I am pleased to share the Nemours Children’s Health System 2019 Annual Report, *Built For Impact*. This year’s report reflects the continuous investment in people, technology and processes driving Nemours’ ability to help each child reach his or her full potential.

As I pen this greeting, the COVID-19 pandemic has seized our global community — bringing tragedy to many and forcing change upon nearly every facet of our lives. While the U.S. health care system has been teetering on the edge of change for decades, our new reality could provide the shove necessary for its full transformation.

Nemours embraces that change. In fact, Nemours has been “under construction” for years — expanding the definition of health, creating new pathways to improve health outcomes, and embracing new frontiers in medicine and modality.

In the pages that follow, you’ll learn how Nemours is:

- developing a pediatric value-based model of care addressing all factors that influence health;
- building an analytic infrastructure to mine data for insights that can change the trajectory of pediatric diseases;
- facilitating a culture of continuous improvement, constantly striving for excellence and transparency;
- empowering families to navigate their child’s health through access to care, information and support delivered where, when and how they want it; and
- preparing future health professionals with the tools and skills they need as advocates and providers to navigate the future of health.

To Nemours’ esteemed associates, partners, volunteers and donors, I hope you are filled with pride knowing the critical roles you play in service to nearly 500,000 children in our care. For anyone interested in joining Nemours’ pursuit to deliver the healthiest generation of America’s children, I encourage you to connect with our health system.

Nemours’ journey to create a better system began with the future in mind — that future is now upon us. We stand at the threshold of a transformational opportunity for our children and for our country. Over the last year, the foundation supporting Nemours’ efforts has been exposed — we are built for impact.

R. Lawrence Moss, MD
President & Chief Executive Officer
Nemours Children’s Health System
In this year’s Annual Report, we share the work Nemours is doing to help build a better U.S. health care system — starting with the nation’s youngest patients.

Strategic investments toward the well-being of children yield massive returns for future generations. To achieve maximum impact, all stakeholders of children’s well-being must work together.

At Nemours, that means we extend our health expertise and partner with other professionals in areas such as education, food security, housing, justice, adverse childhood experiences, and other social determinants, to develop models that address the whole health of a child. Nemours’ journey to a better health system begins with the future in mind.

Built upon a solid foundation, our investments support the connections that enable the exploration of healthier possibilities for us all. As Nemours navigates the future of health, be assured — we are built for impact.
To Address SDOH, You Must Assess Nonmedical Factors

Nearly two-thirds of U.S. parents of children under age 18 report nonmedical factors limit their family’s ability to live a healthy life. These factors, known as social determinants of health (SDOH), are a central focus for Nemours and include societal, community and economic factors that impact health over a lifetime.

In 2018, associates across the Nemours enterprise developed a standard SDOH screening tool to gather information on nonmedical patient needs in a variety of care settings. The development phase in 2018 and early 2019 focused primarily on the content of the screener, both in terms of phrasing and domains addressed. The pilot team also explored family and staff comfort discussing sensitive topics.

In late 2019, under the leadership of Nemours’ Population Health Management team, a version of the screener incorporating electronic health (EHR) records began a pilot phase at 11 Nemours locations in a variety of clinical settings. This phase is looking at the operational workflows of the survey instrument such as how often families should be screened and how to address new resource needs that are being revealed.

More recently, the screener has been operationalized across the 20 primary care practices in the Delaware Valley so Nemours Care Coordinators can consistently document the needs of families through their outreach and follow-up calls.

Identifying needs is imperative. However, even more important is ensuring the care coordination team can connect families to resources based upon those needs and have reliable follow-up to ensure they are received.

A “PAY FOR HEALTH” MODEL

While over 400 Nemours VBSO associates are “on the ground” developing a value-based care model, the Nemours National Office of Policy & Prevention is working at state and federal levels to inform policies and promote funding that supports value-based principles for all children.

In 2019, Nemours co-hosted a meeting with Duke-Margolis Center for Health Policy in Washington, D.C. bringing together leaders from across the U.S. to share insights on value-based payments and social determinants of health (SDOH).

Based on the meeting, teams from Nemours and Duke developed two issue briefs to spotlight accelerators, barriers, and policy and practice recommendations related to pediatric payment and delivery models that address SDOH.

BUILT TO TRANSFORM

Nemours Value-Based Services Organization (VBSO) is taking steps to transform the current health system from a model that pays for sickness to a model that pays for health.

Nemours supports an expanded definition of children’s health as an investment in a healthier future for us all. Cultural and structural shifts within Nemours have led to a value-based model that leverages primary care, medical management, data analytics and technology, population health management and clinically integrated networks. By the end of 2019, the VBSO secured seven value-based contracts, covering commercial and Medicaid patients across Delaware and Pennsylvania, with a total of 32 metrics, and is participating in two additional value-based programs.

THE KEY TO VALUE? DATA

From electronic health records data to disease process mapping, predictive modeling using machine learning transforms data into value for Nemours. Data modeling provides standardization, reduces variability and provides predictive analyses — lowering expenses and delivering higher quality care.

Predicting health outcomes, such as mapping complex disease, provides critical information used to personalize patient treatments, maximize health and minimize waste. Evaluating data using clinical risk groupings helps to reduce emergency department admissions and properly allocate resources to ensure that children with high risk factors receive timely, optimal care.

Data utilized in forecasting supplies, usage and expenditures further drives efficiencies enabling value-driven procurement. On the horizon, the ability to seamlessly merge clinical and operational data in large enough sets for artificial intelligence to observe and recommend ordering through seasonality or other factors that can further efficiencies and reduce waste and costs.
Using Data to Identify Populations Who Can Benefit From Interventions

A community-based research study funded by the Institute of Education Sciences of the U.S. Department of Education has enabled a partnership among New Jersey’s Camden City School District, Nemours Children’s Health System and the Camden Coalition of Healthcare Providers to focus on an issue of shared importance: students experiencing homelessness. To date, the two-year grant has built capacity within the district and helped merge disparate data sources to better identify all families struggling with homelessness who could benefit from available resources.

