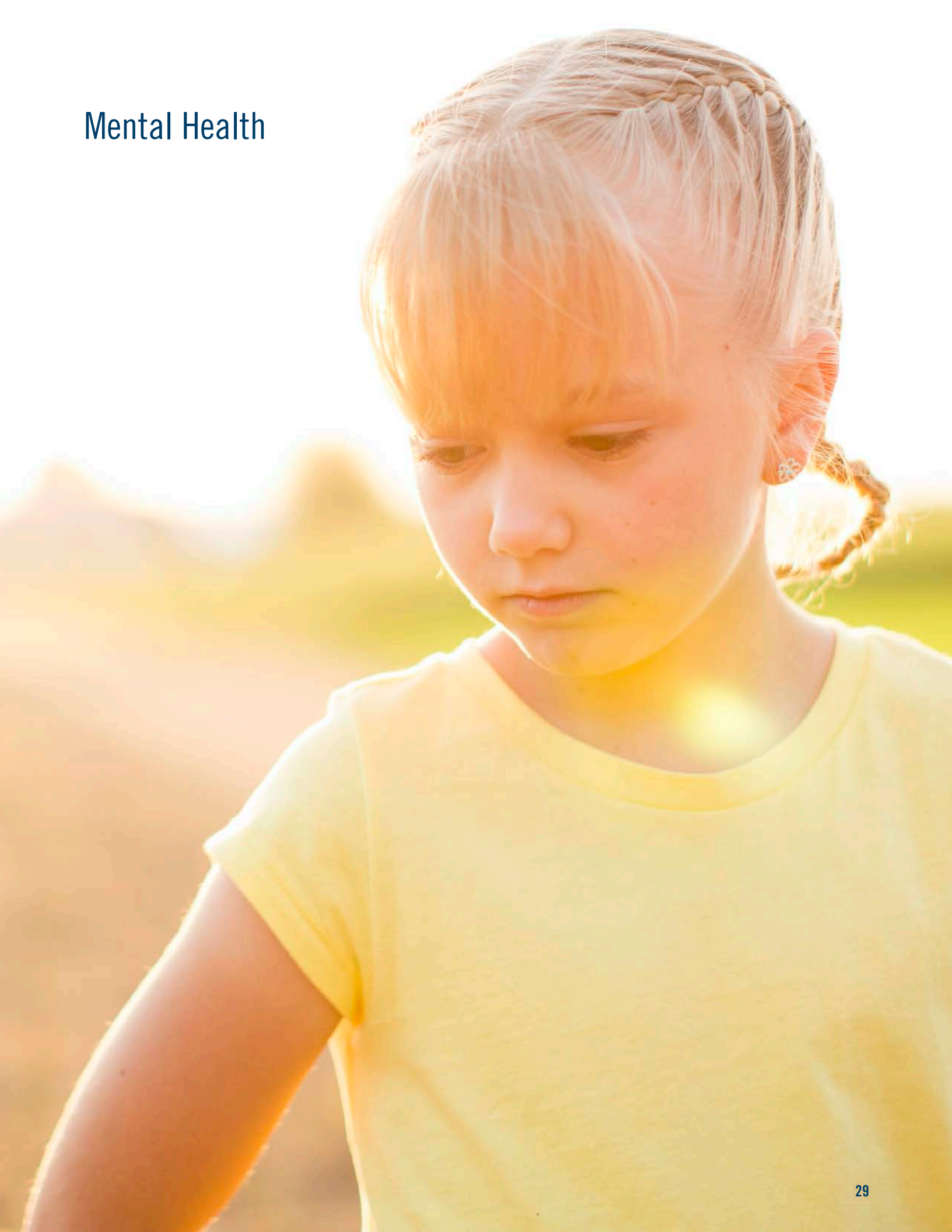
One of the top concerns reported by our needs assessment was the correlation of mental health with physical health. One example of how Nemours focuses on the whole health of children is in our cystic fibrosis clinic. The gastroenterology, endocrinology, otolaryngology, nutrition and psychology departments at Nemours work together to provide patients and patient families with the education and resources they need for dealing with cystic fibrosis on a day-to-day basis. Due to the mental and emotional effect that health conditions have on children, we make behavioral health counselors and social workers available to patients and families receiving inpatient treatment and outpatient care in our clinics.

