



INFINITE POSSIBILITIES

2017 REPORT
TO OUR COMMUNITIES



Nemours. Children's Health System
Your child. Our promise.

VISION

Freedom from disabling conditions.

VALUES

Building and sustaining a culture of trust.

EXCEL | RESPECT | SERVE | HONOR | LEARN

MISSION

To provide leadership, institutions and services to restore and improve the health of children through care and programs not readily available, with one high standard of quality and distinction regardless of the recipient's financial status.

COMMITMENT

“I will do whatever it takes to make every contact with Nemours a uniquely satisfying experience ... for our patients, parents, visitors, colleagues and business partners.”



A MESSAGE FROM DAVID BAILEY



TO OUR FAMILIES, FRIENDS AND PARTNERS,

Over the last decade Nemours has had many remarkable achievements. This year was a watershed in leveraging these accomplishments to accelerate our goal of helping all children grow up healthy. Nemours has continued to excel in the three dimensions that point us toward our True North (*helping families receive the care they need and want, exactly how and when they need and want it*): patient experience, clinical outcomes and value. The accomplishments featured in this year’s *Report To Our Communities* will enable our success in pediatric health well into the future.

For example, more than 80 percent of our patient families rate their service experience at the highest level in every service across our health system, including our telemedicine program. In addition, either Nemours Children’s Hospital or Nemours/Alfred I. duPont Hospital for Children (N/AIDHC) — anchors of our pediatric regional networks in the Delaware Valley and Florida — has been recognized by The Leapfrog Group as one of the top one percent of safe hospitals nationally in four of the last five years. Nemours Nursing at N/AIDHC, which achieved Magnet status in 2012, was granted redesignation in 2017 by the American Nurses Credentialing Center Magnet Recognition Program®.

Furthermore, Nemours continues to be seen as a leader in pediatric population health. This is in part due to our successful advocacy for child health policies at the federal level, scaling our obesity prevention model to 11 states, providing tools for health literacy to parents and educators across the nation, and making significant contributions to pediatric research and medical education.

Underlying our progress on all fronts has been our firm commitment to the philosophy of continuous improvement and the effective use of its tools to remove waste, improve quality and increase efficiency. Along with the determination of more than 7,000 Nemours Associates — committed to pursuing best practices, breaking down barriers that limit optimal child development and exploring every opportunity to increase the value of care — we will continue to leverage our relationships with families, collaborators, donors and the communities we serve to help each and every child achieve their full potential.

Your child. Our promise.

David J. Bailey, MD

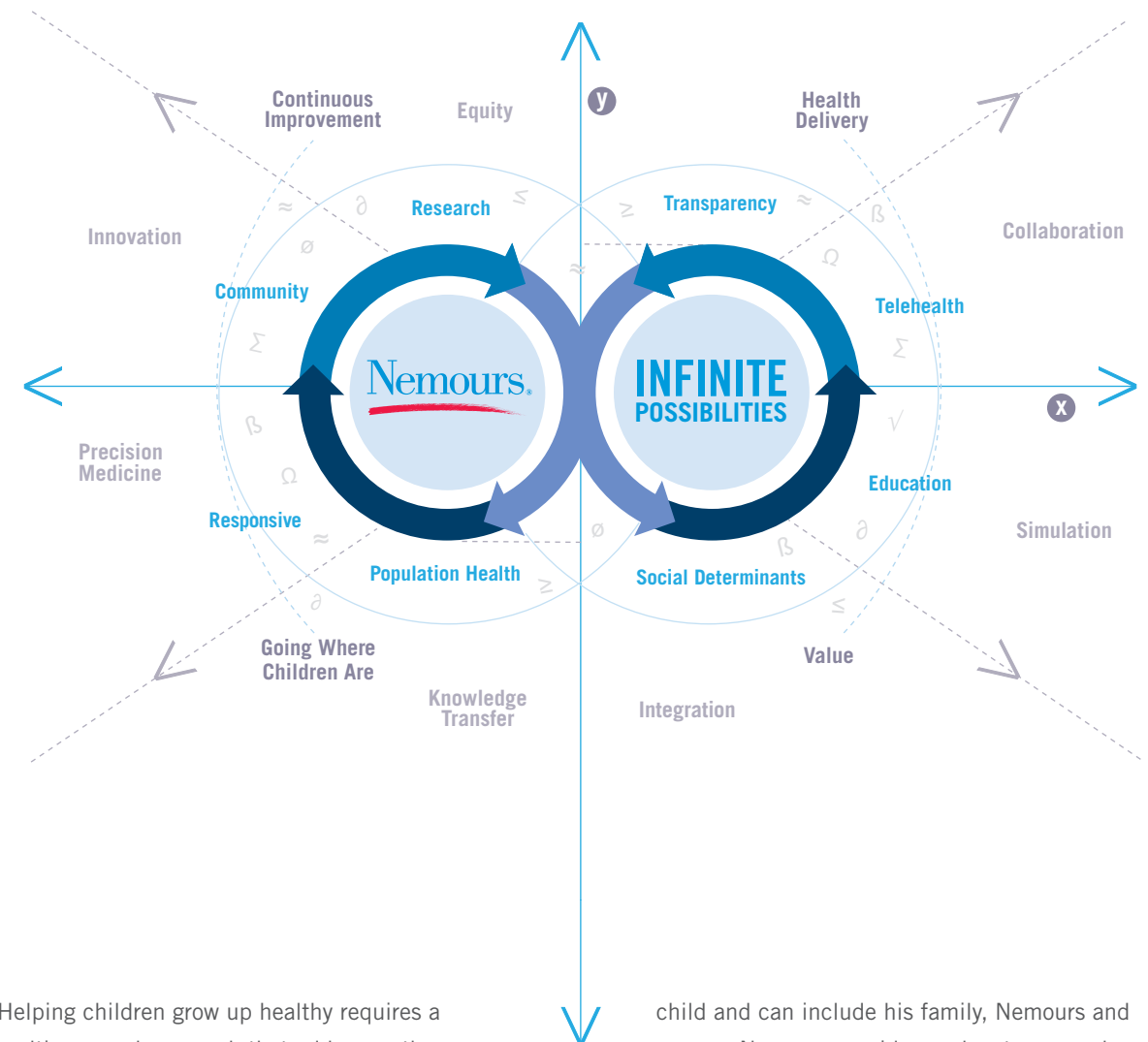
David J. Bailey, MD, MBA
Nemours President & CEO

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INFINITE POSSIBILITIES

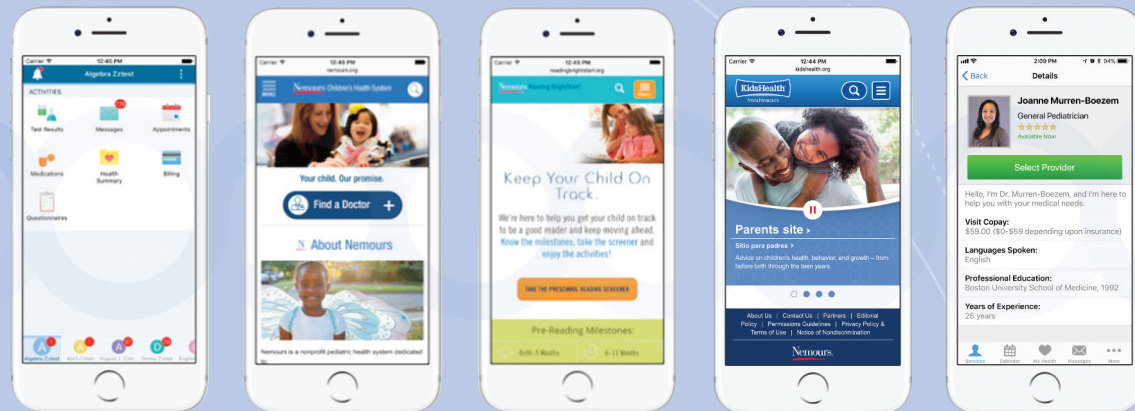


Helping children grow up healthy requires a multi-pronged approach that addresses the physical, emotional, social and educational needs of each child. To make positive contributions to the health of the whole child, Nemours leverages its own network of child health experts as well as our communities. The definition of community is unique to each



child and can include his family, Nemours and non-Nemours providers, educators, coaches, policymakers and others. When we push beyond the traditional boundaries of what constitutes care, collaborating as a broader community and addressing health at every level to help children reach their full potential, we discover ... infinite possibilities.

PUTTING HEALTH IN YOUR HANDS



MyNemours

Nemours.org

ReadingBrightStart.org

KidsHealth.org

CareConnect

EMBRACING NEW WAYS TO EMPOWER FAMILIES AND IMPROVE HEALTH

Smartphones and tablets are mainstays of modern families, used for everything from ordering dinner to educating and entertaining children. As digital natives, today's parents want and expect digital options in health care as well. For more than 20 years, Nemours has continued to embrace and develop digital tools with a focus on increasing access to care and health information, and improving quality and outcomes.

With the launch of the Nemours Center for Health Delivery Innovation (CHDI), Nemours is leveraging all its digital assets to create a seamless virtual experience unique in today's health care environment.

For families, this is a single, comprehensive source for finding doctors, making appointments and monitoring medications. The app makes accessing telehealth and patient instructions, understanding conditions and sharing action plans with other care providers much easier.

For clinicians, a single platform will help them monitor and gain a better understanding of what's occurring with their patient's condition between office visits.

Ultimately, through Nemours.org or the Nemours app, clinicians and families will have a single point of access to tools customized to a child's condition or relevant health information.

The CHDI works across all of Nemours providing a springboard for developing new, research-driven, consumer-focused digital health solutions that

Nemours Center for Health Delivery Innovation is working to build a seamless patient and provider experience — making it easier for both.

support clinician and patient-family experience and facilitate optimal health. The Center fosters collaboration aimed at the future of consumer-based digital solutions by engaging clinicians, digital developers, innovators, technicians, designers and content developers throughout Nemours. New opportunities for digital solutions are shared with patients and their families.

THE NEMOURS APP FOR ASTHMA IS THE FIRST PRODUCT FROM THE CHDI

The first major project for the CHDI was the development of the Nemours App

for Pediatric Asthma. This groundbreaking app is planned as the platform for a series of conditions slated to help patients, parents, caregivers and clinicians track and manage care.

For families, understanding and complying with an asthma action plan is essential but can be challenging. When not properly managed, children with asthma are more likely to miss school or end up in the emergency room, leading parents to miss work and experience stress and worry.

100
clinicians, parents, kids and developers worked together to create the asthma app

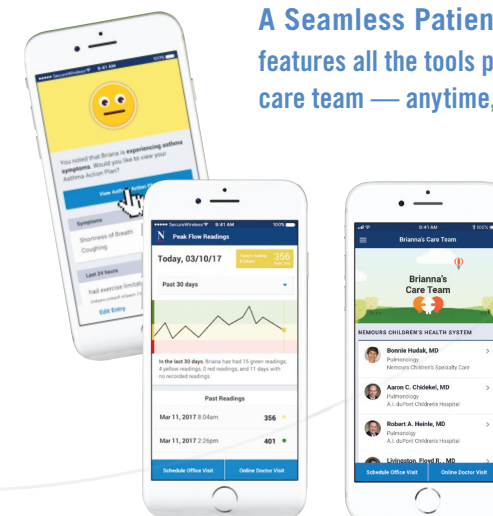
That prompted CHDI's operating officer P.J. Gorenc to ask, "What are the stumbling blocks? Can we develop digital tools to help solve them?" The asthma app was developed through a year-long process engaging more than 100 people, including physicians and families.

"The Nemours asthma app is an example of how Nemours' clinical and technological experts can work together to put digital health care innovations into the hands of families. As an asthma care provider, it was exciting to watch our ideas evolve into something that gives families easy access to the information they need."

— Bonnie Hudak, MD, department of pulmonology, Nemours Children's Specialty Care, Jacksonville

The app, launched in February 2018, helps parents and clinicians work together to monitor care plans, manage flare-ups, track medication and collect a comprehensive portrait of treatment efficacy in and out of the doctor's office — all within one single location. Gorenc noted, "It's important to put tools into people's pockets but it's just as important to get information about how the patient is experiencing the condition outside of the clinic setting and use that data to help inform the care plan. That closing of the loop is where we can really impact the quality of the care experience and health outcomes."

A Seamless Patient Experience Enabled By Nemours App For Asthma features all the tools parents need to manage asthma and connect with the child's care team — anytime, anywhere.



- Online appointment scheduling, electronic reminders, alerts and directions
- Online doctors' visits to triage exacerbations
- Interactive asthma action plan and asthma journal integrated with Nemours electronic health record
- Ability to "share" action plan with child's other caregivers
- Personal medication reminders and instructions
- Localized air quality index monitoring
- Direct message with members of child's care team
- Educational videos, articles and tips

CONSUMER DIGITAL HEALTH RESIDENCY ROTATION



From patient-centric communications to telehealth, we are

increasingly enabling an improved health care experience and better outcomes. A new resident elective rotation highlights technology's role and piques pediatric medical residents' interest through several customizable elements within CHDI:

- **Exposure to Nemours online clinical content:** Introduces residents to the importance of health literacy and the nuances of medical editing and medical illustration
- **Telemedicine:** Demonstrates telemedicine's infrastructure and applications for health delivery service and leveraging peripheral devices
- **Nemours Reading BrightStart!:** Uses evidence-based tools to identify the key role of pediatricians in promoting literacy, risk factors and critical connections of literacy to health

- **Healthcare Informatics:** Examines the clinical application of informatics through a work product addressing transparency, usability, quality or data integrity

Resident Jacqueline Phillips worked on a hybrid elective that included editing Nemours patient-facing

"I never really thought of the possibility that I could use my medical education to write articles and illustrate patient instructions — content like this really streamlines the patient visit."

content and telemedicine. "It was fantastic! While I was in med school I never had any experiences like this. This is all new. I think this is the future of medicine.

Getting a history from parents over video and then doing a physical exam via telehealth takes a different skillset. I don't think I would've been as comfortable with it if I didn't see somebody else do it."