A $1.7 million NIH Environmental Influences on Child Health Outcomes (ECHO) grant is helping Nemours establish other connections in the community: advanced pediatric clinical research networks in rural and medically underserved areas. Nemours Pediatrics in Milford, Del. is one of the rural sites poised to bring clinical trial research direct to children who can benefit. The iAmHealthy Feasibility Trial, conducted by Thao-Ly Phan, MD, MPH, an expert in prevention and treatment of pediatric obesity, is designed to establish best practices for identification, recruitment and retention of children with obesity in rural clinics. To begin, data extracted from Nemours’ EHR greatly reduced the time to identify more than 300 children who met inclusion criteria. Enrolled trial participants (up to 32 children) will be provided with tablets so they can participate in a telehealth lifestyle intervention in their own homes.

“Many students who experience homelessness go on to show resilience because families, schools, health care providers and social services keep children on track, even when adversity threatens development.”

— J.J. Cutuli, PhD, Nemours senior research scientist

Delaware Children’s Health Network (DCHN) is a physician-led, statewide, clinically integrated network of more than 24 Nemours and non-Nemours primary care practices that serve more than 70 percent of Delaware’s kids. DCHN participant providers use evidence-based care methods, standardized clinical pathways and metrics collected in Healthy Planet — a population health management platform. Healthy Planet helps identify gaps and effectively target pediatric interventions. DCHN partners share best practices and agree to work on targeted initiatives to improve health such as:

- flu immunization rates
- well-child visits (age 0 to 15 months)
- pneumococcal 23 vaccination rates

“Non-Nemours providers are playing a huge role in recruiting for the DCHN, saying, ‘you really need to be part of this, we’re collaborating to improve the health of pediatrics in our state’.”

— Jamie Clarke, Nemours’ Chief Value Officer

Additional efforts to improve preventive health measures for Delaware’s children were put in place leveraging Nemours community health workers to reach out to families with children under age 15 months who are behind on vaccinations.

The DCHN will execute its first value-based payment contract as a clinically integrated network in 2020, and is planning on two additional contracts.
UNPRECEDENTED RESEARCH OPPS

Nemours National Office of Policy & Prevention helped successfully lobby the federal government to reauthorize the Patient-Centered Outcomes Research Institute (PCORI). The reauthorization provides for 10 additional years of funding and the expansion of the PCORI-supported PEDSnet research network.

Nemours played an essential role in building the infrastructure alongside seven children’s hospitals in 2013 and is consistently one of its largest contributing institutions in terms of data.

Shifting Clinical Research Studies From Investigator-Driven to Patient-Centered

Through PEDSnet, eight contributing institutions including Nemours convert EHR data from more than 6.2 million de-identified pediatric medical records to a common data model and make it available in an analysis-ready database. This collaborative infrastructure affords researchers from all institutions access to uniform data to conduct research. To date, PEDSnet has been the source for 37 studies. Active PEDSnet institutions also leverage the network data for internal studies.

“We’re gaining the ability to extract important information about patients in a defined cohort with a particular disease. We can drill down into factors that distinguish them from the average Nemours patient — and that can tell us what we need to watch out for.”

— Tim Bunnell, PhD, PEDSnet Site PI and Site Informatics Lead

The Nemours Bioinformatics team is using advanced machine learning methods within PEDSnet datasets to develop the analytic infrastructure necessary to map out a predictive course for certain pediatric disorders. The results will establish dashboards that direct clinicians in what to look for in defined populations as well as potentially generate new research questions related to conditions such as epilepsy, obesity, cerebral palsy and asthma.

With this information, Nemours clinicians can be proactive in delivering health interventions to children — helping them avoid unnecessary emergency department visits, hospital stays and even common colds.

DATA WAREHOUSE
COMPUTER LEARNING
ADDITIONAL FUNDING SECURED
8 SYSTEMS LINKING EHR DATA
K-12 SCHOLARS RESEARCH
MENTORSHIP

Pediatric research holds the key to unlocking mysteries that could prevent or reverse the course of disease across an entire lifespan.

Throughout Nemours, mission-driven physician and research scientists are engaged in nearly 200 externally funded grants and 216 clinical trials. This work is focused on improving the lives of today’s children — and contributing to a body of knowledge that will guide the future of health. These efforts are buoyed by cross-institutional cooperation and the most extensive network of longitudinal pediatric patient data.
MAKING PRACTICE MORE PRECISE

At age 18 months, Piper Lee was diagnosed with Denys-Drash syndrome characterized by kidney disease that leads to kidney failure. Children with this condition also face a 90 percent chance of developing Wilms tumor, a rare kidney cancer.

Genetic testing plays a critical role in treating certain kidney diseases categorized as steroid resistant nephrotic syndromes (SRNS), as a variety of mutations complicate the efficacy of treatment. At the time of Piper’s diagnosis, there were no labs in the U.S. that could quickly offer the genetic tests that Piper required. Special genetic testing done in England, arranged by her Nemours doctors, proved essential in guiding Piper’s treatment. Determined to make testing accessible to other families at Nemours and throughout the country, Piper’s parents, Chris and Erin Lee, formed Piper’s Kidney Beans Foundation (PKBF).

With funding from PKBF, Nemours developed a 46-gene SRNS panel that is certified by Clinical Laboratory Improvement Amendments, affordable and provides reliable results quickly. By understanding the genomic variants present for each child, Nemours can determine the best course of treatment and ultimately save lives.

