A MESSAGE FROM DR. MOSS

I am pleased to share with you Future Forward, the Nemours Annual Report to our communities and beyond. This year’s report shares highlights of our health system's journey during 2018 and the ever-evolving work we’re doing to help each child reach his or her full potential.

I joined the organization in October 2018 because I was deeply inspired by Nemours’ commitment to being a leader in the overall health and welfare of America’s children. This aligns with my deeply held values that children’s hospitals should be the stewards of children’s health in our society. I believe Nemours is ideally positioned to take the bold steps necessary to lead the way. I could not be more enthusiastic about the power and limitless potential of this outstanding organization.

I have been a doctor caring for children my entire professional life and have grown keenly interested in transforming how we deliver medical care in the United States. Here at Nemours, we are committed to redefining the meaning of child health. We believe medical care is only a part of health and are committed to improving social and societal factors that comprise the health of a child. I believe that this is the most exciting time in history to lead a health system.

We’re starting to have conversations that we’ve needed to have for decades. These are the conversations that will forever alter the future of children’s health. In fact, it was during my first week that Nemours hosted its Pediatric Moneyball Conference in Washington, D.C. — a national meeting of leaders focused on our country’s journey toward a better health care system for our children.

At Nemours, we believe that better health begins by working to align all of the incentives of our nation’s health care system with those of the patient and family. That means working to create a system where health institutions are paid for keeping the child healthy and out of the hospital; working to bring discovery from the bench to the bedside faster than ever; and finding new ways to overcome barriers to better health. It also means doing our part to address the factors that influence 80 percent of a child’s health — nutrition and food security, literacy, optimal education, freedom from poverty, and other adverse childhood experiences.

Indeed, the future is now at Nemours — the future exists within every child with whom we come in contact as well as those who may never enter our doors. Together, each day with each action, we are making a remarkable impact on the health of children. I promise that we will always put the interest of the child first.

Your child. Our promise.

R. Lawrence “Larry” Moss, MD
Nemours President & CEO
To be a leader in children’s health brings with it a responsibility to guide all who care for children forward in meaningful and impactful ways. Health care is experiencing dynamic evolution and Nemours is leveraging disruption in health care models, delivery and technology to continuously improve the quality of life for all children — ultimately, creating a healthier future for whole communities. The way forward for our nation and our world is through the health of children. Knowing this, and possessing the tools and resources to effect positive change, means we cannot delay. The sense of urgency has never been greater: the future is now. Nemours must bring the future forward.
“Cost” may be the first thing that comes to mind when thinking about the value of care. Yet, like value, cost can be defined in many ways. What are the costs when families miss work or school because of a child’s illness? What are the costs for unnecessary emergency services? What are the costs when a patient misses an appointment because they don’t have reliable transportation? The truth is, there is a cost to our communities when these factors compound. What we can no longer afford is inaction — our children’s future depends on it.

SHIFTING TOWARD VALUE-BASED CARE

Nemours’ commitment — in communities where it has a physical presence and beyond — is to be an important leader in designing the future of caring for children. To create and sustain a future of systematic value, Nemours will dig even deeper into its work to:

• improve health outcomes;
• advance quality of care;
• increase accessibility of care;
• address social determinants of health;
• enhance quality of life; and
• reduce health care costs.

VALUE-BASED SERVICES ORGANIZATION LAUNCHES IN DELAWARE

Conceptualized in 2017 and finalized in 2018, infrastructure has been solidified by Nemours to support its move toward value-based care. The Nemours Value-Based Services Organization (VBSO) combines both new and existing competencies for the medical home, analytics, medical management, population health and clinically integrated networks.

The VBSO is built on Nemours’ successful practices. This includes mastery of the medical home throughout its primary care network; the extensive data capabilities of Nemours’ fully integrated electronic health record system; and more than a decade of promising practices in population health. This is all combined with the collaborative spirit among pediatric and adult providers, community health workers, school districts and other partners.

The state of Delaware is a unique environment with increasing readiness to move in more progressive ways toward value-based care. With 200,000 children, half of whom are covered by Medicaid, Delaware is indicative of many states across the U.S. Nemours will share its learnings — both pitfalls and best practices — as the shift to value becomes a reality.
CREATING GREATER VALUE FOR FAMILIES

Nemours VBSO team members, along with collaborators from the Nemours Office of Health Equity & Inclusion and operations areas across the enterprise, kicked off a project focused on the development of a standard Social Determinants of Health Screening Tool that could be used to gather information on non-medical patient needs across Nemours. The goal of the tool is to assess areas known to be critical to patient success and healthy living but often overlooked in the health care visit.