CROWDSOURCED DIABETES WEBSITE FOR T1D PARENTS



When very young children are diagnosed with type 1 diabetes

(T1D), parents are challenged with a complex map of disease management often made more difficult by a lack of relevant information or support. Through an National Institutes of Health grant, Drs. Tim Wysocki and Jessica Pierce of the Nemours Center for Health Care Delivery Science crowdsourced a team of affected families to build a website that filled the gap.

Families of children under six years old diagnosed with T1D were the key advisors and contributors to the content. "Our daughter was diagnosed at 22 months old. She was near comatose when they triaged her. Within about five minutes they said, 'We're pretty sure she has type 1 diabetes.' Then, they left us," remembers Anthony Tamayo, a participant parent. "We took out our phones and started Googling. We had a hard time finding information. Everything was geared toward older kids not toddlers."



"How could we manage diabetes in somebody so young? We had basic questions like: how many carbs are there in breastmilk? What complicated it further was that our daughter couldn't tell us what was wrong."

"The researchers didn't guide parents through their vision. They really utilized our input so we truly feel the site belongs to families."

After nearly two years consulting with parents, the result is a website that offers

families of very young children immediate, vetted medical information and much needed social support. The site will continue to grow and evolve in response to the parent users' needs and preferences. Dr. Wysocki noted that the community aspect is central to the website, "We heard what families wanted and needed and developed articles on those topics written by parents or health professionals. The Parent Forum is where we think many parents will spend their time. Their lives are very hectic and complicated. They don't view health professionals as having all the answers they need. For example, how do you have a birthday party or travel or use child care? Anyone who doesn't live with it doesn't get it; other parents do."

A PLACE FOR COMMUNITY AND SUPPORT

Ivy H. thought her five-year-old daughter Hanna's exhaustion and constant thirst was a byproduct of a long family trip, summer heat and the transition away from naps. She did not expect a diagnosis of type 1 diabetes or have much exposure to what it was. "I was naively asking the doctor, 'Okay how do we get rid of it?'" The next day we were in training. They told me I would be giving her multiple injections a day. I was emotionally and physically exhausted."

She joined every website and program she could find, "I was starving for information and I want to help people with what I now know." Through social networking, Ivy heard about the Nemours clinical trial to build the website and wanted to contribute. In biweekly phone calls and brainstorming sessions, Ivy worked in collaboration with other parents, developers, clinicians and medical professionals to craft the new site. "Parent input changed quite a bit about the site. For the newly diagnosed, we wanted a prominent presence on the navigation. We wanted it to have immediate resources. We all have contributed articles. I wrote one about our diagnosis journey and another on advice for how to create work/life balance when you have a child with diabetes."

Today, Ivy reflects on the participation and outcome with enthusiasm, "I've never felt so involved in a community. The parenting of a child with diabetes can be lonely. There are a lot of camps but those are one-time things. On this site, you ask a question and you get a heartfelt response from people with experience and passion. The community is there whenever you are in need."

GOING WHERE CHILDREN ARE

EXPANDING LOCATIONS, SERVICES AND PROGRAMS TO KEEP CARE LOCAL

Nemours' mission to care for children means ensuring care is accessible. Through new partnerships, outreach, services and expansion, Nemours is increasing its ability to provide more children with the care they need closer to home.

NCH CELEBRATES FIVE YEARS AND PLANS FOR CONTINUED GROWTH

Nemours Children's Hospital (NCH) celebrated its fifth birthday in 2017,

both realizing and broadening a dream. Serving more children than ever, in more ways than ever, NCH is playing a pivotal role in developing a statewide network of primary, specialty and urgent care.

From the outset, NCH was designed to grow with a Sixth Floor built and available to meet future demand. Today, NCH is ready to grow to meet the needs of the community and is building out that sixth floor. The expansion will provide 30 additional critical care capable beds and dedicated space to create the Nemours Children's Hospital Cardiac Center for Excellence.

The Center will include an operating room, cath lab and the cardiac intensive care unit. By co-locating these services, heart patients and their families can be served on a single floor and other floors will have room for growth as well.

In addition to Nemours' own locations, NCH has relationships with six collaborating hospitals throughout Central Florida to provide care options that meet children and families where they are.



A recent partnership with **Lakeland Regional Health Medical Center** will complement its pediatric primary care with Nemours' specialty care in their new Carol Jenkins Barnett Pavilion for Women and Children. The Pavilion will have the only Level III neonatal intensive care unit in Polk County.

A UNIQUE PARTNERSHIP MOVES CARE ON CAMPUS

Nemours and Orange Blossom Family Health teamed up to provide a novel care delivery solution for children and families in Orlando's underserved Parramore community. The satellite practice, operated by Orange Blossom with pediatric physician services from Nemours Children's Primary Care, is located on the campus of **Orange County Public Schools' Academic Center for Excellence**. The practice includes primary care, preventive health screenings, immunizations and dental health. Acting as a community center and resource, the facility is open to serve local children of all ages whether or not they attend the school.

A NEW PARTNERSHIP IN WEST FLORIDA TO DELIVER HIGH-QUALITY CARE

To better serve children in the Florida panhandle, Nemours

Children's Specialty Care entered into a partnership with HCA's **West Florida Healthcare** (WFH) in Pensacola in 2017. Nemours physicians performed inpatient and outpatient surgeries at WFH along with consults and admitting post-surgical patients. In 2018, our outpatient clinics will provide specialty care in orthopedics, urology, otolaryngology, cardiology, pulmonology, GI, nephrology, endocrinology and rheumatology. When WFH's PICU is completed (in 2019), Nemours will be able to help care for more complex patients. The partnership is expected to improve care to children throughout the region.

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collaborating hospitals in five states offer children and families access to Nemours' pediatric specialty care



Nemours is building a specialty center on Bayhealth's new medical destination campus in Milford, Del., bringing much-needed pediatric specialty care to families in the central and southern part of the state.

"Our partnership is about the family and the experience. We want to care for children closer to where the child and family lives and works — getting them to the closest available location. West Florida Healthcare is an A-rated Leapfrog Hospital, recognizing its commitment to the highest quality, safest care for patients. Our agreement is non-restrictive and allows us to work with other community hospitals to keep care local whenever possible."

— Mary Mehta, MD, chief medical officer, Nemours Children's Specialty Care, Pensacola

FURTHERING OUR COMMITMENT TO FAMILIES IN ALL AREAS OF DELAWARE

In southern Delaware, access to pediatric specialists may

be limited. Many children in need of specialty care travel long distances to Nemours/Alfred I. duPont Hospital for Children or another Nemours Specialty Care location. Nemours has partnered with Bayhealth at its Milford campus to bring high-quality pediatric care closer to home for these patients. Located mid-state, the new **Bayhealth Sussex Campus** will create better accessibility for central and southern Delaware with an innovative campus developed to serve population growth into the future. The new medical office building, slated for completion in 2020, will offer pediatric primary and specialty care, imaging, therapeutic services and audiology, and will also provide select services to seniors (Nemours SeniorCare) at the Sussex campus. Pauline Corso, chief operating officer, physician network, Nemours duPont Pediatrics, sees the collaboration as a way to help children receive exceptional care, "Our commitment to Milford is key in responding to the needs of southern Delaware. Patients won't have to travel to Wilmington for all of their specialty services."

EXPANDING THE USE OF TELEHEALTH TO SAVE TIME, MONEY AND LIVES

Telemedicine is transforming the way patients “see” and seek care. Using secure, remote technology, clinicians improve outcomes and access through virtual visits reaching children where and when they need care. Nemours continues to expand and advocate the use of this valuable health resource.

PUTTING TELEHEALTH INTO PRACTICE

Via tablets, smartphones, iPads and

computer screens, clinicians are using the Nemours CareConnect telehealth program to reach beyond brick and mortar locations. Using CareConnect’s video capability, Nemours also provides pediatric specialty support to all of its collaborating hospitals’ emergency departments, NICUs and PICUs. Nemours intensivists — doctors specially trained to care for critically ill and medically complex patients — deliver specialized care to babies and children reducing the need for transport and keeping patients and families close to home.

Critical care consults have resulted in a 34% increase in direct transports to the PICU and a 27% decrease in ED utilization.

When children must be transported, CareConnect is helping transport teams coordinate

seamless transitions. In emergencies and when transfers happen from referring hospitals, children must be stabilized. Nemours’ transport team’s use of CareConnect frees nurses and respiratory therapists to attend to the patient and consult with parents while the referring hospitals can communicate with a Nemours clinician “face-to-face” to provide up-to-the-minute patient information.



BRINGING NEMOURS SPECIALISTS TO PRIMARY CARE

Nemours is also expanding the use of CareConnect to

deliver specialty care services to both Nemours and non-Nemours primary care offices in Delaware. Last year, 20 Nemours pediatric specialties, including nutrition, weight management and behavioral health, provided CareConnect consults to areas where access is limited or to reduce travel for families. Overcoming distance and socioeconomic barriers, CareConnect provides an opportunity to expand care to children in need wherever they live in the State of Delaware.

“It’s hard enough to manage the day-to-day of raising children — and a simple task like driving to the doctor can be overwhelming based on a family’s circumstance. Telehealth offers families another avenue to receive the same care closer to home. We are committed to bringing care closer to children and leveraging new and innovative technologies for the families we serve.”

— Carey Officer, operational vice president, Nemours CareConnect, CHDI

A LIFELINE TO CARE IN EMERGENCIES

Natural disasters like hurricanes often bring unanticipated health care concerns and barriers to care. Flood waters can carry danger and families may have lost homes, power and even necessary prescriptions.

“I just used this app for my three-year-old son who had tonsillitis since everything is closed due to the hurricane.”

The ability to secure timely medical help is imperative. In

2017, a busy hurricane season brought the importance of access to expert medical care front and center. Nemours CareConnect helped parents find help when leaving home was not an option.



- During Hurricane Irma, the CareConnect app was downloaded 2,100 times and CareConnect carts were deployed to three special needs shelters, so parents could receive expert pediatric care for their children leaving emergency departments to manage critical issues.
- Puerto Rico’s power infrastructure was devastated by Hurricane Maria so Nemours CareConnect carts were set up in Orlando’s airport to quickly assist evacuees and provide needed medical interventions.
- During Hurricane Harvey, Texas lifted restrictions that prevented out-of-state health care providers from offering assistance. Nemours provided free access to pediatricians through CareConnect to Texans in need.

KEEPING KIDS HEALTHY — WHEREVER THEY LIVE, LEARN OR PLAY

AT HOME Nemours CareConnect provides 24/7, on-demand coverage to consumers across six states. More than a video chat, CareConnect can share information with primary care doctors to preserve the medical home. 98% of users rated CareConnect experiences as the same or better than in-office visits.

In Delaware, Nemours is piloting a program that feeds a digital footprint of vital signs for medically complex children to clinicians. Using a combination of CareConnect visits and data from connected medical devices, clinicians will be able to perform many of the tasks that used to be reserved for in-office visits. For families, this can reduce the need for sometimes difficult and costly travel as well as mitigate the risk of infection.

AT SCHOOL Children spend a lot time in school or childcare. Few institutions can afford staff nurses. Nemours CareConnect is helping manage health care issues as they arise right on the campus. In four Orlando schools, with plans to expand in Florida and Delaware, CareConnect school-based telemedicine helps treat kids on-demand using its secure audio/video links.

ON VACATION When families travel, CareConnect provides a safety net that offers easy access to Nemours’ pediatric experts. Nemours has partnered with a cruise line to provide specialized training for cruise medical staff as well as access to Nemours clinicians via CareConnect to evaluate patients onboard when issues arise. Often patients, who might otherwise be flown to the nearest hospital or have the cruise ship head back to port, can be treated via CareConnect and return to their family vacation.

DEVELOPING THE WHOLE CHILD



BRINGING VITAL SERVICES AND CARE TO ADDRESS GROWING NEEDS

When parents are concerned that physical, emotional, behavioral or social development is not on track, Nemours’ developmental pediatrics and behavioral health clinicians can provide answers. Through specialized screenings, facilities, research, programs and tools, Nemours is providing hope and helping kids reach their full potential.

THE SWANK AUTISM CENTER AT N/AIDHC



Autism spectrum disorder (ASD) encompasses a

wide range of neurodevelopmental disorders which share impaired social and communication skills and repetitive behaviors. Affecting 1 in 41 children in the U.S. — an increase of more than 100 percent in one decade — ASD requires comprehensive evaluation for diagnosis. Early intervention is essential for the most positive outcomes. Nemours provides interdisciplinary resources to support families and help children flourish.



In 2015, donors Susan and Dan Katzin gave a transformational gift toward the development of a comprehensive clinical and research program for children with autism and other neurological disorders. Their gift was a catalyst for a groundswell of additional support from the community, leading to expansive development in the Nemours Neuroscience Center as well as the Center for Behavior and Development.

Building upon the Katzin’s vision, The Howard W. Swank, Alma K. Swank and Richard Kemper Swank Foundation recently made a \$5 million gift to support a unique and comprehensive autism program in the Delaware Valley. The multi-million dollar Swank Autism Center at Nemours/Alfred I. duPont Hospital for Children will serve families throughout Delaware, Pennsylvania and New Jersey. This integrated care facility will expand services and offer cutting-edge research and treatment protocols with space designed for reducing common stressors. Special features like a feeding therapy and eating clinic will be supported by functional tools like a full kitchen with observation capabilities.



A GIFT THAT KEEPS ON GIVING



In Florida, renewed gifts from The Harvey and Carol

Massey Foundation have supported Nemours’ efforts to create centralized and integrated services for families whose children have, or may have, autism spectrum disorders. In 2017, funds supported a portion of more than 259 free autism screenings and assessments, the provision of applied behavior analysis therapy, the award-winning REACH (Respecting Each Awesome Child Here) program at Nemours Children’s Hospital, and other support services, training and educational resources directed toward families.



GOING THE EXTRA MILE

Born premature at 23 weeks, Kylie has experienced a host of medical complications affecting her brain, eyes and lungs. Making matters more challenging, Kylie was diagnosed with autism around age four.

“We are frequent visitors to Nemours for specialty and emergency care,” said her father Josh. “In fact, Kylie was one of the first patients to arrive by ambulance at Nemours Children’s Hospital the day after they opened in 2012. With her epilepsy, Kylie may have six seizures in an eight-week span, so we end up spending a lot of time in the ED.”