The genetic testing program went live in March 2019. During the next nine months, 12 patients were tested for SRNS, providing physicians with personalized genetic information to guide clinical care.

IGNITING PRECISION

The University of Florida is working with Nemours as its pediatric partner in pharmacogenetics under the NIH-funded Implementing Genomics in Practice (IGNITE) program. This collaboration focuses on postsurgical patients who need to be treated with opioids and a group of patients being treated with selective serotonin re-uptake inhibitors (SSRIs) for depression.

In postsurgical patients, genetic testing will allow for customization to create individualized pain management plans. In children diagnosed with depression, the goal is to use genomic testing to speed the alleviation of depression symptoms in children taking SSRIs by choosing the SSRI best suited to their gene panel. With suicide as the second leading cause of pediatric death and opioid addiction on the rise, Nemours is committed to ensuring pediatric patients get the right medication, in the right dose at the right time.

The study will last six months, then data will be analyzed to improve clinical relevancy in treatment.

Nemours Precision Medicine Launches Clinical Pharmacogenetics Service

By understanding how a patient’s genetic make-up may affect drug response, providers can choose safer, more effective medications.

The Nemours pharmacogenomics team developed an in-house panel that encompasses 10 genes associated with response to more than 50 medications commonly prescribed to Nemours patients. These include certain antidepressants, opioids, NSAIDs, thiopurines, and many others.

“When a physician prescribes the medication, we want them to have this pharmacogenomic information right away, so they can either choose a different drug or a different dose if need be, for that particular patient.”

– Kathryn Blake, PharmD, Director, Nemours Center for Pharmacogenomics & Translational Research

The clinical service includes:

- pharmacogenomic testing on an in-house multigene panel orderable within the EHR
- clinical consult service orderable within the EHR to determine:
  - appropriateness of testing and test selection
  - pharmacogenomic-based drug and dosing recommendations
  - assistance with insurance authorization for test coverage
- active clinical decision support in the form of Best Practice Alerts
- pharmacogenomics profile within the EHR with links for more information
- education for providers, nurses, researchers and clinical staff

The service launched at Nemours in the Delaware Valley in February 2020 and will expand to Nemours’ Florida locations by late 2020.

They raised money to develop reliable genetic testing for nephrotic disorders, as well as cover the cost of testing for families with limited means.

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FIGHTING FIRE WITH FIRE

Researchers are one step closer to determining if Zika virus may hold potential as a cancer treatment for neuroblastoma, a rare but deadly childhood cancer.

A basic research study, published in 2018 by a group of researchers from Nemours Children’s Hospital and Burnett School of Biomedical Sciences at the University of Central Florida College of Medicine, showed Zika virus successfully destroying most neuroblastoma cells that had been cultured in the lab.

“We have begun initial discussions with the FDA to start laying out the roadmap to a phase one clinical trial.” — Tamarah Westmoreland, MD, PhD, Nemours Children’s Hospital

This collaborative research was an early, but important first step in the potential use of Zika virus as a cancer therapy. During 2019, the same research collaborative was able to move the study to an animal model, opening the door to a possible clinical trial in the near future. The one-time dose of Zika virus was shown to decrease the size of the neuroblastoma tumors grown in mice by more than 50 percent.

Giving Kids a Unique Voice

With the support of a National Science Foundation grant, Nemours is working to provide an authentic voice to children through advancements in speech synthesis. Current systems do not convey inflection or the subtlety of meaning that is a product of natural speech. By leveraging a lesser-used technology called Corban synthesis, Nemours is exploring new algorithms to learn the patterns associated with different types of expressiveness, to control a speech synthesizer that is more expressive, conveys more accurate meaning, and is just as good at capturing the voice of an individual user.

The goal is personalized speech synthesis where the synthetic voice sounds like the child — or as they would sound if they were able to speak for themselves. Even for nonverbal children, researchers can extract some characteristics of the child’s voice quality and impose that on the speech synthesizer so that every child can have a unique voice.

Some of this research is funded by a fee-for-service program that allows adults with neurodegenerative disease to submit their speech to the Nemours Center for Pediatric Auditory and Speech Sciences lab to have a synthetic voice created for them to use when they are unable to speak.

“Where we’re hoping artificial intelligence will be most beneficial to us is triaging, screening and prioritizing which study comes to the top of our list to be read next.” — Dan Podberesky, MD, Radiologist-in-Chief

Using AI and Machine Learning to Help Triage Radiology Reads

Nemours employs one of the largest groups of pediatric radiologists in the nation. Reading for the Nemours health system providers and many of its collaborating hospitals and other institutions, Nemours experts read more than 320,000 images in 2019 with a median turnaround time on stat exams of approximately 14 minutes.

With its investment in Fuji’s new leading edge Picture Archiving and Communications System (PACS) and Vendor Neutral Archive (VNA), Nemours is positioned to potentially further reduce turnaround time. Clear imaging can now even be visualized securely on mobile devices. Nemours is working on industry partnerships that will enable the system to aggregate imaging data using machine learning to increase efficiency in triaging, screening and prioritizing scans.

“Where we’re hoping artificial intelligence will be most beneficial to us is triaging, screening and prioritizing which study comes to the top of our list to be read next.” — Dan Podberesky, MD, Radiologist-in-Chief

Active research studies are already being conducted to teach the computer to quickly and accurately flag congenital dysplasia of the hips from ultrasound screening exams. Nemours is also exploring other projects to look at AI for identifying brain bleeds on CT scans and picking up pneumonias or pneumothoraces on chest X-rays. In these scenarios, critical scans could automatically be prioritized to ensure children with the most urgent care needs are attended to most quickly.