This pilot project consisted of identifying stakeholders across Nemours currently engaged in work addressing patients’ social needs.

Medical care represents less than 20 percent of the TOTALITY of a CHILD’S HEALTH. Complete health DEPENDS on a NUMBER OF FACTORS such as good NUTRITION, LITERACY, optimal EDUCATION, freedom from poverty, EQUITY and other factors.

identifying the domains of interest for a screening tool and selecting questions; administering 400 screeners (in English or Spanish) to patients in a variety of settings (emergency, specialty clinic, primary care and PICU); and conducting analysis on the results. In addition to the questions on the screener, families were asked how they felt about these questions — were they intrusive or personal? Did the role of the person asking the questions impact their level of comfort?

The VBSO team is finalizing analysis of the pilot data and working on a system-wide rollout for the screener and a repository of resources to which families can be referred, as needed.

SCHOOL-BASED WELLNESS EXPANDS

With a year under its belt, Delaware’s first elementary school-based health center has now become the state’s first Elementary Wellness Center system. At the start of the 2018-2019 school year, the partnership among Colonial School District’s Eisenberg Elementary School, The Life Health Center and Nemours expanded to four additional neighboring elementary schools (Pleasantville, Carrie Downie, New Castle and Wilmington Manor).

As a district composed of a largely underserved population, many families are uninsured, underinsured or have significant gaps in their health care coverage. All three partner organizations have deep ties to the community and are passionate about providing access to high-quality services to maximize the children’s opportunity for success. Approximately 25 percent of the Center enrollees report that they do not have a primary care provider. The most critical objective of the Wellness Center system is connecting students with primary care providers in the community to help them establish a medical home. Other objectives include acting as a source for referrals to outside medical care, specialty care or other comprehensive health services.

During the 2017-2018 school year, The Life Health Center’s dedicated social worker, child psychologist and therapist served 187 Eisenberg students during 3,290 behavioral health encounters. Early results indicate the model of prevention and early intervention is working. Compared to four years ago, there has been an increase in early identification of behavioral health concerns, and instances of student discipline issues have dropped dramatically at Eisenberg.

The number of children with six or more referrals dropped from 37 to nine.

Optimizing Health for All Children

Nemours National Office of Policy & Prevention has successfully competed for $35 million in grants over the last seven years to accelerate pediatric population health improvement and health system transformation. Most recently:

• Nemours was awarded a two-year, $500,000 grant from the Kresge Foundation to highlight effective networks for population health and clarify the roles and functions that hospitals and health systems play as integrator partners within such networks. Integrator Learning Labs will build upon the successful Policy Learning Lab model Nemours developed as part of its Moving Health Care Upstream initiative.

MEDICAL NEIGHBORHOOD

Informed by the 2017 assessment of the West Center City neighborhood in downtown Wilmington, Del., the Nemours Medical Neighborhood initiative kicked off across the state in 2018. The primary goal is to develop consistently documented profiles of each Nemours practice, its structure, and patient and neighborhood population demographics — ultimately, integrating both assets and needs. During 2018, members of the VBSO, primary care practices and data analytics teams designed and completed data collection for all 12 Nemours primary care practices in Delaware. These and other data sources will help inform decision-making to help Nemours hyper-localize efforts to improve total health.
PROMISE IN PRECISION

Affordable, quality genetic information will transform the way providers diagnose patients, develop and deliver targeted treatments, and help entire populations avoid, prevent or mitigate diseases. The degree to which investments are made in pediatric precision medicine — where it can bear the greatest impact over a lifetime — will forever alter health for generations to come.