Kylie, now age 8, is often unconscious when she arrives at NCH. Once she is alert and stable, the ED team takes her down to the REACH sensory room — a specially-designed room for children with autism or similar conditions that can help alleviate anxiety and reduce over-stimulation that is common in an emergency room setting.

“It’s calming for her,” said Josh. “She really likes pushing all the buttons on the bubble machine. Nemours even has a traveling version of it that Kylie has used while waiting for outpatient surgery. We think it’s really awesome that Nemours goes the extra mile. They are not just treating a symptom or performing a procedure — everyone at Nemours truly wants to know what they can do for you as an individual to make the entire experience better.”

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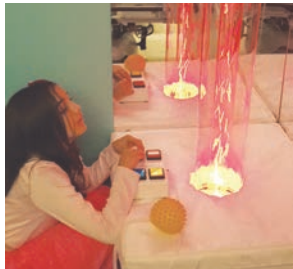
free autism screenings and assessments provided since 2014

AUTISM-FRIENDLY ENVIRONMENTS



Bringing any child for medical services can be

stressful but there are special challenges for children with autism. Changes are being made throughout Nemours to make the experience of receiving medical care less overwhelming for children with autism:



- special sensory rooms, designed by autism specialists, allow children to receive care in a room with calming light, sound and sensory-friendly activities; sensory equipment at Nemours Children’s Hospital was generously funded by the Doug Flutie, Jr. Foundation for Autism
- clinical and non-clinical personnel receive training in developmentally-appropriate approaches to reduce anxiety in children with autism

The emotional, social and behavioral development of children is integral to enduring health. Underlying medical conditions, chronic illness and other psychosocial factors can affect a child's sense of wellbeing and cause families distress. Through an integrated approach, Nemours is expanding support of children, families and the community.

BUILDING COMMUNITY RESILIENCE



Adverse childhood experiences (ACEs) such as chronic illness, the loss of a

parent, homelessness, violence or sexual abuse have lasting impacts on children's mental and physical health. Nemours joined a national collaborative with four other children's health systems to look at ways to systematically identify and address ACEs in its patient population. Through this collaborative, Nemours recognized that a reduction in the impact of ACEs required a coordinated approach with community partners to educate families about the issue and subsequent short- and long-term effects on health. To further the dialogue about ACEs, Nemours shared the documentary "Resilience" with more than 1,200



community partners in 2017 to begin to heighten awareness of this growing public health crisis. Additionally, through a joint symposium with Delaware Trauma Matters, Nemours helped to provide culturally-competent information to hundreds of educators and community representatives.

The commitment of Nemours to addressing these issues is evident in a recent allocation of \$3.5 million to study and assess social determinants of health, lower the costs of health care and improve health outcomes for children.

TRAUMA-INFORMED CARE SUPPORTED BY PLAY



Up to 80 percent of children and their families experience some traumatic stress reactions following life-threatening illness, injury or a painful medical procedure. The use of trauma-informed care incorporates practices that recognize this traumatic potential.

A \$400,000 grant from and collaboration with The Toy Foundation (TTF) has helped researchers from the Nemours Center for Health Care Delivery Science to develop new qualitative research on the role of play in helping children and families manage and emerge from trauma. Through focus groups with parents, caregivers, clinicians, children and siblings, Nemours researchers analyzed benefits and barriers to play therapy. A second grant of \$425,000 from TTF will build upon the current data and focus on developing and piloting innovative programs that use play materials to reduce and prevent traumatic stress reactions in children. These studies are being conducted at both Nemours children's hospitals.



REDUCING BARRIERS TO BEHAVIORAL HEALTH SERVICES



Nemours' longstanding commitment to the integration of

behavioral health in primary care, in part, contributed to Nemours' patient-centered medical home (PCMH) designation from the top accreditation programs in the country. PCMH status, at the highest levels, has been earned by all Nemours primary care practices in Central Florida and Delaware.

To expand training efforts in behavioral health and integrated primary care, Nemours secured more than \$1 million in grants from the Health Resources and Services Administration including its Behavioral Health Workforce Education and Training program. This grant supports integrated primary care development for professionals and paraprofessionals of underserved populations. Behavioral health trainees receive intensive training in areas such as cultural competence, ethics and prevention provided by interdisciplinary faculty from Nemours and the community. Collaborations with existing partners such as Delaware's Christiana Care Health System

ASSESSING RISK AND CONNECTING TO SUPPORT



The psychosocial assessment tool (PAT) is a screener that parents/

caregivers complete online, telling clinicians about their psychosocial risks. The information is sent back to the health care team, so that it can be incorporated into care planning. Developed by Anne Kazak, PhD, ABPP, co-director, Nemours Center for Health Care Delivery Science, the PAT has become the standard tool used for assessing families facing pediatric cancer throughout the United States.

Available in English and Spanish, the PAT has been adapted for use with families facing other serious pediatric diagnoses. Results provide clinicians data for forming interdisciplinary teams to support the social and emotional health of children and families.

and Children's Hospital of Orange County, CA, are being used to develop diversity training and recruitment initiatives to support the mental health and wellness of communities in need.

As leaders in the drive for greater integration in the primary care setting, Nemours hosted 120 participants from 20 U.S. states at the inaugural DREAM IPC (Developing and REsearching Advanced Models of Integrated Primary Care) conference.

"The diversity panel was great. I learned some scripts to consider implementing into practice. I'm also reconsidering how I screen for trauma."

The first of its kind national, bi-annual conference convened experts in the field of behavioral health and related

specialties to share leading-edge strategies for primary care integration, including using clinical data from the electronic health record to inform care and program development.

Nemours is currently piloting an integration of psychology into well baby visits and exploring ways to consistently embed psychology into care for patients with diabetes, cardiac and GI conditions.

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pediatric oncology centers in the S.E. received PAT training in 2017 through a CureSearch grant awarded to Nemours

"The PAT does what clinicians cannot easily do without a tool to help. How do you pick out which families need which support and how critical is that support in the beginning? That's what the PAT does and it's an excellent, well-studied tool. We are able to connect families to appropriate services at the beginning of care."

— Paul Pitel, MD, division of pediatric hematology/oncology, Nemours Children's Specialty Care, Jacksonville

ENSURING EACH CHILD'S FULL POTENTIAL

EARLY IDENTIFICATION AND INTERVENTION TO HELP CHILDREN GROW UP HEALTHY

Nemours is integrating its clinical expertise and services to provide preventive screenings and programs that foster children's healthy development. From newborn through adolescent screenings, Nemours is working with community partners to deliver preventive health services and promote healthy growth along the continuum of childhood.

IMPROVED SCREENINGS FOR NEWBORNS IN THE STATE OF DELAWARE

As of January 2018, screening for all of

Delaware's 11,500 newborns will be handled by Nemours/Alfred I. duPont Hospital for Children. Newborn screenings are performed through a simple blood test that screens for 47 conditions. Test results that used to take up to a full week are now being handled in one to two days so intervention, when needed, can happen as early as possible. The change is also resulting in fewer false positives, which cause unnecessary stress for families.

When test results are positive, Nemours' integrated network of specialists provides assistance to families and coordinates with family pediatricians. "We have six doctors in the diagnostic group. If a follow-up screen is needed, our team contacts the pediatrician. If it's more significant, we call the pediatrician to discuss the results and make recommendations. We follow every patient that had an abnormal screening until we have confirmed a diagnosis and that treatment has been initiated or confirmed a false positive," said Michael Cellucci, MD, medical director, newborn screening program.



A unique partnership between Nemours and the Clinic for Special Children (CSC) provides a highly specialized, integrated health option for children with rare genetic disorders. As an extension of this collaboration, the partnership also provides culturally-sensitive care for the Old Order Amish near Dover, Delaware.

Most Amish children are delivered at home by midwives. These midwives collect newborn blood screens and Nemours and CSC work together to process the tests, communicate the results and seek culturally competent recommendations for this special population. Dr. Michael Cellucci shared how this partnership, close connections with local communities and preventive screenings saves the lives of newborns. "We had a midwife who collected the screen from an Amish newborn. In five days, we diagnosed severe combined immune deficiency, a potentially fatal disorder. We called the midwife that day and she brought the family to the hospital for molecular testing. We contacted the NICU, got a bed for the baby and confirmed the diagnosis with the CSC. Within two hours the baby was scheduled for bone marrow transplantation."

PROVIDING CRITICAL SCREENINGS IN THE PRIMARY CARE OFFICE

Nemours' commitment to the wellbeing of children goes

beyond simply treating those who become ill. Our mission also includes prevention and early intervention to address issues that may challenge a child's long-term physical, social and behavioral health outcomes.

In Delaware, Nemours' efforts are providing greater access to critical early screenings in the pediatric and primary care setting. In 2017, targeted developmental screenings were performed on more than 7,400 children from birth to age three. Nearly 480 children were identified and referred to developmental and behavioral support through statewide early intervention programs.

480

children were identified and referred to developmental or behavioral support through statewide early intervention programs

New for 2017, an oral health risk assessment and fluoride varnish treatment program began in Nemours duPont Pediatrics practices. Throughout the year, Nemours providers were trained in the procedure as well as educating families on the importance of screening and dental health. In its first year, 17 providers were trained and nearly 840 treatments were completed. Nemours continues to coordinate with the American Academy of Pediatrics, Delaware State Dental Society, Division of Public Health and the Oral Health Coalition to improve referrals, communication and educational opportunities.



ASSESSING DEPRESSION IN ADOLESCENTS

The American Association of Pediatrics (AAP) estimates one out of

five teenagers experience depression. The APP recommends that primary care providers screen adolescents at annual well visits. At Nemours, this screening is already a standard practice. Nemours uses a nine-question screening tool that assesses suicidal ideation and the primary symptoms of depression such as:

- sadness or irritability
- feelings of hopelessness
- loss of pleasure
- difficulties with sleep or eating

The screening tool is built into the Nemours electronic health record, so it automatically alerts the provider to assess for risk if the child is 12 years or older. In 2017, depression screenings were conducted with 9,755 adolescents at Nemours duPont Pediatrics locations to identify at-risk youth and provide interventions such as referrals to psychology, medications or other crisis interventions. Nemours has established registries to follow these referrals and ensure children have received the necessary services.

ENSURING CHILDREN ARE READY TO LEARN

Nemours is committed to helping children achieve their full potential, which includes academic success. There are multiple health factors that can affect a child's ability to learn. The Nemours Florida Prevention Initiative (FPI) created a series of modules around the health and development of children as young as age two and up to five years old.

Two of these modules, "Our Healthy Eyes" and "Our Healthy Ears," are collaborations among FPI, Nemours Reading BrightStart! (Nemours' early literacy initiative) and Nemours pediatric ophthalmologists and ENT specialists. Each module includes an education component that teaches children the importance of prevention and safety to

A SIMPLE SCREENING SAVED GIOVANNI'S SIGHT

Teachers at Giovanni's childcare center noticed that he always seemed to struggle. "He was always squinting and he would hold his papers right up to his nose," remembers Megan Brown, director of family services, Orlando. His mom, Jamie, noticed too, and called plenty of doctors, "They kept telling me that because of his age and because there wasn't anything pathologically wrong with him, they couldn't do the eye exam." Through an "Our Healthy Eyes" module at his childcare center, Giovanni was able to receive a vision exam that checked for nearsightedness, farsightedness, astigmatism, amblyopia and strabismus. His screening showed serious problems and he was referred for a comprehensive exam. "The doctor said, 'He can't see anything.' He held a lens over my eyes to show me that Giovanni was just shy of being legally blind."

When Giovanni received his first pair of glasses, his whole world was changed. "I put them on him," Jamie

protect eyes and ears, and aims to minimize anxiety a child may have when getting their eyes and ears checked. These learning opportunities are followed by screenings where parents receive information about follow-up care.

More than 1,150 preschool-age children in four Central Florida counties received hearing and vision screenings and education in 2017.

Both of these programs are being deployed in childcare centers and with community partners throughout four Central Florida counties. In 2017, vision and hearing screening of 1,158 children resulted in 163 referrals for further follow-up with the child's pediatrician or a comprehensive examination by a pediatric specialist.



remembers, "and he grabbed my face and said, 'Mom, you look so different — you are beautiful!' Now he's so excited to come to school and learn. It's really amazing what one simple screening has done to help my son."

PREPARING FOR READING SUCCESS

Recognizing the connection between literacy and health outcomes, more than 12 years ago, Nemours launched Nemours Reading BrightStart! (NRBS!), its early literacy initiative. In that time, NRBS! has been developing tools and sharing resources to help parents, educators and health providers across the U.S. identify children at risk and intervene to ensure reading readiness.

The NRBS! validated screening tool, for children ages three to five, is available for free at ReadingBrightStart.org and used in community screenings at libraries, doctors' offices and preschools throughout the country.

15,000+
parents completed the early literacy screener at ReadingBrightStart.org

In addition to its research-based tools and resources, NRBS! continues to collaborate with like-minded organizations to raise awareness of the importance of reading readiness. In 2017, **Reach Out and Read**, a national organization that encourages families to read



PARTNERSHIP TO EXTEND SCREENINGS

Nemours Florida Prevention Initiative (FPI) will be partnering with Head Start in

Orange County, Fla. to pilot its vision and hearing education and screening program with their centers.

FPI was asked to partner with the county because of Nemours' pediatric expertise, prior successful experience with Nemours' ECE (early care and education) learning collaboratives as well as the education component offered to children and families.

A broader series of educational modules and screenings is currently under development, including "Our Healthy Heart" and "Our Healthy Bones."



aloud together, published an article from NRBS! — "Empowering Parents Of Preschoolers With The Nemours Preschool Reading Screener" — along with a link to the screening tool.

In October, Nemours partnered with **Jumpstart!**, a national early education organization, for its **Read for the Record** program. Nemours Associates and leaders read the book *Quackers* to 316 patients, families and Child Life participants at nine Nemours locations in three states.



EMBRACING NEW FRONTIERS



COLLABORATION AND EXPLORATION LEAD TO NEW DISCOVERIES

Personalized (or precision) medicine is an approach to disease treatment, prevention and management that takes into account the things that make each child different. By analyzing individual data, Nemours is working to provide personalized treatments that produce fewer side effects and better outcomes for children.