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BUILT TO EXCEL

From the board room to the front lines, all that Nemours strives to achieve begins with putting children first and drives the continuous journey toward excellence.

Nemours has accelerated efforts to build upon its foundation of delivering safe, high-quality care to children. In 2019, Mission Zero launched at Nemours Children’s Hospital with the Culture of Safety Leadership Summit followed by 14 mini-summits to fortify high reliability and just culture. Associates across the system have focused on workstreams that range from becoming “brilliant at basics” to improving leadership accountability.

QUALITY & SAFETY: A REWARDING EFFORT

The commitment to quality and safety is recognized throughout the Nemours system by objective, measurable outcomes that keep children safe. Using over 30 databases for clinical standards and customer survey tools, Nemours compares its progress to industry standards and guides its continuous efforts to provide consistent, high value experiences to every patient family, everywhere, every time. Some highlights of Nemours’ 2019 recognition for the provision of safe, high-quality care include:

- U.S. News & World Report recognized seven specialties at Nemours/Alfred I. duPont Hospital for Children (N/AIDHC) in its 2019 “Best Children’s Hospitals” rankings
- For the third time, The Leapfrog Group recognized Nemours Children’s Hospital (NCH) among its “Top Children’s Hospitals” in the U.S. for exceptional quality and safety, Wolfson Children’s Hospital, Nemours partner in Jacksonville, was also among the 10 pediatric hospitals awarded
- The Logistics Center celebrated seven years monitoring inpatient vitals across the Nemours enterprise, enabling early detection and response to potential adverse events, including sepsis
- The Emergency Nurses Association has once again honored N/AIDHC’s Level 1 Pediatric Emergency Department with its “Lantern Award” for quality and safety — one of only 28 U.S. EDs
- Zero post-operative infection rates for two years straight for Nemours providers in partnership with its collaborating hospital, West Florida Healthcare – Pensacola

Nemours strives not only to improve its targeted metrics but to instill a culture of quality and safety that supports, communicates and corrects course when issues arise. Quarterly updates track, benchmark and report progress to plan back to every associate from the C-suite to the nursing teams. Emphasis is placed on a just culture where associates feel safe speaking up for safety, in addition to understanding what is expected, and being empowered to succeed with the right training, tools and procedures.

A Mission to Zero Harm: Making It Easy to Do the Right Thing

More than 18,000 issues were elevated and addressed from daily safety huddles across Nemours in 2019.

A culture of quality and safety provides appropriate feedback mechanisms, like daily safety huddles, where all associates are compelled to share successes, visions for improvement and address errors with compassion. Open communication, reliable methods, standards and metrics are essential to Mission Zero.

GETTING BETTER

Continuous improvement efforts play an important role in Nemours’ journey toward excellence. During 2019, cross-functional teams throughout the enterprise participated in multi-day improvement events, day-long workshops, daily huddles, breakthrough improvement efforts and “gemba” visits all designed to improve processes, reduce waste and increase value.
A HEART FOR HIGH-QUALITY CARE

The Cardiac Center at Nemours duPont Hospital for Children has served as a standard bearer in excellence, with a record of superior outcomes over the course of more than 20 years. The Center was one of the first to be designed as an integrated cardiac practice unit — now considered the hallmark of a quality cardiac program.

The all-new Cardiac Center at NCH is elevating Nemours’ vision for superior service by further innovating its model of integration.

Using Integrated Facilities Design, the process for planning the new Cardiac Center at Nemours Children's Hospital (NCH) applied lean principles and leveraged the expertise of multiple stakeholders, from respiratory therapists and pharmacists to nurses, physicians, and patients and families.

All cardiac services are co-located within the 40,000 square-foot Cardiac Center, including a cardiovascular operating room and hybrid catheterization lab. Thirty critical care beds are stationed adjacent to the cath lab, providing for a safer and more seamless experience. Rather than one large nurses’ station, multiple desks populate the unit to ensure nurses are close to their patients. Line of sight between nurses and physicians is maintained at all times by the all-glass physician workroom. New IT systems ensure providers can securely monitor their ICU patients from their computer or phone.

The NCH Cardiac Center helps buoy Nemours’ cardiology team throughout Florida, including 13 outpatient sites. Further integration across the health system is anticipated as Nemours deploys a single echocardiography system.

Extending Quality to All Children, Regardless of Where Care Is Provided

A commitment to keep kids close to home means, on any given day, Nemours providers are managing as many children within Nemours’ collaborating hospitals as within the walls of Nemours’ freestanding children’s hospitals.

To ensure one high level of quality regardless of where care is provided, Nemours and its partners are developing integrated care pathways. This work takes on many forms, depending on the type of services provided or goals for improvement, to ensure consistent care across the Nemours network.

“Using the Nemours Neonatal Nurse Practitioner program, our discharge times have decreased significantly and our quality measures and patient satisfaction continue to increase.”

— Brenda Morgan, MHSA, BSN, RNC-OB, Perinatal Services Sr. Nurse Manager, AdventHealth Heart of Florida

Going Wider and Deeper to Help Cardiac Patients

The Nemours Cardiac Center at N/AIDHC has continued to find new ways to support children with heart conditions and their families. In recent years, its multidisciplinary team has expanded to include a genetic counselor and an embedded psychologist. New technologies are also being employed to support care and outcomes.