CUSTOMIZING CARE, CHANGING LIVES

The Nemours Precision Medicine program leverages genetic screening and sequencing, genomics and bioinformatics, gene therapy research and pharmacogenetics to target specific genetic information about patients and their conditions. Together, physicians and researchers throughout Nemours are working to provide customized solutions to some of the most challenging pediatric diagnoses — and expediting those solutions from the bench to bedside. Benefits include:

- more efficient diagnoses
- more effective treatments
- fewer side effects
- reduced costs

ONCE THE LEADING GENETIC CAUSE OF DEATH IN INFANTS, SMA IS NOW A TREATABLE DISEASE

The successful collaboration between Richard Finkel, MD, chief of neurology, Nemours Children’s Hospital, and pharmaceutical companies changed the life-limiting trajectory for children diagnosed with spinal muscular atrophy (SMA), a genetic disorder affecting voluntary muscle movement. Nusinersen (a.k.a. Spinraza®), the FDA-approved drug proven to halt and reverse typical SMA disease progression, has shown such benefit that the FDA accelerated approval to include SMA in newborn screening.

So far, 17 U.S. states have added SMA to their newborn screening panels for early diagnosis and intervention with this life-saving treatment. Research shows that when the therapy is administered to very weak infants and children affected by SMA, it increases production of a critical motor neuron maintenance protein, effectively inhibiting the progression of SMA, increasing the chance of survival and even leading to improvement in muscle function.

Astoundingly, pre-symptomatic newborns treated with Spinraza are often completely normal, suggesting that this therapy may allow children with SMA to grow up without experiencing the devastating effects of this disease.
A TRADITIONAL APPROACH TO MODERN MEDICINE
Imagine a place where patient care, community engagement and research are tightly integrated. A place where house calls are still commonplace, even as some of the most advanced work in genetic research is taking place. That place is Nemours Kinder Clinic — a community-based, patient-centered medical home serving medically complex children from the Amish Plain community of Delaware.

One such patient is Grace, who at two years old is reaching milestones that other family members sadly did not. Grace is part of a very small population born with a rare genetic disease called YARSopathy (seven known cases in the U.S.). Because of her cousins’ experiences, Nemours doctors were able to identify Grace’s YARS gene early on and have been able to keep her healthier as a result.

“Based on genetics of the Amish population, we know the exact genetic mutations; you can’t say that about diseases among the general population — yet,” says Michael D. Fox, MD, division chief of pediatric hematologic-oncology, Nemours Children’s Hospital.

Genetics Stewardship Program
Whether a child is born with medical issues or they develop over time, genetic testing can provide valuable insight. The Nemours Genetics Stewardship Program employs genetic counselors to ensure:
- appropriate tests are chosen based on the clinical features of the child;
- resulting reports are received by clinicians on a timely basis;
- care and treatment plans are developed based on test results;
- information is shared with families in a responsible manner; and
- guidance and coordination occur throughout the genetic testing process.

A personalized approach to treatment through PRECISION medicine truly EMBODIES the Nemours MISSION: involving the patient and the family in their care, for BETTER HEALTH outcomes.

A PARADIGM SHIFT FOR CANCER CARE
Tropomyosin receptor kinases (TRK) gene mutations can be common in pediatric cancers, especially treatment-resistant cancers. Previously, the only treatments for these cancers were chemotherapy, radiation, and, in some cases, surgery — all of which can have serious adverse effects. A targeted drug therapy, aimed at treating genetic mutations in the tumors (rather than risking “off-target” damage to normal cells), is offering new hope to children with these types of cancers.

The multicenter clinical trial was conducted at Nemours by Ramamoorthy Nagasubramanian, MD, division chief of pediatric hematology-oncology, Nemours Children’s Hospital. Designed to test the safety, dosing and effectiveness of the oral medication called larotrectinib (LOXO-101), the trial results are promising. More than 90 percent of the patients with solid TRK fusion-positive tumors in the trial showed sustained tumor regression.

Of further significance, LOXO-101 is being tested in children nearly simultaneously with adults. Typically, this type of pediatric research lags years behind adult research.

KIDS DESERVE BETTER
The survival rate for children with acute myeloid leukemia (AML) hovers around 60 percent.* With support from the Leukemia & Lymphoma Society, Nemours is determined to do better. Using 2,000 samples from more than 900 children with AML, researchers are studying gene mutations at diagnosis, remission and relapse. Applying predictive analytics, the goal is to understand genic events (that happen within the whole patient, not just the leukemia cells), define risk factors and better understand the components of relapse. The $1 million sequencing project will examine total body DNA and leukemia DNA. Using data, modeling and AI to identify similarities and differences, the team will also work to develop precisely targeted therapies for pediatric AML.