Nemours is developing a new precision medicine program to continue its leadership role and commitment to improve the health of all children. In alignment with Nemours’ clinical and research priorities, The Nemours Precision Medicine (NPM) program will work in collaboration with academic and clinical institutions, community stakeholders and other programs in the Delaware Valley and Florida to conduct and share research.

The NPM program will maximize existing data and build on Nemours’ current partner programs to drive increasingly personalized and precise care solutions in pediatrics.

The Nemours Precision Medicine program will integrate three research thematic areas:

- **Applied Clinical Genomics:** Use genomics and related big data to improve the ability to prevent, diagnose and treat disease at the individual patient level
- **Clinical Research Services:** Further develop the capacity to analyze big data sets and patient and population dashboards to improve outcomes, risk stratify patients and evaluate population-level effects
- **Healthcare Delivery Science:** Build analytic capacity to understand the processes that affect delivery, safety, outcomes, cost, quality and the value of pediatric health care, by integrating quality of life measures in big data sets



BIG DATA TO BENEFIT KIDS



Pediatric research faced serious challenges.

Institutions that treated children were not adequately connected and many pediatric conditions are uncommon or rare, making the sample sizes at each institution too small or too expensive to study. PEDSnet was created to be part of the solution by creating a clinical data research network that includes eight of the nation’s largest children’s health systems. PEDSnet provides a diverse population for conducting pediatric research and houses data sets for 6.25 million kids.

The data network includes patients with every type of pediatric disorder and every pediatric specialty. PEDSnet is exploring ways to grow the network through memberships and research

“Having institutions from different parts of the country, like the deep South, brings diversity to the PEDSnet data set, even if it’s sometimes fairly small numbers. With that diversity, you can begin to answer whether there are environmental or geographic factors that are having a measurable impact on health.”

— Tim Bunnell, PhD, director, Nemours Biomedical Research Informatics Center

grants, and broaden its use for locating clinical trial subjects.

Nemours, one of the initial PEDSnet collaborating institutions, is part of several active studies among the network and is utilizing PEDSnet data for other Nemours-initiated studies.

PHARMACOGENETICS AND PRECISION MEDICINE



A Nemours clinical trial in pediatric asthma patients identified a connection between children using proton pump inhibitors (PPI) for gastric reflux and children being predisposed to having upper respiratory infections. Clinicians wanted to know if PPI medications were causing harm. Using PEDSnet, Nemours researchers conducted a study of 14,000 children with asthma involving 80,000 asthma visits which suggested some children are at increased risk of pneumonia, bronchitis and gastroenteritis based on how their bodies metabolize PPI medication.

By identifying a specific gene that helps break down the PPI medications in the liver, researchers discovered that individual genetics affected the rate that children metabolized PPI medication. In collaboration with the University of Florida, Nemours researchers are comparing conventional dosing of PPI medications against genotype-guided dosing. The pilot study showed trends that the genotype-guided approach reduces the

risk for infections. The second phase of the study hopes to further define which children will benefit from specific dosing to increase efficacy and reduce negative outcomes. Using on-site genetic screening to quickly analyze children’s genes, clinicians will then be able to customize PPI medication dosing.

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Nemours is ranked 11th in the U.S. for NIH pediatric research funding

BIOINFORMATICS AND MACHINE LEARNING



Bioinformatics is an interdisciplinary

science combining computer science, biology, mathematics and engineering that collects and analyzes complex biological data. Using data, such as the information collected in PEDSnet, researchers and clinicians can process the information using algorithms that “learn” to make predictions or interpret patterns. Integral to the success in machine learning is creating useful bioinformatics which start with common language.

With its rapid ability to identify variations in genomic sequences, bioinformatics will be a critical component driving precision medicine.

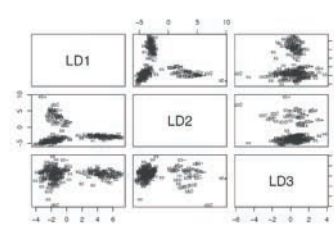
By standardizing the concepts and terms used in collecting information, the data becomes a more powerful tool.

In one example, Nemours is using **machine learning** to examine data collected on pediatric patients with sickle cell disease. The goal is to identify patterns in data that predict genotype in sickle cell patients. It is also being used to help recognize the “image” of disease — similar to the way social networks use data to recognize faces, animals and objects. Algorithms are used to map health care information shared by a group of patients to abstract image-like grids in which the computer learns to recognize patterns and “predict” whether a child has a specific disease based on the child’s “image” map compared to the “image” map of the disease.



CREATING A COMMON LANGUAGE AND USING DATA TO BENEFIT CHILDREN WITH SICKLE CELL DISEASE

Researchers at Nemours are using genomics and clinical data to look for factors that predict all sickle cell disease-associated adverse events, including stroke and kidney disease.



A “smart form” was created and provided to clinicians to standardize the intake of data from patients and

families. The data collected shares common vocabulary and can be used most effectively in determining similarities and differences that could be predictive of the disease process. Using bioinformatics, researchers hope to pinpoint specific genetic markers that predict complications, like kidney disease and arterial disease, to provide individualized treatment plans that target and prevent disease progression in children.

THE “NOBEL PRIZE” OF RESEARCH



Children born with spinal muscular atrophy

(SMA) are getting new hope from a drug developed by pharmaceutical companies Biogen and Ionis and tested by Richard Finkel, MD, chief of neurology, Nemours Children’s Hospital. SMA is the result of a faulty or missing gene responsible for producing a protein required for neuromotor development. Without the protein, muscles atrophy and children die. For decades, the only option for most parents was palliative care. As reported last year, a new drug called nusinersen was approved by the FDA for use in these children and is allowing them to regain muscle movement improving their lives and chances of survival.

Nusinersen modifies the SMN2 gene, a back-up gene, with a tiny fragment of synthetic DNA. The drug is delivered through a spinal tap where it

“This treatment is transformative for the entire SMA community. One thing we have learned, though, is that the closer to symptom onset that children begin treatment, the more substantial the improvement in motor function. However, even with delayed use, we observed significant improvements in older children with SMA on nusinersen.”

— *Richard Finkel, MD, chief of neurology, Nemours Children’s Hospital*

finds nerve cells and binds to the back-up gene enabling them to produce the missing protein.

Biogen and Ionis were awarded the 2017 Prix Galien USA Award for Best Biotechnology Product for SPINRAZA®, the commercial name for nusinersen. The Prix Galien is considered the “Nobel Prize” of pharmaceutical research and development.

INNOVATIVE PEDIATRIC DEVICE RESEARCH



When a ventricle of the heart does not work properly, a ventricular assist device (VAD) can be implanted in adult patients to prevent heart failure and allow patients to go home. For pediatric patients such a fully implantable device does not exist.

Through a **small business innovation research grant** from the National Institutes of Health, Peter Wearden, MD, director, Nemours Cardiac Center in Florida, and Oklahoma-based company, VADovations, are working to develop one of the smallest VADs. The design will work in pediatric



The pediatric VAD, roughly the size of an AA battery (left) vs. the size of an adult VAD.

patients and offer market scalability to make the technology affordable. Dr. Wearden notes the importance of this aspect, “It’s my obligation as a scientist to help design solutions that provide better care for patients and to figure out ways to reduce the cost of care.”

Children incapable of oxygenating their blood properly are often also relegated to hospital-only care because they are supported by extracorporeal membrane oxygenation, which can only be used in the hospital. New technology in the form of a wearable lung would allow children to return home to recover and build strength while awaiting transplant. Nemours and the University of Pittsburgh are

collaborating to develop a wearable artificial lung so that children can leave the hospital — increasing time with their families and reducing risk of infection.

TARGETED IMMUNOTHERAPY RESEARCH FOR “SAFER” CURES

Innovation and partnerships are helping Nemours deliver on the legacy to end suffering and restore children to health. In the fight against acute myeloid leukemia (AML), researchers at Nemours Center for Cancer & Blood Disorders, Fred Hutchinson Cancer Center (FHCC) in Seattle, and Bayer, are working toward a targeted immunotherapy to help combat the disease in children.

As part of a collaborative effort in next-generation sequencing with Nemours, Seattle researchers noticed a protein called mesothelin that is abnormally expressed on the surface of AML cells in about a third of all pediatric patients.

In patients with AML, leukemia cells look like normal bone marrow cells. This makes one of the most promising AML therapies, CAR-T cell therapy, risky because it kills both the AML cells and the bone marrow. The abnormality of the mesothelin protein gave researchers the idea that this difference could be used by the child’s immune system to identify and target only leukemia cells.

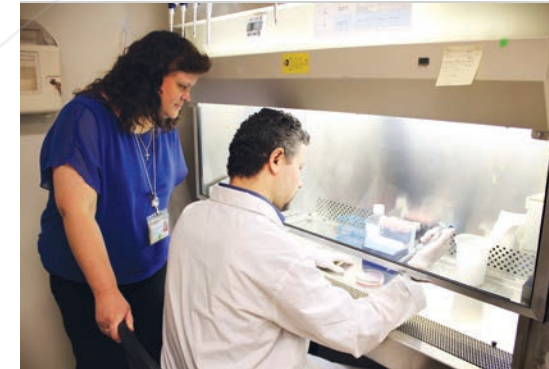
A drug developed by Bayer to target mesothelin in adults with mesothelioma and pancreatic cancers already existed as a proof-of-concept. Using this knowledge, the goal is the development of a

Immunotherapy treatments can use antibodies to deliver toxic therapy directly to cancerous cells — and only those kind of cells — reducing damage to normal cells.

pediatric immunotherapy that borrows from Bayer’s success in adults to develop a new pediatric drug that targets only AML cells and minimizes

the toxicity to children. Through a **\$1 million therapy acceleration program (TAP) grant** from the Leukemia & Lymphoma Society, Nemours, FHCC and Bayer are now working to move the immunotherapy for AML into Children’s Oncology Group clinical trials.

Additional “custom” precision approaches to fight AML cells are also under development at Nemours and FHCC. Thanks to research grants from **St. Baldrick’s Foundation** and the **Leukemia Research Foundation of Delaware**, next generation, bi-specific T-cell engagers (BiTES) anti-bodies are being reviewed for their ability to deliver cancer-fighting cells versus toxins to maximize outcomes and further reduce unwanted side effects.



NOVEL THERAPY SHOWS PROMISE IN TREATMENT-RESISTANT CANCER

Researchers at Nemours Children’s Hospital

(NCH) and the University of Central Florida (UCF) were looking for **alternative ways to treat high-risk neuroblastoma**. Neuroblastoma has a 40 to 50 percent survival rate and is the most common extracranial solid tumor in infants.

The partnership between NCH and UCF resulted in combining nanoparticles and a component of a common spice to destroy treatment-resistant neuroblastoma tumor cells in children with this devastating diagnosis. According to Tamarah Westmoreland, MD, PhD, pediatric surgeon, NCH, the uniqueness of the work is in overcoming

“There have been advancements in the treatment of neuroblastoma but we are not seeing the big bump we need to see in overall survival, which is what everyone wants. If you have a little improvement in a few months, that’s wonderful, but if it’s not changing the overall survival, then, in the end it’s the same for families.”

— *Tamarah Westmoreland, MD, PhD, pediatric surgeon, Nemours Children’s Hospital, and lead author of an exciting new study in neuroblastoma treatment*

solubility problems, “Curcumin is not soluble. The nanoparticle overcomes that solubility barrier. Cancer cells, in general, are more acidic than non-cancer cells. A nanoparticle is affected by the pH of the cell and, when it is near more acidic cells, it releases the curcumin right where we need it.”

Researchers hope to conduct clinical studies in animals using curcumin and nanoparticles at the site of tumors. This use of curcumin could be used to treat tumors directly and to treat areas where tumors were removed to inhibit re-growth with fewer adverse effects for children. “The advantage of curcumin is that it’s natural, and will have much less deleterious side effects. This is a definite advantage,” said Dr. Westmoreland.

BIOMARKER RESEARCH SHEDS LIGHT ON PEDIATRIC OBESITY

Nemours Children’s Specialty Care,

Jacksonville researcher Babu Balagopal, PhD, has been studying childhood obesity and associated comorbidities for more than 15 years. His long-term goal is to find biologically unique molecules called biomarkers that can shed light on obesity in children and related conditions such as diabetes

and cardiovascular disease. Biomarkers help in the early detection of diseases so that interventions could be made before the condition worsened.

Working with clinicians throughout Nemours, Dr. Balagopal’s lab performed a series of studies looking for answers. Recently, they found that a novel molecule, called *Spexin*, produced in fat could potentially be a biomarker of obesity and related comorbidities. Little is known about *Spexin*

in humans. He noted, “We found that *Spexin* alone is sufficient to discriminate between lean and obese children with extreme accuracy.” Further, Dr. Balagopal, in collaboration with Mayo Clinic, Minnesota, and the University of Colorado, found that gastric bypass surgery enhanced *Spexin* concentration in adolescents with severe obesity. His research on *Spexin* and other biomarkers will continue in collaboration with Nemours’ bariatric surgeons and others. Dr. Balagopal is also

conducting other studies related to childhood obesity. One study involves children with nonalcoholic steatohepatitis (NASH), which can lead to cirrhosis of the liver. There is currently no treatment for this condition. Researchers are investigating the use of an amino acid supplement to counteract a defective antioxidant system in these children. He is also studying the connection between vitamin D deficiency and childhood obesity.

SHARING KNOWLEDGE TO IMPROVE CHILD HEALTH



Nemours is committed to extending educational opportunities and other health-related support to professionals and caregivers who guide children’s health and wellness. This support from Nemours begins at birth with programs, services and information-sharing designed for all ages and stages of a child’s life, including resources to assist the child with their transition to adult health care.



SUPPORTING PROFESSIONALS WORKING WITH CHILDREN

GIVING CHILDREN A HEALTHY START FROM THE VERY BEGINNING

Breast milk gives babies the best chance at a

healthy start. To support breastfeeding and infant health, Nemours Children’s Hospital (NCH) partners with the **Healthy Children Project** to host a five-day, 40-hour **Certified Lactation Counselor (CLC) Training** program for NCH staff and those with an interest in supporting and promoting breastfeeding.