- genetic testing can offer further insight into the genetic cause of a cardiac condition, informing the course of treatment and benefiting the immediate and extended family of the patient
- developmental screening can help identify children who may experience developmental delays, ADHD or learning disabilities as a result of a serious heart condition or its treatment; earlier identification can result in earlier intervention and improve quality of life
- advances in noninvasive imaging enable access to information that once was only discernible through a cardiac catheterization

Partnership support is intended to elevate care for the community and add value to the institution, and may include:
- initial assessments to identify care gaps
- establishing shared dashboards to measure quality improvements and daily management systems
- expanded access to providers or nurses, as needed
- monthly check-ins with hospital administrators
- assistance in identifying recommended hardware, software and other health care resources
- retrospective review of transfers to improve efforts to keep care local
- variety of education and training as well as on-site simulation for codes and rare events
- hosting partner providers within Nemours locations to familiarize culture

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VALUES

MISSION + VISION

17
REINFORCING PATIENT EXPERIENCE

In addition to broadening the concept of patient experience, in 2019, the revamped Nemours Patient Experience Department emphasized the importance of patient and family perspectives by:

• strengthening and expanding the family advisory committees, including engaging more families in virtual committees;
• facilitating associate-led improvement projects designed to enhance the patient experience;
• encouraging ownership and involvement across all levels of the enterprise; and
• reinforcing Nemours’ unique identity as a patient experience-focused culture.

The department’s innovative approaches to the measurement and improvement of patient experience has culminated in over 100 improvement projects across the health system to be implemented in 2020. These include COVID-19 related projects that will enhance the safety and quality of care as well as provide virtual care through pioneering techniques.

Empowering Patients Before, During and After Their Experience

The award-winning “Path to Home” program at Nemours Children’s Hospital is a patient flow process that prepares families for discharge the moment their hospital admission begins. “Path to Home” is based on process improvements such as modifying questions to better identify a patient’s barriers to discharge; integrating those responses into the EHR; and implementing daily rounding with the entire interdisciplinary team so discharge planning stays top-of-mind.

Other Nemours programs focus on preparing adolescents to assume primary responsibility for their health care. Navigating the Health Care System is a four-unit health literacy curriculum that Nemours designed for high school students in classroom and community settings. Students learn things like how to understand an insurance card and where and when to seek appropriate levels of care.

Launched in Delaware, the curriculum has been embraced nationally, with 446 registered users across 52 U.S. states and territories. The series has been recreated for adults and used in community colleges and is currently being modified for use with elementary school students.

Beyond education, Nemours is working in collaboration with adult health providers like Christiana Center for Special Healthcare Needs. Together, clinicians from Nemours and Christiana work with young adults and their families to co-manage care. Working as a team ensures an informed transition and tapers from pediatric care to adult care connecting young adults to the next stage in their lives and supporting optimal health.

Nemours has developed a myriad of ways to prepare children and families for managing their health.

The shift to an experience-focused culture at Nemours began by broadening the narrower construct of service excellence to reflect the importance of all facets of a patient and family experience. This comprehensive view includes how, when and where services are delivered, and the safety and quality of those experiences. It also recognizes the relationship those factors play in health outcomes.
“In a sense, when a patient comes to Nemours, they are not seeing one person, they’re seeing 20 people because we truly work together.”

— Howard Katzenstein, MD, Co-Director, NCCBD

improvement. Through NCORP, Nemours brings the most innovative therapies to children in their community-based settings.

NCCBD hematology/oncology physicians and research scientists collaborate closely across the Nemours enterprise. Additional efforts to further integrate this complex specialty across Nemours began in 2019. By bringing teams together and looking at evidence-based care, the NCCBD nurses are focused on clinical standard work — aligned with clinicians — so that care across the enterprise seamlessly meets the same goals. Translating best practices and looking at the model of care at infusion centers, they are developing practice guidelines focused on patient-centered experiences such as chemotherapy safety teams.

Donors and community partners also make critical contributions to round out the patient experience. The “Home Team” at Jacksonville’s NCCBD site has formed a safety net to ensure families have access to everything necessary to successfully navigate their journey. Collectively, this group provides access to hospital services, art and music therapies, a full-time Child Life specialist, psychosocial support, family activities and help with basic living expenses.

“You can have the best treatment in the world — the drug that reverses some major health condition or a technology that could transform health. However, if we don’t think about the potential barriers to access, understanding or use of those modalities, we won’t be able to fully realize advances in science.”

— Anne E. Kazak, PhD, Director, Nemours Center for Healthcare Delivery Science

Finding the Best Ways to Help Families Receive the Care They Need

Nemours Center for Healthcare Delivery Science (CHDS) is an enterprise-wide research center that studies the many influences that affect outcomes, quality, cost, safety and value of care. CHDS builds scientific evidence to connect the best methods for delivering care to children and families.

CHDS is currently conducting more than two dozen studies, including an innovative eHealth intervention for parents of children with cancer. This work, supported by a NIH R03 award from the NCI, is based on earlier in-person versions of the Surviving Cancer Competently Intervention Program, designed to reduce cancer-related anxiety and improve the coping abilities of a patient and family dealing with cancer.

Data from the R03 study will be used to power a randomized clinical trial to establish clinical efficacy of the intervention.
A recent symposium for Nemours physicians and associates offered a day-long immersion in education about social determinants of health (SDOH). “Attacking the 70%: Understanding the SDOH” included presentations on disparities in the justice system, the role of medical-legal partnerships and the significant role of social workers, along with information on Nemours’ current programs, resources and efforts to promote value and address SDOH. Providers eager to improve social determinants.

“Fantastic conference! Appreciate the opportunity to discuss and learn.”

Symposium attendees also participated in “The Cost of Poverty Experience,” an interactive simulation that portrayed real stories of families impacted by poverty. The experience gave participants insights into factors that patient families may deal with outside of their medical needs.

Parents, educators and health professionals all have important roles to play in assuring children have the best chance to grow up healthy. From its inception, the Nemours Children’s Health System has designed programs and tools that share best practices, policies and the latest information to support decisions related to children’s health — at home, in the classroom, in the clinic and in local, state and federal government.