### Collaboration With Nemours Primary Care Providers

The Nemours Pediatric Pulmonary Division collaborates with Nemours Children's Primary Care to provide continuous education on the use of office spirometry, asthma education modules and asthma action plans. In keeping with the patient-centered medical home approach, Nemours understands the critical role that our primary care providers play in the day-to-day management of asthma. Our providers work with families to develop asthma action plans to help avoid asthma triggers, prevent flare-ups and keep children out of the emergency room.



# Mental Health



## SECONDARY HEALTH CONCERN

## Mental Health

The majority of TSA respondents with children ages five to 17 years rate their child’s emotional or mental health — which includes stress, depression and problems with emotions — as “excellent” (39.8 percent) or “very good” (30.2 percent). However, 11.3 percent of parents in the TSA reported that their school-age child’s emotional or mental health is “fair” or “poor,” which is double the national average (5.5 percent). This trend has increased significantly over the last three years. Very low-income families reported the highest level of “fair” or “poor” mental health at 20.2 percent.

Among Orange County high school students, 9.1 percent report attempting suicide in the past year, this rate is significantly higher in high school girls than boys.

Among TSA parents of children age 5-17, 5.1 percent indicate that their child has been diagnosed with autism, which is higher than the national benchmark of 1.4 percent. Of the children reported with autism, 11.5 percent of parents characterize their child’s autism as “severe.”

A total of 13 percent of children in the TSA are reported to have ever suffered from or been diagnosed with ADHD, which is higher than the national average of 8.7 percent. Of the children reported with ADHD, 9.7 percent of parents characterize their child’s ADD/ADHD as “severe.”

### Early Autism Screening, Treatment, & Training Program

NCH is proud to offer the region’s most comprehensive program for children diagnosed with autism spectrum disorder. Through early screening and educational training, the autism specialists at Nemours are actively involved in identifying autism spectrum disorders at an early age, while teaching parents and care providers how best to help children thrive. We also help advocate for children to receive available services in the community and in school.

Diagnosing children with an autism spectrum disorder is complex and requires comprehensive evaluation by experienced pediatric specialists in different medical disciplines. Early intervention is proven to significantly improve symptoms and offer children the best chance to adapt, grow and thrive into adulthood. As a regional referral destination, we’re uniquely experienced to evaluate, diagnose and treat autism spectrum disorders in children, from infants to adolescents. Our autism experts include a team of pediatric neurologists, psychologists, psychiatrists, behavior analysts, therapists (speech and language, physical and occupational) and others who work with you to give your child the best chance for success at home, at school and in the future.

Research shows that early autism screening using a simple parent questionnaire can help identify the signs of autism and other developmental disorders in children as young as 12–18 months. Through an initiative with our pediatric primary care network, our autism specialists provide local pediatricians with the tools to recognize the signs of autism so we can begin treatment as early as possible, for the best results possible.

### **Imbedded Clinicians Within Medical Specialty Clinics**

One of the top concerns reported by the TSA is correlation between mental health and physical health. At Nemours, we take a holistic approach to health care and treat every child as if they are our own. The Nemours Cystic Fibrosis Clinic is an example of how we develop multidisciplinary teams to treat the “whole” child.