Kelly Rogers, program manager for Nemours Florida Prevention Initiative, said the conference is an outreach effort that is gaining traction, “The lactation conference is a way to extend our commitment to child health outside our walls. This will be the fourth year of the conference. It’s produced 11 CLCs at NCH and trains approximately 60 people each year. Trainees from around the world come to Nemours for this course.”

HELPING EARLY CHILD CARE EDUCATORS BUILD LANGUAGE SKILLS

Many children enter

kindergarten significantly behind their peers in literacy skills, yet early childhood educators often have few resources and little training regarding literacy. “It was very important to be able to work with caregivers and help them understand that infants and toddlers, whose language skills are primed for development, need rich conversation very early,” said Becky Henderson, manager, intellectual property, **Nemours Reading BrightStart! (NRBS!)**.

To address this issue, Nemours added an infant and toddler toolkit to its successful NRBS! program. *Early Language and Literacy Success: Infant and Toddler Toolkits* are flexible, developmentally-appropriate, instructional tools that provide caregivers a practical set of materials, strategies and experiences appropriate for children from birth to 36 months.

Through a \$107,000 grant from the **Pensacola Bay Area Impact 100**, the **Early Learning Coalition (ELC)** of Escambia County, Fla., will be the first to implement the NRBS! program from infancy through preschool to measure its impact.

Nemours trained six coaches through the ELC who will help implement the program in 45 classrooms. The theme-based content covers a full year of learning with the same foundational best practices and helps early childhood educators build the basis for early literacy in their classrooms.

3,000

early childhood educators took part in professional development from Nemours Reading BrightStart! during 2017

SUPPORTING SCHOOL-AGE CHILDREN

School nurses provide essential care to children, many of whom have complex medical

conditions that require careful management and care coordination. Nemours has several initiatives to support these nurses and the integral role they play in a child’s care team. The goal is to better serve children through enhanced continuity of care across care team members.

Nemours CareConnect (NCC): Available in four Central Florida schools, NCC allows school nurses to directly connect with a Nemours board-certified pediatrician through the smart device of their choice. Telemedicine visits are intended for minor injuries and acute health issues, such as fevers, vomiting and 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.

“The experiences were written in a way that encouraged me to ask a variety of questions and provide a longer wait time before responding to give the children time to think. Dialogue helped me to improve the quality of conversations and interactions with children. It made a difference and improved the quality of the conversation.”

— An *Early Head Start* classroom teacher and participant in the initial pilot of NRBS! toddler curriculum



Nemours Student Health Collaboration (SHC): With parental consent, school nurses across the State of Delaware can log into NemoursLink, Nemours’ web-based portal for health providers, to see a child’s plan of care and information to understand their medical history with Nemours. They can also monitor “events” such as an admission, and initiate non-urgent messages to Nemours providers. This program promotes a partnership between Nemours primary and specialty care providers, the school nurse and Nemours’ patients and families. In 2017, the SHC was piloted in Philadelphia at HMS School for children with cerebral palsy.

Training/Seminars: Nemours offers specialized training classes for school nurses, health aides and clinic assistants on many topics including diabetes, sickle cell, infectious disease, trach care, asthma, allergies, injuries, common cardiac diseases and rheumatology.

Annual School Health Conference: This two-day event is 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 also includes hands-on training through the Nemours Children’s Hospital simulation lab and small group discussions on topics relevant to school health.

AMBULATORY NURSE TRAINING AND RESIDENCY

At Nemours Children’s Specialty Care, Jacksonville (NCSCJ), nursing

takes the form of a complex specialty called ambulatory care. Since these nurses are not physically located in a hospital, they must be prepared to serve children that may have complicated medical conditions. Ambulatory nurses rely on several programs designed for both new and seasoned nurses to ensure top-level care and prevent children from being hospitalized or going to the emergency room.

Using a newly constructed medical simulation lab, clinic nurses and medical professionals recreate medical emergencies using a specially-designed mannequin that replicates both the body processes of a child and symptoms of an adverse medical event. Participants can practice everything from simple vital signs and EKG readings to intubations, catheterizations and full code blue. Donna Pingel, a respiratory therapist, noted, “It is an amazing tool and close to having a real child to prepare for an emergency. Working together with peers was a great experience; it gave me reassurance on our response, if a real event were to occur.” Participants say it is also improving interdisciplinary communication skills.

NCSCJ is also starting an ambulatory nurse residency program. The two-tiered program will be provided to



“Working together with peers was a great experience; it gave me reassurance on our response, if a real event were to occur.”

new nurses and senior nurses moving from inpatient care to ambulatory care. The program is based on patient-centered care, collaboration, evidence-based practice, and quality improvement outlined by **Quality and Safety Education for Nurses.**

Nurses serving as preceptors are also being offered new training opportunities. The training focuses on positive precepting behaviors like supportive guidance, providing quality feedback, and coaching and mentoring methods.

ENGAGING STUDENTS IN THEIR OWN HEALTH AND HEALTH CAREERS

PRESCHOOL STEM HEALTH LEARNING

Nemours Children’s Hospital and Nemours Florida

Prevention Initiative (FPI) partnered with a new science, technology, engineering and math (STEM) early education program to integrate health and health career elements into learning for preschoolers.

The **Amazing Explorers Academy** features a new mobile exhibit called “Our Amazing Body,” that will travel to their local STEM preschools. The exhibit uses health challenges kids can relate to, like a child who has put something up his nose. Kids use STEM thinking to come up with solutions. They also learn about prevention, “We always have a prevention message about hand-washing so they learn, What does it take to prepare for surgery? Who is involved in doing a surgery? They get to see an x-ray of a child who swallowed a coin. They are presented that scenario and a follow-up message to remind them that nothing goes in our mouth except for healthy foods and healthy drinks,” said Kelly Rogers, program manager for FPI.



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STEM-Up Delaware students participate in programming at Nemours/Alfred I. duPont Hospital for Children

EXPLORING CAREERS IN HEALTH CARE

Throughout Nemours hundreds of high school students take part in interactive and informative explorations of health care professions every year. At Nemours Children’s Hospital (NCH) a bi-annual event, called **Career Exploration Day**, offers students the chance to learn about different career paths and discuss real-life scenarios related to each job.



During 2017, students from five Florida high schools visited NCH. The students rotated through different areas of the hospital learning about career paths and even getting time to see the medical simulation labs. The program exposes students to areas such as respiratory therapy, radiology, child life services, the rehabilitation gym and the pet therapy program. The students were able to see advanced technology at work through a demonstration of Nemours CareConnect and a visit to the Clinical Logistics Center, which monitors Nemours’ inpatients 24/7 at both NCH and Nemours/Alfred I. duPont Hospital for Children. The program also introduces students to outreach programs such as the Florida Prevention Initiative so they can see how Nemours works within the community to improve the health of children.



EMPOWERING ADOLESCENTS THROUGH HEALTH LITERACY



As children grow into early adulthood they are tasked with

taking charge of their bodies and health care decisions. Nemours developed *Navigating the Health Care System*, a series of lesson plans, aligned with National Health Education Standards, intended to help teens mature into knowledgeable advocates for their own health care and empower their decision-making. Learning and activities include: finding appropriate care, understanding their medical history, insurance and privacy, and how to schedule an appointment and complete medical forms.

“We know that as health literacy increases, people are more likely to seek preventive services and enter the health system healthier, have lower rates of preventable hospital and emergency department visits, resulting in lower overall health care costs, and are less likely to report poor health.”

— Allison Gertel-Rosenberg, operational vice president of practice and prevention, Nemours Children’s Health System

Originally piloted in Delaware, Nemours National Office of Policy & Prevention is working with Nemours Health & Prevention Services to expand this program across the U.S. Nemours is currently engaged in piloting its national expansion of the program in Illinois, Wisconsin and Texas.

The program is available at no cost (in English and Spanish) and all materials are supplied by Nemours. It can be used as a full classroom-based health unit or divided into smaller supplemental content that supports existing curricula.

KIDSHEALTH CONTENT CONTINUES TO PROVIDE ANSWERS AND COMFORT



Nemours’ KidsHealth.org attracts more than 10 million

visits a month, making it the most-visited website devoted to children’s health and development. In 2018, KidsHealth.org will welcome its 3 billionth visitor! New content written and designed specifically for parents, kids and teens — articles, animations, games and more — is continually generated by Nemours’ editorial staff, which includes pediatricians and other children’s health experts. Recently, Nemours has developed new sections of content on KidsHealth.org related to autism, cerebral palsy and preventing premature birth.

165,000,000
kids, teens and adults visited
KidsHealth.org during 2017



PREPARING FUTURE PEDIATRIC PHYSICIANS



As Nemours grows its children’s health

system throughout Florida, it is also investing in future pediatric physicians with a residency program set to open in 2019 at Nemours Children’s Hospital (NCH) in Orlando. When NCH opened its doors in 2012, it established connections to the state’s medical schools, offering limited electives and acting internships with pediatrics. At that time, NCH had about 50 medical students participating. Today, the program offers 30 acting internships or electives representing every department, including research, and serves 300 medical students annually. The planned, incremental growth of these foundational programs has prepared NCH for the 2019 residency launch.



The residency program is a strategic milestone on a long-term academic roadmap. “The benefits to the community and

Nemours are significant,” said Andre Hebra, MD, chief medical officer, NCH. “Research shows when students complete their residency locally, they tend to stay local. Thinking ahead to the next 10, 20 years, creating this residency in general pediatrics will open the door for us to start specialty programs and

“Research shows that when students complete their residency locally, they tend to stay local.”

fellowships — training fellows who will likely stay regional. So, not only will we have control of the quality of the

people we’re training, but we will also enrich the quality of specialty care in the region. This is how nearly every major academic program starts and it will all be Nemours-based. So when people are asked, ‘Where did you get your training?’ the answer will be ‘Nemours.’”

3,845

medical students, residents, fellows and allied health professionals trained at Nemours during 2017



EDUCATION LEADS TO IMPROVED QUALITY OF CARE

A NCH partnership with the University of Central Florida’s College of Medicine created early opportunities to build strong foundations for the new residency program in both faculty and research development — including student research with award-winning results.

NCH expects its first residents in Summer 2019. Medical students seeking pediatric residency are gaining a leader in pediatric care and Nemours has much to gain from residents and fellows.

As Heather Fagan, MD, pediatric critical care physician and vice chair of education, department of pediatrics, NCH, pointed out, “When a physician is training and doesn’t understand the attending physician’s practice, she asks courageous questions: ‘Why did you do this or why did you do that? Should we be doing it this way?’ As you increasingly leverage evidence-based care, it enhances the quality and safety of your institution.”

COMMITTING TO “PERFECT CARE”



CONTINUOUSLY IMPROVING THE QUALITY, SAFETY AND VALUE OF CARE

It has been more than six years since Nemours launched its continuous improvement (CI) journey. This critical work is improving safety, quality and satisfaction for patients and families, while lowering the costs of delivering care.

Hardwiring CI has been a multi-year strategic focus that continues to guide Nemours toward its True North. Embedding improvement as a cultural norm moves Nemours ever-closer to the goal of delivering the care families need and want, when and how they need and want it.

A DAILY COMMITMENT TO IMPROVEMENT

Across Nemours, daily huddles bring a renewed commitment to build on quality, safety and value for patients and families. These stand-up meetings focus on surfacing problems, eliminating barriers, identifying opportunities to improve and provide

a forum to check in on previous improvement implementations. The informal setting encourages all stakeholders to contribute, share feedback and suggest adjustments.

Connecting frequently provides a tangible reminder of larger improvement goals while fostering open communication to address immediate opportunities. “Readiness” is addressed

Raising issues and finding and tracking solutions is the goal with daily huddles.

first thing every morning: Do we have what we need to meet today’s needs? What can we learn from yesterday? As gaps are identified, huddles are also used to track progress to plan. Are the improvements we put in place achieving the targets we established? Nemours’ inter-professional teams utilize CI tools to define problems and create action plans. In addition, teams “swarm” adverse events to rapidly understand, learn and improve.

STANDARDIZATION OF CLINICAL WORK



Standardization of clinical work is another

significant area where CI is evident. Partnering with physicians and a multi-disciplinary workgroup, the CI team is facilitating a documented approach to the management and treatment of specific diseases to reduce variations in practice, drive quality, improve resource utilization and increase value. Through cross-campus collaboration, Nemours specialists discuss clinical standard work and areas to improve care.

To ensure CI tools are understood, many managers and directors receive training in process confirmations and conduct routine audits to ensure the new processes are being implemented. More than 3,300 Nemours Associates have received training and/or participated in formal CI activities.

The goal in creating clinical standard work is to reduce variations in practices, improve quality and optimize resource utilization. In 2017, CI teams focused on the following six clinical standard protocols:

- Tracheostomy Care
- Pre-operative Spine Work-Up
- ED Diabetes Care
- Liver Transplant
- Sepsis Pediatric ICU Huddle Process
- Crohns: Diagnosis to First Treatment

Every Nemours pediatric specialty tracks and reports outcomes. These can be viewed at Nemours.org/about/why/outcomes.html

3,300

Nemours Associates have received training and/or participated in formal CI activities

The commitment to CI has resulted in sustainable, proactive achievements that benefit patients and have earned national recognition for Nemours:

- Nemours performs better than average on the new national initiative to recognize sepsis early with ICU-free days, alerts to potential sepsis and early treatment
- Results from the National Leapfrog Safety Survey show that both Nemours Children’s Hospital and Nemours/Alfred I. duPont Hospital for Children performed better than other pediatric hospitals in medication safety, ICU staffing, national safe clinical practices and antibiotic stewardship
- Quality and safety scores in all specialties tracked within the *U.S. News & World Report* survey are comparable or exceed all highly ranked pediatric hospitals
- Nemours readmission rates at both 7- and 30-days are more than 40 percent better than performance rates (meaning fewer readmissions) and in the top 25 percent compared to other children’s hospitals
- A greater than 99.9 percent error-free rate for medication administration errors
- Preventive immunization rates for children under age three are better than benchmark
- Nemours performs better than national mean in preventing venous thromboembolism and central line-associated bloodstream infections (CLABSI)
- Nemours performs in top 25 percent of pediatric hospitals regarding cardiac ICU, CLABSI, adverse drug events and patient falls

AN INTEGRATED SPECIALTY BRINGS RAPID IMPROVEMENT



Nemours 24/7 enterprise radiology team, which includes 35 employed radiologists, processes the largest volume of pediatric imaging of any children's health system. In 2017, the team completed 295,218 reads. Serving all of Nemours and five partner hospitals, continuous improvement (CI) efforts underscore the growth and success of this specialty.