From medical students and residents to physician fellows, senior physician leaders and all stages in between, Nemours provides opportunities to build, enhance and refresh the skills necessary to support the future of health delivery.

- Using pediatric simulation to develop clinical proficiency and communication skills
- Creating pipelines to ensure inclusivity and building understanding toward health equity
- Encouraging curiosity and providing access to innovative technologies, unparalleled data and research mentors
- Emphasizing wellness and self-care, including access to dedicated mental health resources

WELL-ROUNDED MDs

Nemours welcomed its first class of pediatric residents in July 2019. The flagship residency program at Nemours Children’s Hospital (NCH) is part of Nemours’ movement to enhance pediatric medical education and practice.

The NCH residency began with robust skills-based and communications-based simulation training, and includes continued in-depth simulation opportunities throughout the residency.

Each day, residents participate in a conference or didactic curriculum that provides insight into specialized training or community-facing medical and social advocacy. In addition, residents are expected to interface in daily huddles and on a variety of hospital committees, including quality, med safety and ethics. Residents will also select a research focus as well as engage in community outreach activities.

Recognizing the connections between self-care and patient outcomes, every resident and member of the medical staff, including department chairs, receives a mandatory review with a psychologist for baseline evaluation. A 24/7 crisis hotline and access to immediate therapy sessions provide on-demand intervention to support mental health.

THE EVER-EVOLVING PROVIDER SKILLSET

Driven by purpose and mission, Nemours continuously invests in models that advance caregiver skills, knowledge and confidence to positively impact children’s health.

Parents, educators and health professionals all have important roles to play in assuring children have the best chance to grow up healthy. From its inception, the Nemours Children’s Health System has designed programs and tools that share best practices, policies and the latest information to support decisions related to children’s health — at home, in the classroom, in the clinic and in local, state and federal government.
Healthy Kids, Healthy Future Technical Assistance Program (HKHF TAP) is funded by a five-year CDC Cooperative Agreement. This program provides high-quality technical assistance (TA) and supports 12 state partners’ efforts to integrate healthy eating and physical activity best practices into Early Care and Education (ECE) systems and settings.

The HKHF TAP program advocates best practices such as ensuring toddlers and preschoolers receive fruits or vegetables at every meal and that infants have short periods of ‘tummy time’ every day.

Using the CDC’s Spectrum of Opportunities framework, Nemours collaborates with departments of health, child care resource and referral agencies, and other ECE organizations to accelerate the integration of best practices into broader state systems, such as TA networks, professional development, licensing, Child and Adult Care Food Program, and Quality Rating and Improvement Systems.

Simulation Builds Confidence for Parents and Providers

Nemours Institute for Clinical Excellence (NICE) is on the leading edge of pediatric simulation. For the NICE team in Delaware, that includes pediatric patient- and family-centered simulation that is both nationally and internationally recognized.

Nemours/Alfred I. duPont Hospital for Children (N/AIDHC) is in its 10th year of delivering eight different simulation-based courses that attract multidisciplinary participants from across the U.S. In 2019, N/AIDHC was only the fourth site in the U.S. to host the international Trauma Resuscitation for Kids course in conjunction with the Royal College of Physicians and Surgeons of Canada and the U.S.-based Pediatric Trauma Society.

Since 2016, Nemours has required simulation training for caregivers of children who receive a tracheostomy before they are discharged home. In an effort to keep skills from declining, plans are in the works to offer quarterly refresher courses for families at N/AIDHC. In Central Florida, the NICE team is also developing after-hours sessions at Nemours Children’s Hospital through a donor-supported initiative called Simulation Enhanced Learning for Families (S.E.L.F.) Care.

In addition to improving the quality and safety of patient care, NICE teams use simulation to improve systems integration. Across Nemours, that includes “day-in-the-life” simulations to identify latent safety threats or hiccups in processes, allowing for changes before opening a new facility.

Several new Nemours locations participated in these simulations in 2019 — Nemours Sports Medicine at the 76ers Fieldhouse, the Advanced Delivery Unit at N/AIDHC (pictured at right) and the Nemours Cardiac Center, Florida.

Tools to Guide and Teach with Empathy

Children who exhibit disruptive behaviors in the classroom may have more going on than meets the eye. Root causes like speech or language delays or trauma in the home may be contributing factors. If left unattended, these factors can have a deleterious impact on a child’s health and their long-term quality of life.

New programs developed by Nemours Florida Prevention Initiative are designed to help early childcare educators learn how to identify at-risk children and work with their parents to manage behaviors.

With funding support from the Winter Park Health Foundation, Nemours developed GATEway (Guiding and Teaching with Empathy), a program designed to build a strong alliance between parents/caregivers and childcare educators. The multiversion approach aims to improve the emotional, behavioral and mental health of children by teaching them skills and techniques to self-regulate and improve resiliency. These are reinforced by guiding positive parenting strategies and self-efficacy to help the child at home, including access to telehealth consultations when parents may be struggling in the moment.

A pilot will launch in 2020, with a cohort of four early care and education centers with children as young as infants through age five.

“Residency is typically viewed as hospital-based learning. However, Nemours recognizes that when community members lack access to health care, we have to bring health care to them. Being able to interact with the community during my residency is incredibly pivotal to my learning, and also reminds me why I do what I do.” — Emily DiLillo, MD

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Since opening its doors, Nemours has invested more than $3.3 billion in delivering a higher standard of medical care for children. Nemours’ 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:**
$25.2 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, Nemours also seeks to investigate and understand processes that affect the delivery, safety, outcomes, cost, quality and value of pediatric care.