There is an emotional toll on children living with cystic fibrosis (CF) and they often have periods where they cannot interact with other children because of the risk of developing infections. Nemours CF experts understand how lonely this can be, so we’ve developed resources to help children cope with these feelings. Nemours licensed clinical social workers provide comprehensive psychosocial assessments, resource coordination and mental health screenings for patients and families living with CF. The hematology, oncology and psychology departments at Nemours work together to provide patients and patient families with the education and resources they need for dealing with cystic fibrosis on a day-to-day basis. Due to the recognized mental and emotional effect of health conditions on children, we make behavioral health clinicians available to patients and families receiving inpatient treatment and outpatient care in our clinics. In addition, we offer newsletters and support groups, and often pair children of similar ages so patients can develop friendships among their peers.

### **Pain Management Clinic**

The Nemours Pain Management Clinic is staffed by physicians of different specialties and other nonphysician health care providers who specialize in the diagnosis and management of patients with chronic pain. Our facility differs from a multidisciplinary pain center only because it does not include research and teaching activities in its regular programs. A multidisciplinary pain clinic may have diagnostic and treatment facilities which are outpatient, inpatient or both. At NCH, the pediatric pain program consists of a primary physician, who is board-certified in both pediatric anesthesiology and pediatric pain management, a psychologist, a social worker, a nurse/coordinator, and a physical and occupational therapist.

### **Community Partnerships & Collaborations**

The Nemours Behavioral Health Department is actively working with community partners including the Orange County Mayor’s Youth Mental Health Commission to address mental health issues in our Central Florida community.



## Vision, Hearing & Speech



## SECONDARY HEALTH CONCERN

## Vision, Hearing & Speech

Nemours pediatric ophthalmologists encourage early vision screenings by primary care physicians at newborn visits and at all well-child visits. In fact, the American Academy of Pediatrics (AAP), the American Association for Pediatric Ophthalmology and Strabismus (AAPOS) and the American Academy of Ophthalmology (AAO) all recommend that children's eyes be examined at timely intervals. This is because pediatric eye exams result in early detection and treatment of eye disorders leading to more successful treatment outcomes and protecting a child's vision. Within the TSA, a total of 81.6 percent of parents reported that their child has received an eye exam within the past three years. However, 16.3 percent of parents reported that their child has never received an eye exam.

In addition to vision screening, hearing evaluations should start at birth and continue on a regular basis throughout life. Approximately 11 percent of the TSA indicate that their child has never received a hearing test, which is slightly higher than the national average.

### Spot Vision Screenings

The Nemours Ophthalmology Department and FPI partner together to providing free vision screenings at community events and promote early detection of vision problems. A handheld, portable device allows Nemours to take a Spot™ Vision screener to these events and into preschools in order to reach children who do not have access to routine screenings. This Spot Vision screener reduces the time it takes to determine if a child has a potential vision concern which, if not treated, can result in irreversible vision problems later in life.

### Our Healthy Eyes

Nemours' *Our Healthy Eyes* is a collaborative program developed by Nemours FPI and Nemours BrightStart! in order to reach young children, educate their families about eye and vision health, and identify those who need follow-up care. Nemours provides early child care centers with a lesson plan about eye and vision health. The one-day lesson is followed by a vision screening event where Nemours provides additional resources including a family newsletter and information for follow-up care.

### Eyeglass Recycling

In most dresser drawers, one can find a pair of eyeglasses that are no longer used. That same pair of eyeglasses can change another person's life. That's why the Nemours Florida Prevention Initiative, in partnership with the Lions Club's Recycle for Sight program, collects used eyeglasses. These glasses are delivered to Lions Club recycling centers where they are cleaned, sorted, packaged and distributed to needy children and adults in our community, free of charge.

### Our Healthy Ears

Modeled after *Our Healthy Eyes*, Nemours' *Our Healthy Ears* is a collaborative program developed by Nemours Florida Prevention Initiative and Nemours BrightStart! in order to reach young children, educate their families about ear health and hearing, and identify those who need follow-up care. Nemours provides early child care centers with a lesson plan about the ear and hearing. The one-day lesson is followed by a hearing screening event where Nemours provides additional resources including a family newsletter and information for follow-up care.