*Survival rate for most common pediatric cancers is 80%.
Rapid advancements in technology have been truly revolutionary in health care, enabling possibilities that were once only imagined. As technology has become more accessible, new products, applications and delivery methods help solve age-old challenges, create new opportunities to share knowledge and connect us in ways that are driving optimal health.

A BRIDGE TO BETTER HEALTH

NOT JUST FOR TECHNOLOGY’S SAKE

Beginning with physician order entry systems in the 1980s, Nemours has been on a steady journey toward the future. Its fully integrated electronic health record (EHR) system was deployed enterprise-wide nearly 20 years ago. Today, Nemours’ wealth of data coupled with early adoption of emerging technologies has had positive impacts on the health of children everywhere and earned HIMSS Stage 7 revalidation. Benefits of advancements include:

• efficient patient care
• improved public health
• reduced errors
• increased understanding
• decreased costs
• reduced wait times
• improved access
• better communication

KEEPING COMPLEX CARE CLOSER TO HOME

For children facing very complex or life-limiting conditions, attending doctors’ visits is not only challenging for families, but can be risky for patients. With a focus on quality of life, the Nemours Medically Complex Coordination Clinic (MCCC) at Nemours Children’s Hospital helps to supplement the primary care of more than 170 medically fragile patients. These are patients who rely on assistive/adaptive medical technology and have other special medical needs due to causes like rare genetic syndromes or neurologic diseases.

The MCCC has started to use telehealth to eliminate unnecessary travel for families, many of whom live in different cities throughout Florida. “Our team has started to offer and perform follow-up visits via telehealth, including me, the nurse practitioner, nutritionist and health coach,” says Amber Hoffman, MD, director, MCCC. “These visits can include reviewing subspecialty recommendations, test results, checking in on the care plan, addressing new health concerns, and just being the listening ear that is not always possible during a regular doctor’s visit.”

EXPANDING TELEHEALTH

Deployed in 2014, Nemours CareConnect has expanded in use and benefit to patients, families, providers, students and educators. In 2018, Nemours was awarded the American Telehealth Association’s President’s Award for Health Delivery Innovation.

NICU/PICU/EO Consults in Collaborating Hospitals
First Pediatric 24/7, On-Demand, Direct-to-Consumer Urgent Care
Participant Screening for Research Studies
First School-Based Partnership
Specialty Care Access in Primary Care
Cruise Ship Consults and Pediatric Training
Integration with mHealth and Remote Monitoring
Child Care-Based Pilot
Interdisciplinary Clinic Access
On-Field Ortho/Sports Medicine Consults
BUILDING CONNECTION TO IMPROVE COMPLIANCE

Kathryn Blake, PharmD, director, Nemours Center for Pharmacogenetics and Translational Research, was awarded a five-year, $3.74 million NIH R01 grant. The grant will study the combined effects of telehealth and remote monitoring on improving patients’ asthma medication adherence and health outcomes.

For all participants, the study will include remote sensors that attach to daily and emergency-use inhalers. Sensors will track patients’ usage through an app. Data will also be uploaded into a single, cloud-based platform that displays the total sum of medication use.

Half of the study participants will also be paired with a pharmacist to help them keep track of their health and medicine with interactions via smartphone. This will be key to studying the importance of continuity, convenience and context in helping patients better understand and control their condition.

“In addition to real-time data for the patient, our hope is that the interactions with the pharmacist provide better instruction and build relationships. From age 14 to 30 [the age of study participants], there is so much transition in life: high school to college, then starting a career and family… this is often where we see a breakdown in adherence for a variety of reasons,” explains Dr. Blake.

A prior study conducted by Dr. Blake used FaceTime to observe and triage to a telehealth visit or put on treatment for adolescent hypertension. If the child’s BP is out-of-range or abnormal, an alert is sent via in-basket and the patient is triaged to a telehealth visit or put on Nemours CareConnect.

Two new use cases for remote monitoring are now available for Nemours patients. For cardiac patients who have received an implanted device, the Nemours nurse practitioner is able to pull data directly from the Medtronic pacemaker, load it into Nemours’ EHR and conduct routine follow-ups with patients via Nemours CareConnect.