With 24/7, 365 Nemours-wide radiology, turnaround time for an after-hours ED imaging study is 14 minutes.

One metric is "turnaround time," or the time it takes from imaging a child, to reading the image, to getting

results to a clinician. Dan Podberesky, MD, radiologist-in-chief, Nemours Children's Health System, points out the improvement and the results,

"Our median time for an after-hours emergency department imaging study is 14 minutes. Having a radiologist available around the clock, also means doctors no longer have to deal with a preliminary report from radiologists without pediatric specialization that is subject to change when read by a Nemours specialist. It's a safety issue, it leaves parents and clinicians dissatisfied and it wastes time. That completely melted away when we went 24/7."

Radiology is also focusing on improving safety during MRI experiences. Through training courses and rigorous CI, the department is creating certified MRI clinical directors and safety directors to standardize screening processes for patients and families with an ultimate goal of reaching a 100 percent ferrous-free environment.

Other CI projects include optimizing radiation doses across Nemours in CT scans, and fluoroscopy and interventional radiology procedures.

LEVERAGING TECHNOLOGY TO IMPROVE SAFETY



Two key technologies employed by Nemours are helping maximize safety and improve the overall experience for patients and families.

Several Nemours locations use Nobel Prize winning EOS imaging because of its benefits to children. The EOS machine takes only seconds to produce higher quality images from a seated or standing position, facilitating a more comfortable and faster experience for children. EOS also enables clinicians treating complex conditions, such as spinal deformities, to get 3D images. EOS offers patients, parents and clinicians more information and options with a fraction of the radiation exposure of conventional x-rays.

Sepsis is a potentially life-threatening response to infection and is a leading cause of death in children. Nemours leveraged its **Clinical Logistics Center**, a command center that monitors all Nemours inpatients' vital signs 24/7, to work proactively against sepsis. Information from the electronic health record and the patient's bedside monitors feeds into an electronic scoring system that alerts clinicians to pre-sepsis conditions. If the risk score increases a rapid-response team is deployed. The scoring system and process has received awards from the **Florida Hospital Association** and has been highlighted by the **Children's Hospital Association** for its work in preventing pediatric sepsis.



A SPECIALTY IMPROVING CARE, OUTCOMES AND RECOVERY



Interventional radiology (IR) uses a range of minimally-invasive, image-guided

techniques that are improving care for children with complex or high-risk conditions, including vascular malformations and tumors. Nemours employs the largest group of pediatric IR specialists in the U.S. and continues to grow. Combined, Nemours IR specialists performed nearly 4,800 procedures in 2017, with half of those benefiting children with cancer.

Allison Aguado, MD, one of the newest members of the IR team at Nemours/Alfred I. duPont Hospital for Children, is also one of only a few pediatric IRs to utilize a minimally invasive radiation treatment, known as Y-90, to treat pediatric liver cancer. Due to the amount of liver that needs to be removed, resecting a tumor in a child's liver is not always possible. As an alternative, the Y-90 procedure delivers a targeted radiation treatment directly to the lesion in the liver, preserving the child's normal liver tissue and surrounding organs.

In collaboration with Howard Katzenstein, MD, chief, division of hematology/oncology at Nemours Children's Specialty Care, Jacksonville, an internationally-recognized expert in pediatric liver cancer, Dr. Aguado has already performed three successful Y-90 procedures since joining Nemours.

3D PRINTING, ADVANCED VISUALIZATION AND SIMULATION KEY IN LIFE-SAVING PROCEDURE

Jack's mom noticed a lump on his abdomen near his belly button. After a CT scan, his doctors made an initial diagnosis of sarcoma and placed a port for chemotherapy.

After two months, the powerful drug therapy showed little benefit to the tumor and was causing several adverse side effects. With conventional surgery to remove the tumor deemed "unsafe," Jack's doctors referred him to Nemours Children's Hospital (NCH) where he saw Craig Johnson, DO, enterprise director, interventional radiology.



Using data sets, life-size 3D modeling of Jack's abdomen and tumor, and other advanced visualization tools, the Nemours IR team coordinated with other Nemours

specialists from general surgery, urology and oncology to discuss the best approach to resecting Jack's tumor.

After simulating the procedure, Dr. Johnson spent eight hours embolizing all the arteries supplying the vascular tumor. The next day, Nemours pediatric surgeon Dr. Tamarah Westmoreland led the five-hour surgery to successfully resect the football-sized tumor — saving the young man's life.

Jack was discharged from NCH three days later and is putting his drivers' license to good use.

NEMOURS INSTITUTE FOR CLINICAL EXCELLENCE



From parents and caregivers to emergency teams, medical simulation allows everyone involved in the health outcomes of children to safely practice real-life scenarios and gain valuable feedback to improve care, spaces, processes, behaviors and communications. Nemours Institute for Clinical Excellence (NICE) uses medical simulation to enhance learning programs and facilitate continuous improvement across Nemours.

In Delaware, the NICE team held 870 simulation events serving 7,025 participants for a total of 12,800 learner hours.

NICE also offered regional and national pediatric skills courses for:

- emergency medicine physicians
- pediatricians
- registered nurses (RNs)
- transport teams
- advanced life support (ALS) providers
- basic life support (BLS) providers
- first-year pediatric emergency medicine fellows

Members of the NICE team delivered 20 presentations at national and international conferences and published three simulation-based, peer-reviewed research articles during 2017.

Maria Carmen G. Diaz, MD, FAAP, FACEP, Nemours medical director of simulation, was recognized by the American Academy of Pediatrics as the 2017 recipient of its “Technological Innovations in Pediatric Emergency Medicine Award,” for her use of simulation to advance the field of pediatric emergency medicine.

24,580

total hours of training delivered by Nemours Institute for Clinical Excellence teams to improve the skills of 12,238 participants



In Florida, the NICE team held more than 361 events serving 5,213 Nemours Associates and community providers totaling 11,780 learner hours.

NICE also used medical simulation to enhance:

- Pediatric Boot Camp for University of Central Florida medical students
- Pediatric Cruise Medicine Program training
- Maintenance of Certification
- ECMO training
- Advanced Pediatric Life Support Course
- Pediatric Fundamentals of Critical Care
- Nemours School Health Conference

NICE also acquired a new mannequin system called Noelle that creates realistic medical simulation for birth. This will be used to train staff and providers for imminent delivery situations.



MAINTENANCE OF CERTIFICATION



The maintenance of certification (MOC) program was

instituted in 2010 by the American Board of Pediatrics among the other 23 certifying boards of the American Board of Medical Specialties. Certification assures patients and families that clinicians are up-to-date with current medical knowledge and continually improving the patient care they deliver.

Nemours was an early adopter in promoting the value of MOC among its clinicians, embedding MOC in quality initiatives and becoming a portfolio sponsor. This allowed Nemours to provide MOC credit to Nemours clinicians for its own quality improvement projects and has led to national recognition.

Over the last eight years, 482 clinicians have completed nearly 900 modules. The modules provide guidance on good practice and let clinicians reflect on their own progress and improve the care they deliver.

“Through the maintenance of certification program, we’re promoting initiatives that reduce medication errors, increase breastfeeding and better brain growth, recognize adolescent depression, and improve our management of sepsis. There’s a lot of good coming out of these projects.”

— Lloyd Werk, MD, MPH, Nemours MOC portfolio sponsor manager, Nemours Office of Quality & Safety, and vice chair, department of pediatrics, Nemours Children’s Hospital

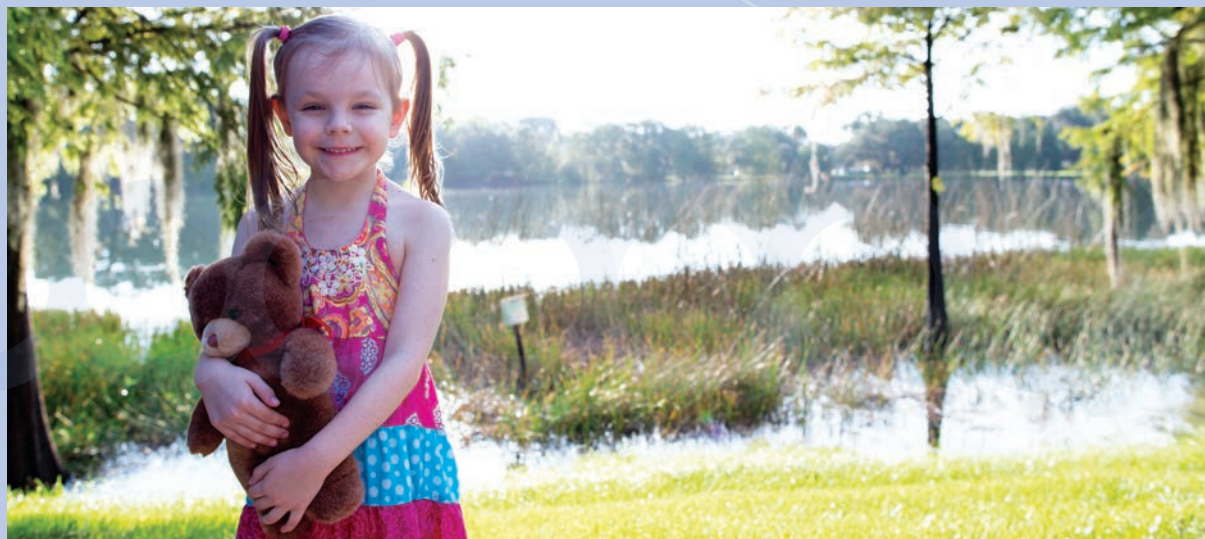
The Nemours MOC modules support the culture of continuous improvement:

Stock Modules: Leverage Nemours’ electronic medical record, integrated health system and Nemours University to share quality improvement metrics generated during the course of patient care. Information is shared with the clinician to improve care and outcomes.

Champion-Led Modules: Promote individual or division-designed projects with support from the portfolio sponsor manager to measure predicted outcomes and test processes to improve care.

QI Tracker: Created at Nemours, the Nemours MOC QI Tracker monitors the progress of clinicians in their project and sends surveys to harvest the process improvements that they achieved. When clinicians have completed at least three cycles of change, they gain the ability to attest to their progress and receive MOC credit.

SUPPORTING BETTER HEALTH FOR ALL CHILDREN



POLICIES, PRACTICES AND ADVOCACY FOR CHILDREN'S HEALTH AND WELLBEING

The Nemours National Office of Policy & Prevention seeks to nurture a nation of healthy children. The Office influences national policies and catalyzes practice changes in areas directly related to Nemours' innovation and expertise to help children grow up healthy. Bringing back what we learn from our partners to Nemours, keeps us at the forefront of innovation.

Nemours' work in federal child health policy during 2017 includes successfully advocating to support pediatric inclusion in the NIH national effort on precision medicine and encouraging increased funding for all pediatric research. The National Office also:

- secured \$4 million for Nemours' National Early Care and Education Learning Collaboratives program
- worked with partners to secure a \$5 million increase in funding for Children's Hospital Graduate Medical Education which supports pediatric residency
- established a leading voice for delivering telehealth services to pediatric populations through key meetings with the Administration and on Capitol Hill, sharing the expertise of Nemours' clinical and telehealth leadership

• advocated to protect children's health care coverage as Congress considered various health reform proposals

Nemours is recognized as a voice for children nationally, ensuring that children's needs are being addressed in innovative areas such as telehealth and precision medicine. What makes us unique is that we also spread what works nationally so that children beyond our walls benefit from our expertise and innovation.

In addition, Nemours published a perspective piece with the **National Academy of Medicine** proposing future community health models aimed at strengthening community assets, promoting early intervention to address upstream social determinants of health and collaborative partnerships that support whole child health. The perspective paper points to early foundations of health, health literacy, access, support and intervention as community-positive and cost-effective alternatives to the long-term chronic health issues that translate into expensive adult care.



BUILDING AND SUSTAINING PREVENTION

Nemours released a toolkit titled *Pathways*

Through Medicaid To Prevention for state Medicaid officials and managed care organizations that helps them build a business case for funding chronic childhood illnesses, including obesity. The toolkit provides sustainable Medicaid and Children's Health Insurance Program (CHIP) implementation strategies that connect clinics to community prevention. Nemours National Office worked with Maryland officials to refine the tool before disseminating for wider use. The toolkit can assist existing program efforts or help states just starting out. It features 40 examples from 23 states providing a practical resource guide of innovative interventions, planning tools, three in-depth case studies and a white paper.

Additionally, a \$105,000 grant from **AcademyHealth** facilitated a partnership between Nemours and AcademyHealth to explore and recommend Medicaid strategies for upstream prevention and population health in Maryland, Oregon and Washington. Nemours prepared and provided the states with six "how-to" briefs to implement and finance these initiatives, leveraging the *Pathways Through Medicaid To Prevention* work funded by the **Robert Wood Johnson Foundation**.

ADVOCATING FOR INCLUSION IN PRECISION MEDICINE FUNDING AND PEDIATRIC RESEARCH

Nemours Children's Health System hosted a policy briefing in July 2017 to highlight the urgent need to include children in pioneering cancer research and the precision medicine initiative.

Senators Christopher Coons (D-DE) and Marco Rubio (R-FL) spoke about the importance of pediatric medical research during the briefing. "Precision medicine holds promise for our future, but we must make sure that pediatric populations are included in this research so that we can offer a brighter future for children here and around the world," noted Senator Coons.