## Newborn Hearing Screening

Most states have a statute requiring universal newborn hearing screening. Since October 1, 2000, newborn hearing screening has been required, unless the parent objects, for all newborns in Florida. The intent of this statute is to provide a statewide comprehensive and coordinated interdisciplinary program of early hearing impairment screening, identification and follow-up care for newborns. The goal is to screen all newborns for hearing impairment in order to alleviate the adverse effects of hearing loss on speech and language development, academic performance, and cognitive development. In addition to providing newborn screening in our own Neonatal Intensive Care Unit, Nemours audiology provides the service for some of our hospital partners including Osceola Regional Medical Center. From the start of this service in June 2016 through December 2016, Nemours screened 1,251 infants.

## The Nemours Cochlear Implant Program

Cochlear implants can help many children who are born deaf or who have become deaf to hear conversation and sounds. The Nemours cochlear implant program takes every aspect of a child's auditory (hearing), developmental and social health into account. Our multidisciplinary team of ENT specialists, audiologists, nurses and social workers collaborate to help each child maximize their communication potential. Nemours assists parents to become experts on their child's hearing loss and learn how to be their child's advocate in all settings.

## Nemours Children's Hospital Audiology Division

NCH's Division of Audiology has the largest group of audiologists in Central Florida and offers comprehensive pediatric audiometric assessment and management, including sedated auditory brainstem response (ABR) testing and a hearing aid dispensary. In addition to newborn hearing testing and the cochlear implant program, Nemours provides other treatment and services including implantable hearing devices, osseointegrated devices (i.e., bone-anchored hearing aids), and treatment for auditory processing disorder and auditory neuropathy spectrum disorder. In order to expand access and convenience, the Division of Audiology offers services at four locations in the Central Florida region.

## Speech Language Pathology Division Highlights

NCH's Division of Speech Language Pathology in the Department of Rehabilitation Services provides specialized therapy for children with communication deficits secondary to hearing loss. In addition to providing auditory verbal therapy as part of the cochlear implant program, the division is involved in several other collaborative endeavors including:

- diagnostics as part of the autism clinic (multidisciplinary team)
- speech and language therapy provided as part of the inpatient rehab program
- intensive feeding therapy program currently in development (multidisciplinary team)

In order to expand access and provide convenient hours, the Division of Speech Language Pathology offers speech and language therapy during the evening hours until 7 p.m.



## Potentially Disabling Conditions



## SECONDARY HEALTH CONCERN

## Potentially Disabling Conditions

From 2013 to 2016, prevalence of activity limitations in the TSA has increased from 8.8 percent to 10 percent due to conditions such as autism, ADHD/ADD, mental health, joint problems, allergies, asthma, Down syndrome, cardiac care, broken bones and other long-term conditions. Essentially, one in 10 children in the TSA is limited or prevented in some way in their ability to do things most children of the same age can do because of a medical, behavioral or other health condition. For children with activity limitations, the vast majority (90.2 percent) are living with a condition that is expected to last 12 months or more.

Oftentimes, these children need support from multiple pediatric specialists. For this reason, the Nemours Model of Care is based upon a unified physician practice. At Nemours Children's Hospital, a team of physicians and subspecialists are available to serve the unique needs of our patients and families in one place. This provides Nemours with an invaluable resource, the ability to pull together a multispecialty team within minutes to treat even the most complex cases.

### Programs and Initiatives

#### Medically Complex Coordination Clinic

Care coordination plays an integral role in treatment for children with complex medical conditions. For this reason, Nemours has established a special consultative service, the [Nemours Medically Complex Coordination Clinic](#), to bring coordination of care to children with special needs. In partnership with our patients' primary care physicians, the coordination clinic helps identify each patient's specific needs and connects family members to community resources, nutritional guidance and psychosocial support. The Nemours Medically Complex Coordination Clinic supports patients seen in the following clinics:

- Rheumatology Clinic
- Cystic Fibrosis Clinic
- Diabetes Clinic
- Inflammatory Bowel Clinic
- Scoliosis Clinic
- Wound Care Clinic
- Williams Disease Clinic
- Epilepsy Clinic
- Motility Clinic
- Eosinophilic Esophagitis EOE (GI) Clinic
- Enuresis Clinic

#### Multidisciplinary Muscular Dystrophy Clinic

Nemours Children's Hospital provides a true multidisciplinary approach to muscular dystrophy care. Our team includes experts in orthopedics (bones and joints), pulmonology (lungs), neurology (brain, spine and nerves), genetics (DNA that determines heredity), physical and occupational therapy (improving muscle performance and motor skills), cardiology (heart), nutrition (help for kids with trouble eating), and psychology (behavioral and mental health). The Muscular Dystrophy Clinic at Nemours Children's Hospital is the only program in Central Florida certified and approved by the Muscular Dystrophy Association (MDA). Our program cares for the whole child, to help children with muscular dystrophy live as independently and actively as possible, as long as possible. This includes providing rapid access (less than one day) for infants with neuromuscular symptoms, to provide care as quickly as possible.

## Redesigned ER Model Limits Stressors for Children With Autism Spectrum Disorder

Eliminating unnecessary stimulation in the Emergency Department, NCH has developed a new model for providing care to children with autism spectrum disorder, developmental delays and other behavioral conditions. The redesigned care model is specially designed to reduce poor outcomes and negative experiences caused by sensory overstimulation in a typical Emergency Department setting.

NCH's Emergency Department instituted a pilot program based on the limited research available. Named "Respecting Each Awesome Child Here" or REACH, it is one of the first in the country to adapt care to the needs of children within the Emergency Department. The complete care model covers all aspects of a visit:

- **Arrival:** Families are instructed to alert Emergency Department staff if a child has autism spectrum disorder or another behavioral condition. From there, families and children are offered options such as headphones, sensory brushes and other resources to help distract children from overwhelming sights and sounds. Patients are also offered the option to occupy a separate, quiet waiting room or playroom while waiting to be seen.
- **Intake and Assessment:** The health care team on the Emergency Department floor is notified of the arrival of REACH families, ensuring the special accommodations are provided. A Child Life specialist is brought in to assess the situation and to make sure that children and parents are comfortable. Frontline staff can decrease stimulation for children by dimming lights, reducing use of unnecessary monitors and limiting the number of caregivers in the room at one time.
- **Treatment:** Families are consulted on their child's preferences and any adverse reactions to medications or to behavioral triggers, enabling providers to expedite decision-making to comfort the patient. The health care team sets up a REACH order that can be followed to expedite choices regarding consults, medications, tests and environmental adaptations.

Prior to instituting REACH, health care personnel at NCH's Emergency Department underwent education and training to learn new techniques and the capabilities of the tools available. Three research studies are underway to evaluate the pilot program and similar efforts, including assessing how emergency departments across the country accommodate children with autism spectrum disorders and similar conditions, analyzing the comfort level of emergency room staff in managing care for these children and measuring patient outcomes and parent satisfaction of the visits.

## Spinal Muscular Atrophy (SMA)

Spinal muscular atrophy (SMA) in children is a genetically based (inherited) neuromuscular disease that disrupts the ability of nerves to communicate with muscles. A child with SMA gradually loses control of most core muscle groups, which grow weak from lack of use. Nemours neuromuscular specialists offer many treatments and therapies to slow its progression and maximize function. Additionally, in 2016, there was a breakthrough in the treatment of SMA in children, allowing some children to live longer and reach developmental milestones. Nemours was on the forefront of the research leading to this discovery. Our hospital was one of four sites in the world to launch a clinical trial of the treatment that has shown amazing results and is creating hope for families around the world.

## Working Hand-in-Hand With Community Partners

As one of the premier pediatric health care systems in the nation, Nemours has made a promise to do whatever it takes to prevent and treat the most disabling childhood conditions. Every day at Nemours, the country's top pediatric specialists, researchers, educators and caregivers are working together with our physician partners, schools and communities to fulfill that promise.