REMOTE MONITORING

Two new use cases for remote monitoring are now available for Nemours patients. For cardiac patients who have received an implanted device, the Nemours nurse practitioner is able to pull data directly from the Medtronic pacemaker, load it into Nemours’ EHR and conduct routine follow-ups with patients via Nemours CareConnect.

A more common monitoring device — a blood pressure (BP) monitor — is used to track twice-daily BP readings for Nemours’ nephrology patients being treated for adolescent hypertension. The data automatically uploads into the patients’ Nemours EHR. If the child’s BP is out-of-range or abnormal, an alert is sent via in-basket and the patient is triaged to a telehealth visit or put on the schedule for an in-person visit.

Technology is only the medium. The real OPPORTUNITY lies in innovation’s ability to build and DEEPEN RELATIONSHIPS — “personable” medicine.

Nemours’ success and leadership in telehealth to convene national leaders, advocate for increased access, and help others identify barriers and accelerators.

• Co-hosted a pediatric health policy conference focused on expanding access to telehealth programs in schools and child care resulting in Roadmap for Action; see p. 15.
• Successfully advocated for language in bills relevant to telehealth, including provisions requiring guidance and studies related to Medicaid payment for substance use disorder treatment via school-based telehealth.

AUGMENTED REALITY: REAL-WORLD RELATIONSHIPS

Being hospitalized can be isolating for children. Medical complexities and equipment can make moving difficult or impossible; immune systems depressed by chemotherapy can make social contact dangerous. Nemours is leveraging virtual reality (VR) to improve the lives of children facing these circumstances.

With support from a top developer of multiplayer video games, Nemours hopes to connect kids in new ways. “We are developing apps that enable kids to pick their own avatar. If they want to look like themselves, we actually have a surface scanner to do that. With VR, kids can see each other and interact; they can play games together, hopefully making their very difficult experience a little bit better,” says Craig Johnson, DO, chair, medical imaging.

The VR applications are also expected to assist children with rare diseases in developing personal connections with others who share those conditions, better facilitate group therapy opportunities and expand education options.
Whether leading change or leading the charge, preparation is key to reaching full potential. Nemours’ pursuit of better health for every child ranges from the importance of education to a child’s future health status, to the opportunity to educate those who impact children’s health. Critical to progress is the desire to never stop learning and the willingness to share knowledge gained to ensure equitable success for all children.

HELP ME GROW UP HEALTHY

Formalized programs throughout Nemours focus on continuing education to benefit better child health outcomes. This transfer of knowledge occurs within the walls of Nemours locations and beyond to early child care professionals, educators, coaches, community and emergency providers, and more — any and all who aspire to help children grow up healthy.

GETTING SICK SHOULDN’T MEAN BEING LEFT BEHIND

What began as a research project to study how children with complex medical issues learn math resulted in PedsAcademy at Nemours Children’s Hospital (NCH) — the world’s first hospital-based “precision education” curriculum.

Through a partnership between Nemours and the University of Central Florida (UCF), faculty and students facilitate research-supported educational practices that are personalized for specific diseases and conditions. Technologies such as robotics and virtual reality along with other creative approaches to STEM learning are provided to NCH patients by a team of 54 UCF-affiliated students and faculty. The ability-informed curricula are keeping kids engaged and on track academically with their peers. The lessons have also been shown to boost socio-emotional health, engage movement to support disease states and improve cognitive function.

PedsAcademy is not just teaching children, it’s also introducing new methodologies to educators and creating opportunities to conduct important educational research for children with diverse needs. In addition to supporting inpatients, PedsAcademy delivers lessons to children who are at the hospital for hours-long infusions or waiting between multiple appointments. “It became my life’s passion when I realized these children do not receive equitable education. We’ve created a model that’s replicable at all children’s hospitals. We can truly do meaningful educational activities with every child, every day at Nemours,” says Megan Nickels, PhD, faculty director, PedsAcademy.