Vicky Funanage, PhD, operational vice president Nemours Biomedical Research, and Christopher and Erin Lee, co-executive directors of Piper's Kidney Beans Foundation, also joined the panel representing Nemours. "Genetic testing saved our daughter's life by allowing her team at Nemours/Alfred I. duPont Hospital for Children the information they needed to diagnose and treat her," said Erin Lee, mother of Piper. Now age 4, Piper underwent a kidney transplant from her dad at 16 months to save her from Denys-Drash Syndrome, a rare disorder that affects the kidneys and often leads to kidney failure in young children.

"Genetic testing is the next frontier in diagnostic medicine. Each year, scientists and doctors identify previously unknown spontaneous and inherited genetic illnesses which typically can only be detected via genetic blood tests. It is our belief that all children should have access to these tests to help identify genetic illnesses early and affordably," added Erin.

ADVANCING EQUITY FOR CHILDREN AND FAMILIES

With the support of a \$2.2 million grant from the **Robert Wood Johnson Foundation**, Nemours National Office of Policy & Prevention is working on a multi-sector project to support families and young children. Through **Harnessing Opportunity for Positive, Equitable Early Childhood Development (HOPE)**, Nemours will advance the vision that every child,

regardless of race, ethnicity or family income, achieves equitable health, development and education outcomes. Nemours will focus on young children and families (pregnancy through age 5), and work with four states over 30 months to help integrate existing systems that care for children. The goal is to create financially stable and accessible avenues that leverage existing systems to ensure very young children and their families can achieve optimal health.

200,000

children in 2,200 child care programs in 10 states have been positively impacted by the CDC ECELC work to date

INTERSECTING HEALTH AND EARLY EDUCATION

Nemours received funding from the Centers for Disease Control & Prevention (CDC) to continue implementation of the National Early Care and Education Learning Collaboratives (ECELC) grant. This grant enables Nemours to continue and expand its work at the intersection of health and early education. Nemours supports early care and education (ECE) providers in 11 states working to improve young children's health. During the first five years of funding, evaluation of providers participating in the ECELC has demonstrated significant increases in best practices related to healthy eating, physical activity, infant feeding and screen time. To secure the extension, Nemours presented program achievements, evaluation findings and case studies on changes made in state ECE systems around obesity prevention during the initial five-year \$22 million grant period. The sixth year work plan will feature learning modules on healthy eating, screen time, physical activity and breastfeeding. The free modules will be available through the Better Kid Care website, which provides training on child health topics to ECE providers in all 50 states.



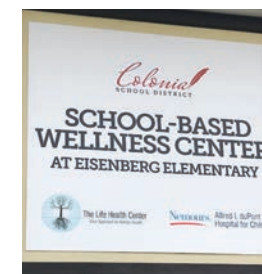
STRUCTURING POLICY TO BETTER ADDRESS HEALTH

As part of its **Moving Health Care Upstream** initiative, funded by the **Kresge Foundation**, Nemours supports innovation, promotes partnerships and collaboration, and spreads what works to improve population health. Nemours implemented three Policy Learning Labs across the country to address the intersection of health care with both asthma and food insecurity. The Policy Learning Labs highlighted expertise from leaders, including Nemours Health & Prevention Services work at the intersection of asthma and health. The labs brought together 17 communities and 10 health care systems to identify accelerators and barriers of health and promote local and institutional policies supporting community-wide health.

SCHOOL-BASED WELLNESS IN DELAWARE

Delaware's Colonial School District (CSD) is

home to the state's first elementary school-based health center (SBHC) at Eisenberg Elementary School. Nemours/Alfred I. duPont Hospital for Children has



created an on-campus clinic in partnership with **The Life Health Center**. The clinic will provide an integrated team of primary medical and behavioral health services to address a broad range of health needs, without regard to the ability to pay. Nemours

will provide medical directorship while The Life Health Center will staff the space provided by CSD.

The SBHC will fill health care gaps and provide or complement patient-centered medical homes for children and families. The clinic will also connect children to specialty care when needed, and families to insurance resources, and provide frontline screening for mental and behavioral health risks.

HEALTH AND NEIGHBORHOOD REVITALIZATION

In Wilmington, Del., Nemours is working with city

officials to improve the health of families in the at-risk neighborhood of **West Center City**. In 2017, in concert with Nemours' Delaware Valley Government Relations, a team of Nemours Health & Prevention Services Associates conducted a thorough assessment of the area to identify health care needs and barriers to care among children residing in West Center City.

The Nemours team shared the assessment with the Mayor of Wilmington and his senior leadership team to highlight top diagnoses for office visits, ED utilization, 30-day readmissions, and information on social determinants of health such as the deteriorating housing, poverty, high crime and unemployment. Through the team's assessment, the Mayor now has a deeper understanding of the connection between community issues and health, to support his administration's **Neighborhood Stabilization Initiative** and reinforce necessary resources for revitalizing the West Center City neighborhood. Nemours is also evaluating ways that it can increase care coordination and leverage other existing assets to support these efforts.

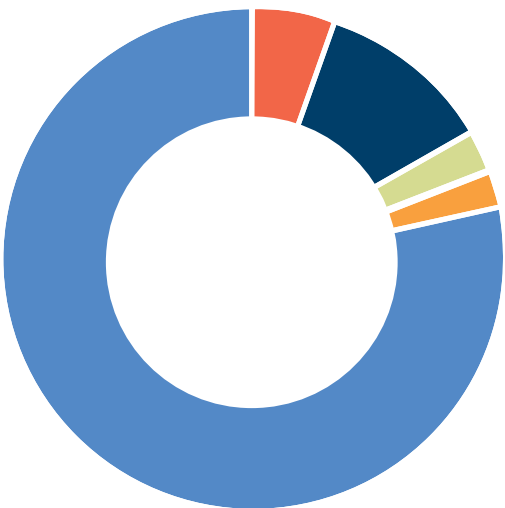
PARTNERSHIPS TO IMPROVE COMMUNITY HEALTH

Healthy environments contribute to healthy citizens and studies show they spark positive behavior changes in eating habits and physical activity. Nemours Health & Prevention Services successfully completed a three-year, \$1.6 million PICH grant from the U.S. Department of Health & Human Services in 2017 and celebrated the following results benefiting the City of Wilmington and surrounding communities:



- Five park revitalizations, including walking trails and play equipment
- Eight farm stands
- 19 stores enrolled in the "Healthy Corner Store" program
- One new bus stop added at a community park
- Nine jobs created through the "Healthy Corner Store" program, farm stands/community garden work and project oversight for parks
- Community beautification, including a revitalized vacant lot in West Center City, community gardens, walking paths and mosaic murals by community artists

2017 COMMUNITY BENEFIT



\$195.8 MILLION

● UNCOMPENSATED MEDICAL CARE	\$154.6
● SUBSIDIZED HEALTH SERVICES	\$4.2
● RESEARCH	\$21.9
● EDUCATION & TRAINING OF HEALTH PROFESSIONALS	\$4.4
● PREVENTION & INFLUENCING CHILDREN'S HEALTH	\$10.7

● UNCOMPENSATED MEDICAL CARE: \$154.6 MILLION

Uncompensated medical care includes **health care services without a direct source of payment**. In 2017, total uncompensated medical care provided by Nemours included:

- **\$9.8 million** in services classified as “charity care” where the recipient could not afford services or lacked adequate health insurance
- **\$102.3 million** in unreimbursed cost, or shortfalls that occur when providers are reimbursed below the cost of providing services for Medicaid and other public health program beneficiaries
- **\$42.5 million** in uncollected patient care charges, underwritten by Nemours, where patients were presumed able to pay, but from whom Nemours was unable to collect

● SUBSIDIZED HEALTH SERVICES: \$4.2 MILLION

Alfred I. duPont was also a benefactor of Delaware’s senior population. Nemours SeniorCare was established in 1981 and has **provided dental, vision and hearing care services** to hundreds of thousands of Delaware’s low-income seniors at little to no cost.

In 2017, Nemours SeniorCare provided the following outpatient services to 6,729 Delaware seniors:

- **9,560** dental care visits
- **15,405** vision care visits
- **1,734** hearing care visits

Since opening our doors, Nemours has invested more than **\$3.1 billion** in delivering a higher standard of medical care for children. Our investment in children, families, research, prevention and education is how we work to fulfill our mission every day — providing leadership, institutions and services to restore and improve the health of children through care and programs not readily available, with one high standard of quality and distinction regardless of the recipient’s financial status.



● RESEARCH: \$21.9 MILLION

By increasing the amount of research activity and creating ever-increasing integration between our clinical and research enterprises, Nemours aims to **decrease the time between discovery and practice**. Beyond treatments, we also seek to investigate and understand processes that affect the delivery, safety, outcomes, cost, quality and value of pediatric care. Currently, Nemours boasts:

- **456** active research projects and clinical trials
- **100+** Nemours physician-scientists
- **25** PhD center directors and laboratory heads
- **210+** research support staff

● PREVENTION & INFLUENCING CHILDREN'S HEALTH: \$10.7 MILLION

Nemours continues to focus leadership and programs in the areas of **health promotion and disease prevention**. These efforts **positively impact population health** within our service area as well as among millions of children who may never know our name.

● EDUCATION & TRAINING OF HEALTH PROFESSIONALS: \$4.4 MILLION

Nemours continues to **train the next generation of pediatric specialists** through its affiliations with Sydney Kimmel Medical College at Thomas Jefferson University, Mayo Clinic School of Medicine, Florida State University, University of Central Florida College of Medicine and the University of Florida College of Medicine. In 2017, Nemours hosted:

- **772** residents
- **809** medical students
- **90** physician fellows
- **2,174** allied health professionals

The online presence of Nemours Continuing Medical Education continues to grow through NemoursEducation.org, with nearly 96,000 registered users.

OUR THANKS TO OUR 2017 VOLUNTEERS

Across the Nemours health system, approximately **1,620** volunteers provided support to nearly every pediatric speciality. Volunteers ranged in age from teens to older adults — all of whom share in compassion and caring for kids. Nearly **113,500** hours of volunteer services were logged during 2017. This included hours in new programs such as Nemours’ neonatal intensive care unit Volunteer Cuddlers and Baby Bookworm. Nemours extends a sincere thank you to all of its volunteers for bringing joy and fun or helping to nurture and support our patients and their families.



CENTRAL FLORIDA VOLUNTEERS

448 Volunteers
42,000 Hours
\$1,013,880 Monetary Equivalent

17 Volunteer Cuddlers in NICU
30 Volunteer Pet Therapy Teams

Volunteer NICU Cuddlers provided 264 cuddles for babies affected by Neonatal Abstinence Syndrome (NAS) and 242 cuddles for babies without NAS for a total of 1,498 hours

JACKSONVILLE VOLUNTEERS

174 Volunteers
9,964 Hours
\$240,531 Monetary Equivalent

2 Clowns
2 Animal Assisted Activities Teams

1,498
HOURS
OF CUDDLING
THROUGH
OUR NICU
VOLUNTEER
PROGRAM

DELAWARE VALLEY VOLUNTEERS

983 Volunteers
61,047 Hours
\$1,473,677 Monetary Equivalent

6 Clowns
35 Pet Therapy Dogs

Our New NICU program, **Baby Bookworm**, is focused on language nutrition for infants 0 to 36 months.

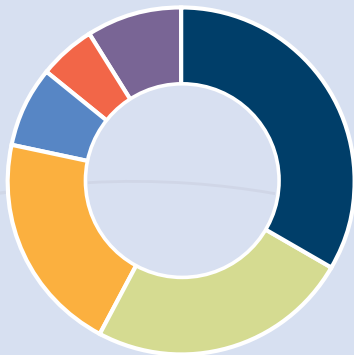
PENSACOLA VOLUNTEERS

15 Volunteers
482 Hours
\$11,635 Monetary Equivalent

2 Pet Therapy Dogs

DONORS MAKING A DIFFERENCE

Philanthropic gifts have a profound impact on the children and families we serve. Donations help Nemours stay on the leading edge of patient care, research and education. In 2017, the Nemours Fund for Children’s Health received nearly **\$12.3 million** in gifts — a \$4 million increase from 2016! These 5,063 diverse donors hailed from 39 states across the U.S.



STATE	DONORS
DELAWARE	1,695
FLORIDA	1,241
PENNSYLVANIA	1,036
NEW JERSEY	385
MARYLAND	257
OTHER	449

DONOR SUPPORT IN THE DELAWARE VALLEY

Child Life
focuses on helping children and families feel

comfortable, playful and safe within the hospital environment. A new **Child Life Activity Center** will open at Nemours/Alfred I. duPont Hospital for Children in Summer 2018 and will provide spaces for art and music therapy, reading, cooking, performing and more. (See page 46.)

Cerebral Palsy Generous donor support has created the **Freeman Miller Cerebral Palsy Endowed Chair**. This fund, named for Dr. Freeman Miller, who founded the Nemours CP Center more than 30 years ago, will provide a reliable source of income to help Nemours improve clinical care, research and education for families with children impacted by cerebral palsy.

Autism and Behavioral Health Services Nemours is greatly expanding the services available for children on the autism spectrum, as well as children with behavioral health issues ranging from anxiety and depression to ADHD. The **Howard W. Swank, Alma K. Swank and Richard Kemper Swank Foundation Autism Center** will open as part of a larger behavioral health center in Fall 2018.



PETER POWERHOUSE
Pete Zucca, a Nemours patient and two-time cancer survivor, started the Peter Powerhouse Foundation to help

other children with cancer. Peter initially raised over \$40,000 and purchased more than 200 patient wagons for Nemours/Alfred I. duPont Hospital for Children. Then, he raised an additional \$75,000, which Nemours used to secure Cinemavision goggles. These devices allow children to watch movies while they are receiving an MRI, which can reduce their anxiety and often allow them to go without sedation.

Pictured above: Peter receives an Inspiration Award for his fundraising efforts from Paul Kempinski, president of Nemours/Alfred I. duPont Hospital for Children.