## Camp Boggy Creek

Nemours Children’s Health System is a long-time medical partner of Camp Boggy Creek, founded in 1996 by Paul Newman and General H. Norman Schwarzkopf. The camp was created so that every child, no matter their illness, could experience the transformational spirit and friendships that go hand-in-hand with camp. Located just a short drive from Orlando, the 232-acre camp serves children ages seven to 16 who have been diagnosed with chronic or life-threatening conditions. Camp Boggy Creek is able to serve thousands of campers and their families through activity-packed weekly and weekend camp programs. Nemours partners with Camp Boggy Creek as a sponsor for special camp events and supports the medical clinic with physician volunteers.

## Come Dance With Us

In 2016, NCH, Orlando Health and the Orlando Ballet collaborated on an event titled *Come Dance With Us*. The program offered 10 children with special needs the opportunity to attend the Orlando Ballet for an introductory ballet course and perform an original score from *Beauty and the Beast*. This unique program required a multifaceted team consisting of many volunteers including two Nemours physicians, five Nemours physical therapists, three Orlando Health physical therapists and four professional dancers from the Orlando Ballet. Following their own performance, the children were invited to a performance of *Beauty and the Beast* at the Dr. Phillips Performing Arts Center and a special meet-and-greet session with professional dancers.

## Give Kids the World

In 2016, Nemours Central Florida Associates volunteered at Give Kids the World Village, a 70-acre, nonprofit “storybook” resort located near Central Florida attractions for families on Make-A-Wish trips. Nearly 200 Nemours volunteers worked directly with Wish Children and their families and assisted with the Give Kids the World Village beautification project.

## Florida Down Syndrome Conference

Over 200 people traveled from all across Florida to attend the 2017 Down Syndrome conference, hosted at NCH. Families and “self-advocates” (individuals with Down syndrome) learned new and valuable information while networking with other families. The two-day conference included a wide range of information on over 20 topics presented by Nemours world-class specialists including:

- Mandy H. Layman, MS, RD, LD/N, CDE  
“[Eat Right, Future Bright: Tricks for Healthy Habits and a Healthy Weight](#)”
- Peter D. Wearden, MD, PhD, and Tomislav Ivsic, MD  
“[Cardiac Issues in Children With Down Syndrome](#)”
- Tarig Ali-Dinar, MD, and Cynthia Chen, MD  
“[Obstructive Sleep Apnea in Individuals With Down Syndrome: A Comprehensive Approach](#)”
- Roberto Gomez, MD  
“[Gastrointestinal Motility Disorders in Children With Down Syndrome](#)”
- Alfonso Mireles, MD  
“[The Parent’s Role in Surveillance](#)”

Nemours Children’s Health System is proud to partner with the Down Syndrome Association and several other organizations to help all children reach their full potential.



### **Be The Match – Bone Marrow Registry Drive**

For patients diagnosed with leukemia, lymphoma and other life-threatening diseases, a bone marrow or cord blood transplant may be their best or only hope for a cure. Yet 70 percent of patients who need a transplant do not have a fully matched donor in their family. For this reason, NCH partners with Be The Match® to host bone marrow donor drives for Associates and the general public. Over the past 25 years, Be The Match®, operated by the National Marrow Donor Program® (NMDP), has managed the largest and most diverse marrow registry in the world. Every day, they work tirelessly to save lives through transplants. Nemours supports Be The Match® to grow the donor registry, support pediatric patients and advance the science of transplants.

Diabetes



## SECONDARY HEALTH CONCERN

# Diabetes

Every year in the United States, 13,000 children are diagnosed with Type 1 diabetes, and more than one million Americans deal with the disease every day.