Currently, Nemours boasts:
- 414 funded research projects and clinical trials
- 107 physician scientists
- 32 PhD center directors and laboratory heads
- 210 research support staff

**PREVENTION & INFLUENCING CHILDREN’S HEALTH:**
$15.0 MILLION

Nemours continues to focus leadership and programs in the areas of health promotion and disease prevention through Nemours’ Value-Based Services Organization, National Office of Policy & Prevention, KidsHealth and Reading BrightStart!

**EDUCATION & TRAINING OF HEALTH PROFESSIONALS:**
$4.3 MILLION

Nemours continues to train the next generation of pediatric specialists through its affiliations with Sidney Kimmel Medical College at Thomas Jefferson University, Mayo Clinic School of Medicine and Science, Florida State University, University of Central Florida College of Medicine and the University of Florida College of Medicine.

In 2019, Nemours hosted:
- 1,022 medical students
- 912 residents
- 107 physician fellows
- 2,190 allied health professionals

**UNCOMPENSATED MEDICAL CARE:**
$161.9 MILLION

Uncompensated medical care includes health care services without a direct source of payment. In 2019, total uncompensated medical care provided by Nemours included:
- $3.2 million in services classified as “charity care” where the recipient could not afford services or lacked adequate health insurance
- $129.0 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
- $29.7 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:**
$4.5 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.

During 2019, Nemours SeniorCare provided outpatient services to 6,094 Delaware seniors. The program also completed its sixth year of partnership with the St. Francis LIFE program. Nemours SeniorCare made progress on the construction of a new facility in southern Delaware, with opening anticipated during 2020.

- 9,157 dental visits
- 14,001 eye visits
- 1,363 hearing visits

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2019 VOLUNTEER IMPACT

Across Nemours Children’s Health System, 1,971 volunteers provided support to nearly every pediatric specialty during 2019. These dedicated individuals shared their time and talent in excess of 111,894 hours — a monetary equivalent of more than $2.8 million.

Nemours extends a sincere thank you to all volunteers for their dedication to bringing joy, comfort, laughter and support to children and families receiving care at Nemours.

### Delaware Valley

- 1,813 volunteers
- 61,750 hours of service
- $1,570,363 monetary equivalent
- 4,320 children read to in our waiting areas by Read Aloud volunteers
- 38 pet therapy teams
- 3,730 NICU babies read to by Baby Bookworm volunteer readers
- 4 clowns

### Central Florida

- 496 volunteers
- 45,000 hours of service
- $1,144,350 monetary equivalent
- 30 animal-assisted activity teams
- 10,000 patients and children interacted with animal-assisted activities teams
- 4,000 escorts from the surgical suites provided by Parental Presence volunteers

### North Florida (Jacksonville & Pensacola)

- 462 volunteers
- 5,144 hours of service
- $127,005 monetary equivalent
- 6 animal-assisted activity teams
- 7 character visits
- 2 volunteer clowns

### Nemours Cares: Associates Engaged in the Community

Each year, associate volunteers engage in activities to further extend Nemours’ compassion and resources to the children, families and communities that often need them the most. During 2019, more than 1,000 associates across the system participated in community volunteer activities. In addition, the annual “Nemours Cares Week” brought out hundreds of associate volunteers and their families to support local causes from food and diaper drives to Special Olympics buddies, beach clean-ups and more! Nemours associates’ commitment to helping children reach their full potential endures beyond clinic hours or hospital walls.

### Access to Care: Shepherd’s Hope

Without a documented physical, children in the State of Florida are unable to enroll in school. Thanks to volunteers from Nemours, children throughout Central Florida have been ready to get “back to school” for six consecutive years. Associates, nurses and physicians from Nemours Children’s Hospital have provided back-to-school physicals and other screenings for uninsured children through Shepherd’s Hope, the largest free and charitable clinic in Florida. In addition, associates provide backpacks and school supplies to help set kids up for a successful school year.

### Nemours Community Funding Program

The Nemours Community Funding Program, based in the Delaware Valley, offers associates the opportunity to be reimbursed for community-based activities that they design and implement to benefit children and families. In 2019, five separate initiatives were funded, including:

- **Stop the Bleed**, which taught more than 100 school nurses and administrators how to use a pediatric tourniquet;
- **EMS Skills Course**, to prepare Pennsylvania EMT professionals for pediatric emergencies through simulation;
- **Journey Unveiled**, which provided a field trip for a group of teen girls involved in a local mentoring program, as well as educational sessions on healthy relationships and emotional health and creative ways to eat healthy and stay active;
- **Garage Summer Nutrition**, which provided fresh vegetables to more than 100 youth; and
- **Heart Health & AED Awareness**, where students and staff from 11 local high schools received CPR Anytime kits and learned how to use AEDs.
2019 DONOR IMPACT

Donors are an important part of the Nemours family. Their gifts to the Nemours Fund for Children’s Health are vital in supporting Nemours’ long-term goal of delivering the healthiest generation of America’s children. Gifts of any size make a significant impact on pediatric care and services today, and help support future programs, treatments and resources.

In 2019, the Nemours Fund for Children’s Health received $13.6 million in gifts from 6,386 generous donors across the U.S.

Where 2019 Donations Came From

How Funds Were Distributed in 2019

Donors Make a Difference

“We are proud to be working alongside the community to raise funds that will have a tremendous impact on so many pediatric cancer patients and their families.”  – Aubrey Edge, President & CEO, Daily’s

Individual gifts, community fundraisers, event sponsorships and attendance ... these are just a few of the ways patients and families receive support through the generosity of donors.

In 2019, the Daily’s Foundation Inaugural Charity Concert held in Jacksonville, Fla. raised more than $350,000 to support children and families receiving services at the Nemours Center for Cancer & Blood Disorders. Daily’s ongoing partnership with Nemours helps raise awareness and funds that benefit kids.