At Nemours/Alfred I. duPont Hospital for Children, the new child life suite is helping to transform the multi-disciplinary program that helps children and families build positive coping skills while receiving medical services. Tripling its size to 6,000 sq.ft., child life specialists, creative arts therapists and activity coordinators will soon have an innovative space for providing evidence-based interventions and programs to families

Individual and group programs will include: arts and crafts, cooking experiences, gaming and technology activities, gross motor activities, dramatic play opportunities, reading and literacy resources, celebrity visits, holiday programming and closed circuit television broadcasting capability

and children of all abilities, ages and interests. The addition of a full kitchen makes it easy for families to cook with their children as they would at home. Jennifer Sciolla, MS, CTRS, CCLS, director of child life, says such activities provide relief from medical stressors and build community, "Food and the act of baking are normalizing. They help families come together. They connect patients. Food is familiar. It can cross culture and language. The kitchen and the preparation of food is very much a family activity." Zones in the new center will include: Closed Circuit TV Zone/Studio, Cooking Zone, Arts and Crafts Zone, Dramatic Play Zone, Infant/Toddler Area, Teen Lounge and Table Games.

**DONOR SUPPORT
IN JACKSONVILLE**



Music & Art Therapy

The music therapy program and fine art experience at Nemours Children's Specialty Care, Jacksonville (NCSCJ), is supported by a \$100,000 grant from the Delores Barr Weaver Fund. The gift will expand these programs from two



to five days per week, for the benefit of our patients who are undergoing cancer treatment. Insurance does not cover programs like music therapy and access to this type of care aids in healing and comfort for patients and families. Through music and art experiences, patients can regain a sense of control, independence and confidence.

Patient & Family Support Fund and Mental Health Fund

NCSCJ received \$75,000 from Hugs From Hunter, a nonprofit organization founded in memory of Hunter Hodges, who passed away last year. The gift supports the Patient & Family Support Fund and the Mental Health Fund, offering financial relief for families caring for sick children.

The Women's Committee Eighteen women from the local community formed a committee to raise funds and awareness for NCSCJ. The committee has adopted the Nemours Center for Cancer & Blood Disorders as the focus of their fundraising efforts and are working to raise money for an endowment to benefit the program in perpetuity.

An Evening of Promise In August, 300 guests attended *An Evening of Promise*, an annual gala in support of NCSCJ. Members of the community raised more than \$119,000 to benefit local children.

**DONOR SUPPORT
IN CENTRAL FLORIDA**



Music Therapy

With generous contributions,

Nemours Children's Hospital (NCH) expanded its art therapy program to include a new music therapy program. Many children with acute and chronic illnesses spend weeks and months at the hospital receiving multiple surgeries and rehabilitation. Music therapy helps patients with cancer, children with ADD, and patients who need help with pain and depression management.

Autism Support Nemours is grateful for philanthropic gifts from The Harvey and Carol Massey Foundation that support the Early Childhood Institute at NCH. The program, which began in 2014, serves families living with autism. Annual gifts of \$100,000 since 2013 have funded an



assessment clinic for children under age five suspected to have autism, the tailoring of intervention services specific to individual children and the coordination of community resources for families. The Harvey and Carol Massey Foundation has pledged to continue this generous contribution for the next five years.

GI Research Nemours received a generous gift of \$200,000 to support a feasibility study and pilot an investigation of diet therapy for esophageal conditions. Recent studies in pediatric inflammatory bowel disease demonstrate that the specific carbohydrate diet not only improved patients' symptoms, but also was effective in healing.

5th Birthday Gala Results

In October, more than 600 guests celebrated the fifth birthday of NCH at an *Alice in Wonderland*-themed gala. Members of the community who attended *A Night with Nemours* raised more than \$438,000 to benefit NCH patients.



**DONOR SUPPORT
IN PENSACOLA**



Nemours Advisory Council

Recently, Nemours Children's

Specialty Care, Pensacola (NCSCP) formed an Advisory Council consisting of 14 local community leaders. The members now raise awareness and funds for a variety of Nemours programs in Northwest Florida.

Audiology Support

Generous donors to NCSCP supported a \$70,000 expansion of the audiology program, allowing all cochlear implants and hearing aid testing, diagnosis and fittings to take place in Pensacola. The expansion brings care closer to home for many families who would have had to travel 700 miles roundtrip for this type of care.



First Annual Costume Ball In 2017, we launched the first annual Costume Ball to support patients at NCSCP. Members of the community raised more than \$95,000 to benefit children.

FISCAL HEALTH



Rodney A. McKendree, CPA
Sr. Vice President and CFO

Thoughtful stewardship and strategic planning have enabled Nemours to grow while continuously delivering excellent care throughout our health system. During 2017, Nemours provided direct care and services to 410,000 children during 1.7 million patient encounters as well as outreach, education, advocacy and support for hundreds of thousands more.

Nemours remains focused on an operational strategy that creates an environment with sufficient flexibility to rapidly address the external pressures and changes facing our organization. During the past year, ongoing efforts to advance continuous improvement activities across the health system are optimizing efficiency and productivity, and helping to control costs, all of which have had a positive impact on our bottom line.

THE NEMOURS FOUNDATION

CONDENSED COMBINED STATEMENTS OF OPERATIONS
YEARS ENDED DECEMBER 31, 2017, AND 2016

(Dollars in thousands)

	2017	2016
Net patient service revenue	\$ 1,054,919	\$ 1,012,578
Contributions from the Alfred I. duPont Testamentary Trust	162,040	155,865
Other income	97,830	86,789
Total revenue and other support	1,314,789	1,255,232
Total operating expenses	1,257,992	1,168,895
Operating income	56,797	86,337
Net assets released from restrictions used for capital purchases	3,059	1,712
Pension liability adjustment	(40,646)	(40,047)
Increase in unrestricted net assets	\$ 19,210	\$ 48,002



THE NEMOURS FOUNDATION

CONDENSED COMBINED BALANCE SHEETS: DECEMBER 31, 2017, AND 2016

(Dollars in thousands)

Assets	2017	2016
Current assets	\$ 536,308	\$ 479,233
Noncurrent assets	1,263,218	1,250,475
Total unrestricted assets	1,799,526	1,729,708
Restricted assets	240,735	224,945
Total assets	\$ 2,040,261	\$ 1,954,653
Liabilities and Net Assets		
Current liabilities	\$ 190,762	\$ 179,896
Non-current liabilities	683,020	643,278
Total liabilities	873,782	823,174
Net assets		
Unrestricted	\$ 925,744	\$ 906,534
Temporarily restricted	233,304	217,994
Permanently restricted	7,431	6,951
Total net assets	1,166,479	1,131,479
	\$ 2,040,261	\$ 1,954,653

2017 GOVERNANCE

Governance for The Nemours Foundation is comprised of a group of people whose skills complement the talented professional, executive and medical staff employed by Nemours. The board of directors and boards of managers collectively possess breadth and depth of expertise in a wide array of disciplines including finance, marketing, distribution, operations, health care management and more. Through these lenses, they contribute to the continued growth of our organization and our focus on improving the lives of children.

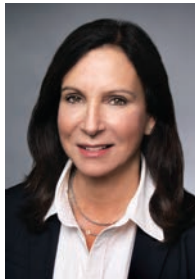
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Baxter International
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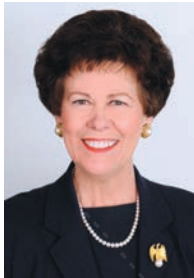
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BOARD OF MANAGERS, FLORIDA

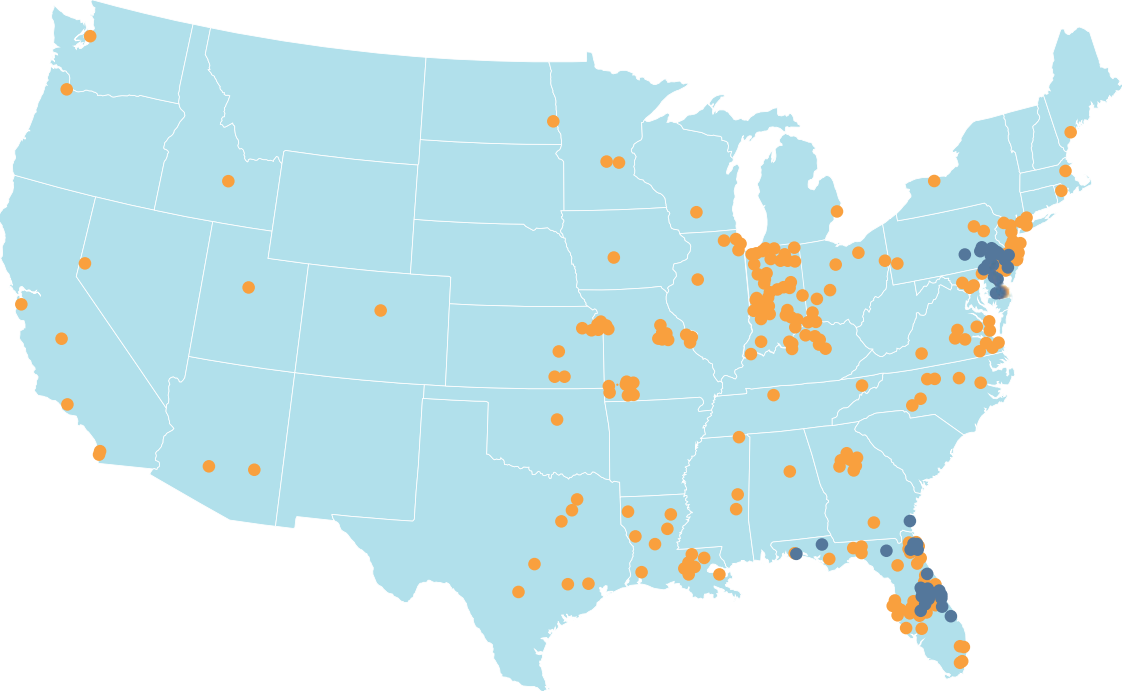
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**Not pictured*

OUR LOCATIONS



REMOVING BARRIERS AND BOUNDARIES TO DELIVER BETTER HEALTH TO CHILDREN EVERYWHERE

Clinical integration and collaboration across **Nemours' regional networks** increasingly enables all of our resources to support the highest level of patient care at the location of our families' choosing. Nemours CareConnect enables 24/7, on-demand access for families in six states. 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.

DELAWARE

HOSPITAL

- Nemours/Alfred I. duPont Hospital for Children, Wilmington

PRIMARY & SPECIALTY CARE

- Bear — Becks Woods
- Dover
- Middletown
- Milford
- Newark
- Seaford
- Seaford — Shipley Street
- Wilmington
- Foulk Road
- Jessup Street
- Pike Creek
- Rockland Road
- Saint Francis

COLLABORATING HOSPITALS

- Nanticoke Memorial Hospital, Seaford
- Saint Francis Hospital, Wilmington

NEMOURS SENIORCARE

- Milford
- Wilmington

NEMOURS HEALTH & PREVENTION SERVICES

- Seaford
- Wilmington

NEMOURS ESTATE

- Wilmington

GEORGIA

SPECIALTY CARE

- Brunswick

MARYLAND

COLLABORATING HOSPITALS

- Union Hospital, Elkton



Nemours' care and services are offered within our two freestanding children's hospitals, more than 80 specialty, primary and urgent care locations in six states, and through 18 hospital collaborations. Beyond our walls, Nemours' specialty expertise extends into the home, at school, on vacation and wherever families live, learn and play.

NEW JERSEY

SPECIALTY CARE

- Deptford
- Vineland
- Voorhees

COLLABORATING HOSPITALS

- Inspira Medical Center Vineland, Vineland
- Inspira Medical Center Woodbury, Woodbury

PENNSYLVANIA

SPECIALTY CARE

- Bryn Mawr
- Glen Mills
- Lancaster
- Newtown Square
- Philadelphia
- Upland

SURGERY CENTER

- Bryn Mawr

PRIMARY CARE

- Collegeville
- Concordville
- Exton
- Media
- Paoli
- Philadelphia
- Villanova
- Wayne

URGENT CARE

- Glen Mills

COLLABORATING HOSPITALS

- Bryn Mawr Hospital, Bryn Mawr
- Lankenau Medical Center, Wynnewood
- Paoli Hospital, Paoli
- Phoenixville Hospital, Phoenixville
- Thomas Jefferson University Hospital, Philadelphia

FLORIDA

HOME OFFICE

- Jacksonville

NEMOURS BRIGHTSTART!

- Jacksonville

HOSPITAL

- Nemours Children's Hospital, Orlando

SPECIALTY CARE

- Bonifay
- Davenport
- Daytona Beach
- Fleming Island
- Fort Walton Beach
- Jacksonville
- Jacksonville South

- Kissimmee
- Lake City
- Lake Mary
- Lakeland
- Melbourne
- Orlando — Downtown
- Orlando — Lake Nona
- Orlando — Lake Nona, Medical City
- Pensacola
- Tallahassee
- Centre Pointe
- Phillips
- Titusville
- Wesley Chapel

PRIMARY CARE

- Celebration
- Clermont
- Kissimmee
- Longwood
- Maitland
- Orlando
- Downtown
- East Orlando
- Lake Nona
- Windermere
- Ormond Beach
- Oviedo
- Palm Bay
- Sanford
- Vero Beach I
- Vero Beach II

- Windermere — Horizon West
- Winter Haven

URGENT CARE

- Kissimmee
- Lake Nona
- Melbourne
- Orlando — Waterford Lakes
- Sanford

COLLABORATING HOSPITALS

- Heart of Florida Regional Medical Center, Haines City

- Indian River Medical Center, Vero Beach
- Lakeland Regional Health Medical Center, Lakeland
- Osceola Regional Medical Center, Kissimmee
- Parrish Regional Medical Center, Titusville
- West Florida Healthcare, Pensacola
- Wolfson Children's Hospital, Jacksonville
- Wuesthoff Regional Medical Center, Rockledge

Nemours/Alfred I. duPont
Hospital for Children

Nemours Biomedical Research

Nemours CareConnect

Nemours Center for Children's
Health Media

Nemours Children's Hospital

Nemours Children's Primary Care

Nemours Children's Specialty Care

Nemours Children's Urgent Care

Nemours duPont Pediatrics

Nemours Estate

Nemours Fund for
Children's Health

Nemours Health &
Prevention Services

Nemours National Office
of Policy & Prevention

Nemours Reading BrightStart!

Nemours SeniorCare

Nemours.org

NemoursEducation.org

KidsHealth.org

ReadingBrightStart.org

Nemours. Children's Health System
Your child. Our promise.