Within the TSA, approximately 2.8 percent of children ages 0 to 17 have been diagnosed with diabetes by a doctor or other health care provider, which is considerably higher than the national benchmark (0.7 percent). Since 2013, the prevalence of childhood diabetes in the TSA has grown significantly from 1.3 percent to 2.8 percent. Those more likely to have been diagnosed with diabetes include children ages 0 to 4, Black and Hispanic children.

### The Nemours Pediatric Diabetes Program

Nemours understands that a diagnosis of diabetes can be very overwhelming for a family. And, although it's a condition that will always be a part of a child's life, early intervention is key to successfully managing the disease. At Nemours, our experienced, board-certified pediatric endocrinologists provide the answers and help that families want and need.

Our diabetes team of pediatric endocrinologists, nurses, certified diabetes educators, registered dietitians and mental health counselors care for children diagnosed with juvenile diabetes (Type 1) and Type 2 diabetes. We have the resources and expertise to evaluate a child's condition, diagnose, and work with the family to determine the right treatment plan for the child.

**The Pediatric Diabetes Education Program** at Nemours Children's Specialty Care, Orlando, is one of only a few in Florida accredited as a Center of Excellence by the American Diabetes Association – making us the first pediatric program in Central Florida to have achieved such an award, and only the second pediatric-specific program in Florida. This recognition means our pediatric diabetes educators are providing high-quality information and care to children with diabetes and support to their families.

### Diabetes Research

Nemours subspecialists include some of the top talent from around the United States, meeting the highest standards related to education, training, experience and clinical competency. NCH doctors consistently rank among the Best Doctors in America®, year after year by *Best Doctors*®, Inc. Because Nemours employs physicians directly, the system allows physicians to be mission driven without commercial restraints. Nemours physicians are able to devote more time to research, publishing and education activities advancing pediatric medicine for the children of Florida.

There are multiple research projects and clinical trials focused on diabetes and disorders of growth and puberty underway throughout the **Nemours Center for Endocrinology, Diabetes, & Metabolism**. Within the Nemours Center for Health Care Delivery Science, there are projects focused on family interactions, developmental psychology, behavior, and use of diabetes technologies that influence type 1 diabetes management and control from very early childhood through young adulthood. The Biomedical Analysis Laboratory is currently providing technical support to several ongoing studies in the areas of growth and metabolism, protein and amino acid metabolism, nutrition, obesity and cardiovascular disease.

Furthermore, many of our investigative researchers are involved in research projects funded by institutions such as the National Institutes of Health, Juvenile Diabetes Research Foundation (JDRF), Patient-Centered Outcomes Research Institute, Genentech Foundation for Endocrine Research and the Abbott Fund, among others. Nemours often offers clinical trials related to diabetes. A clinical trial is a study that evaluates new medicines, new devices, new treatments or new applications for old treatments.

### **TrialNet**

Nemours is actively involved in TrialNet, an international network of leading academic institutions, physicians, scientists and health care teams dedicated to the prevention of Type 1 diabetes. TrialNet offers risk screening for relatives of people with type 1 diabetes and innovative clinical studies to preserve insulin production.

### **Juvenile Diabetes Research Foundation**

Nemours takes great pride in research — so that we can better serve children today and in the future. For this reason, we are a dedicated partner of the Juvenile Diabetes Research Foundation, whose support is accelerating life-changing breakthroughs to cure, prevent and treat Type 1 diabetes and its complications. Over the years, Nemours representatives have served on the JDRF board, participated in the JDRF One Walk®, and provided educational resources to children and families involved with the program.

### **School Partnerships & Education**

Nemours nurse certified diabetes educators provide ongoing diabetes education and support for school nurses and caregivers throughout the state of Florida. Within the TSA, the Nemours nurse certified diabetes educators provide school nurses with workshop training sessions and technical assistance via telephone. In addition, Nemours assists school districts in the TSA to coordinate special accommodations for students managing diabetes.