The Auxiliary at NAIDHC, a partner since 1985, volunteers and raises funds to benefit Nemours patients and families. In recent years, their contributions have brought major resources to the hospital, including an All-Abilities Playground, a Sensory Playroom in the Child Life Clubhouse and the ZeroG Gait & Balance System in the Therapeutic and Rehabilitative Department.

In April 2019, the Jennifer Lynn Schott Childhood Arthritis Clinic was dedicated at Nemours Children’s Hospital. The clinic provides much-needed support to children and families in overcoming the physical, emotional and mental challenges associated with juvenile arthritis (JA). Available resources include physicians, nurses, social work, Child Life, behavioral health, physical therapy, and school-based education through PedsAcademy. The clinic was funded in memory of Jenny Schott, an educator, who lived with JA until the age of 26.
During 2019, Nemours provided direct care and services to 483,320 children during 1.9 million encounters. In addition, through outreach, education and advocacy, Nemours was able to support hundreds of thousands of other children — many of whom may never enter our doors.

Nemours remains focused on its operational strategy to create an environment with sufficient flexibility to proactively address the external pressures and changes facing the organization. Ongoing efforts to advance continuous improvement activities across the enterprise optimize efficiency and productivity, and help control costs, all of which create value and positively impact our bottom line.

“Nemours continues to realize returns on strategic capital, operational and personnel investments. The real beneficiaries of those returns are the children and families we serve.”
— Rodney A. McKendree, CPA, SVP, Chief Financial & Business Services Officer

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### THE NEMOURS FOUNDATION

#### CONDENSED COMBINED STATEMENTS OF OPERATIONS
YEARS ENDED DECEMBER 31, 2019 AND 2018
(Dollars in thousands)

<table>
<thead>
<tr>
<th></th>
<th>2019</th>
<th>2018</th>
</tr>
</thead>
<tbody>
<tr>
<td>Net patient service revenue</td>
<td>$1,236,209</td>
<td>$1,141,716</td>
</tr>
<tr>
<td>Contributions from the Alfred I. duPont Charitable Trust</td>
<td>175,812</td>
<td>176,709</td>
</tr>
<tr>
<td>Other income</td>
<td>128,478</td>
<td>96,099</td>
</tr>
<tr>
<td>Total revenue and other support</td>
<td>1,540,499</td>
<td>1,414,524</td>
</tr>
<tr>
<td>Total operating expenses</td>
<td>1,456,666</td>
<td>1,347,262</td>
</tr>
<tr>
<td>Operating income</td>
<td>83,833</td>
<td>67,262</td>
</tr>
<tr>
<td>Nonoperating gains (losses), net</td>
<td>—</td>
<td>4,596</td>
</tr>
<tr>
<td>Gain on bond defeasance</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td>Net periodic benefit cost, net of service cost</td>
<td>26</td>
<td>7,454</td>
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<tr>
<td>Excess of revenues and gains over expenses</td>
<td>83,859</td>
<td>79,312</td>
</tr>
<tr>
<td>Net assets released from restrictions used for capital purchases</td>
<td>686</td>
<td>3,512</td>
</tr>
<tr>
<td>Other change in net assets</td>
<td>(3,000)</td>
<td>—</td>
</tr>
<tr>
<td>Pension-related changes other than net periodic pension cost</td>
<td>(61,970)</td>
<td>4,833</td>
</tr>
<tr>
<td>Increase in assets without donor restrictions</td>
<td>$19,575</td>
<td>$87,657</td>
</tr>
</tbody>
</table>

### THE NEMOURS FOUNDATION

#### CONDENSED COMBINED BALANCE SHEETS
DECEMBER 31, 2019 AND 2018
(Dollars in thousands)

<table>
<thead>
<tr>
<th></th>
<th>2019</th>
<th>2018</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assets</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Current assets</td>
<td>$621,866</td>
<td>$562,333</td>
</tr>
<tr>
<td>Non-current assets</td>
<td>1,413,461</td>
<td>1,292,467</td>
</tr>
<tr>
<td>Total assets with donor restrictions</td>
<td>2,035,327</td>
<td>1,854,800</td>
</tr>
<tr>
<td>Restricted assets</td>
<td>252,390</td>
<td>222,906</td>
</tr>
<tr>
<td>Total assets</td>
<td>2,287,717</td>
<td>2,077,706</td>
</tr>
<tr>
<td>Liabilities and Net Assets</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Current liabilities</td>
<td>$241,540</td>
<td>$200,830</td>
</tr>
<tr>
<td>Non-current liabilities</td>
<td>759,155</td>
<td>638,913</td>
</tr>
<tr>
<td>Total liabilities</td>
<td>1,000,695</td>
<td>839,743</td>
</tr>
<tr>
<td>Net Assets</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Without donor restrictions</td>
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<td>2,077,706</td>
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</table>
While day-to-day oversight and execution of Nemours’ strategy is led by the Nemours Foundation executive cabinet, governance for The Nemours Foundation is composed of individuals whose skills complement the talented professional, medical and executive 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 help drive Nemours forward in creating a healthier future for all children.
OUR LOCATIONS

WHEREVER NEMOURS IS, ALL OF NEMOURS IS.

Each day more than 8,000 Nemours associates, united in purpose, work to do everything in their power to help children grow up healthy and reach their full potential. These efforts occur within Nemours’ two freestanding children’s hospitals, at nearly 80 specialty, primary and urgent care locations, through 22 hospital collaborations and via CareConnect. In addition, Nemours’ child health expertise extends into homes, schools and child care, and through policy advocacy at all levels to positively impact children across the nation.