# Other Health Services



## SECONDARY HEALTH CONCERN

## Oral Health

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Nearly two-thirds of children in the TSA from ages 2 to 17 (59.4 percent) have received dental care (for any reason) over the last six months. When respondents were asked to specify the reason for their child's most recent dental visit, 84.6 percent of parents mentioned a routine cleaning or checkup, while 5.3 percent described repair work or a cavity fill, 2.8 percent referenced an orthodontic appointment, and 1.2 percent indicated a tooth extraction.

Through Nemours Children's Hospital community partnerships and collaborations, Nemours recommends the following partners to provide pediatric oral health services: Community Health Centers, True Health, Orange Blossom Family Health Centers and Osceola Community Health Services.

## Sexual Health

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One-fourth of Orange County high school students (25 percent) report having had sexual intercourse with at least one person during the three months preceding the administration of the 2013 Youth Risk Behavior Survey. Among Orange County high school students who are sexually active, 37.4 percent report not using a condom during their last sexual intercourse, and 21.3 percent report not using any method to prevent pregnancy.

Through NCH's community partnerships and collaborations, Nemours recommends the following partners to provide sexual health services: Community Health Centers, True Health, Orange Blossom Family Health Centers and Osceola Community Health Services.

# Additional Efforts



## Additional Efforts to Support the Health and Benefit of Our Community

### Boards and Leadership

Engrained in our Nemours culture is a commitment to serve the community by providing our talents and leadership to community organizations. Our administrators, physicians and Associates serve organizations in the community, including but not limited to:

- American Heart Association
- Bacon (Big Awesome Charity of Nona) Foundation
- American Lung Association, Central Florida
- Boys Town
- Crohn's & Colitis Foundation of America, Central and Northeastern Florida Chapter
- Cystic Fibrosis Foundation
- Down Syndrome Association, Central Florida
- Early Learning Coalition of Osceola
- East Orlando Chamber of Commerce
- Florida Hands & Voices
- Give Kids the World
- Health Council of East Central Florida
- Healthy Orange Coalition
- Healthy Start Coalition of Orange County
- Heavenly Hooves
- Hispanic Chamber of Commerce of Central Florida
- Make-A-Wish of Northern & Central Florida
- Mother's Milk Bank of Florida
- Orlando Philharmonic Orchestra
- Primary Care Access Network
- Juvenile Diabetes Research Foundation
- March of Dimes of Central Florida
- Ronald McDonald House of Central Florida
- Runway to Hope
- School Health and Wellness Advisory Committee, Orange County Public Schools
- Oviedo Winter Springs Chamber of Commerce Second Harvest Food Bank
- Shepherd's Hope
- UCF College of Medicine



## Community Events and Sponsorships

Recognizing the expertise and important work of community public health organizations, Nemours Children's Hospital has committed resources to numerous organizations and events.

Additional Events and Sponsorships Include:

- 100 Black Men
- American Diabetes Association
- American Heart Association
- Autism Speaks
- Boy Scouts of Central Florida
- Camp Boggy Creek
- Crohn's and Colitis
- Cystic Fibrosis
- The Epilepsy Association of Central Florida
- Mother's Milk Bank of Florida
- Give Kids the World
- The Holocaust Memorial Resource and Education Center of Florida Campaign
- Juvenile Diabetes Research Foundation
- Healthy Kids Running Series
- Hope and Help Center of Central Florida
- Hugz from Bugz
- Nathaniel's Hope
- Orange Appeal's Woman's Conference
- Lake Nona Schools STEM Initiative
- Miles 4 Milk
- Seminole Chamber of Commerce – Riverside Dash
- Ride for Ronald
- Ronald McDonald House
- Early Learning Coalition of Osceola County's Ready. Set. Grow Conference
- Run Nona
- Runway to Hope Fall Event
- Runway to Hope Spring Event
- FARE National Conference
- Special Olympics
- Shepherd's Hope
- United Arts Association
- Women of Wuesthoff
- MDA: Muscular Dystrophy Association