EQUITABLE & INCLUSIVE

Nemours Office of Health Equity & Inclusion works to ensure the highest levels of care and respect for all patients, families and communities through six core functions:

- Quality
- Cultural Competence
- Community Engagement
- Workforce Diversity
- Language Proficient & Health Care Literacy
- National Leadership in Healthcare Equity Research

Associate Resource Groups help educate, inform and tackle issues that affect representative demographics:

- Adelante
- African Heritage
- Nemours Pride
- Women Leaders

Pipeline Programs support underrepresented minorities in learning about or moving toward careers in health care:

- High School Students STEM Up Delaware
- Health Equity Summer Scholars Program
- Pre-/Post-Doctoral Fellowship
- Under-Represented Minorities Visiting Pediatric Scholars Program
“It is the aim of this Culinary Medicine course that these new physicians will incorporate nutrition knowledge and communication skills learned during this course into their daily medical practice, wherever their professional lives may take them,” says Rob Karch, MD, MPH, FACP, director, Culinary Medicine elective, UCF College of Medicine, and pediatrician, Nemours Children’s Specialty Care, Orlando.

A POWERFUL TRIAD FOR HEALTH: MD, RD & CHEF

Diet plays a critical role in preventing and managing disease. But for most physicians, education about diet is limited to basic nutrition courses in medical school. An interprofessional educational program among the University of Central Florida (UCF) College of Medicine, UCF Rosen College of Hospitality Management and Nemours is offering a Culinary Medicine elective that gets medical students on the farm, in the grocery store, behind the stove and out in the community. Didactic modules coupled with instruction from registered dieticians (RDs) and chefs help future physicians develop communication skills around nutrition and healthy eating concepts with their patients, so families can more effectively incorporate this knowledge and skill base into their daily lives.

The eight-week course, based on curriculum developed at the Goldring Center for Culinary Medicine at Tulane University, is focused on heart-disease prevention and management, and incorporates communication skills learned during the residency program.

Pediatricians will work with the CDC and early childhood literacy curriculum, Navigating the Health Care System; now live in eight states and adapted as a college course.

Advancing Education

Nemours National Office advocates for funding and spreads and scales promising practices that help to educate those who care for children.

- Partnered with other children’s hospitals across the U.S. to secure a $10 million increase for Children’s Hospitals Graduate Medical Education

- Secured language in signed FY 2019 omnibus appropriations bill to fund new work with the CDC and early childhood education providers

- Worked to spread and scale nationally the Nemours-developed adolescent health literacy curriculum, Navigating the Health Care System; now live in eight states and adapted as a college course

LEARNING HEALTH SYSTEMS SCHOLARS

For the next two years, two Nemours junior faculty will be dedicated to studying pediatric learning health systems (LHS) research as PEDSnet Scholars. Corrina Schultz, MD, Nemours hematologist/oncologist, and Erica Sood, PhD, Nemours psychologist, were selected as part of the K12 career development grant.

There is still so much LEARNING to be realized in pediatric health. DIVERSE REPRESENTATION across educational avenues including medical, research, social, policy and more, will be KEY TO ensuring EQUITABLE IMPACT and return on investment for all children.

NCH RESIDENCY

The pediatric residency program at Nemours Children’s Hospital (NCH) will prepare the next generation of exceptional leaders in pediatric health. After receiving ACGME institutional accreditation, NCH’s first residents are set to begin in July 2019. More than 1,200 students applied and 186 were interviewed for the 12 program openings. One distinguishing factor for the Nemours residency is the requirement of a research project as part of the three-year curriculum. The research mandate encourages residents to reach beyond clinical excellence to actively advance pediatric medicine. “It’s about much more than the residents in the program; it’s really what it means to the future of pediatric health,” says Heather Fagan, MD, Nemours’ designated institute official.

FUT U R E  F O R W A R D

The inaugural Match Day at Nemours Children’s Hospital (NCH) welcomed 12 medical students that will be part of its first resident class.

2018 REPORT TO OUR COMMUNITIES
AN EYE TOWARD TOMORROW

Through outreach and assessment, Nemours is able to gauge the current and impending health needs of children. Through investments in research and discovery, Nemours is part of innovative collaborations, finding new ways to solve challenges. By attracting and retaining some of the world’s top pediatric specialists, Nemours enables patients to benefit from new techniques and next-generation technologies. Nemours will continue to be an active participant in shaping the future of children’s health — today and for the tomorrows yet to come.

THE FUTURE IS NOW

To fully realize a healthy future state, Nemours, along with its collaborators, must continue to bring child health to the forefront — through innovations, advocacy, investment and education. By working together toward common goals, progress toward better health for all children will occur more consistently and rapidly.

GETTING AHEAD OF A STEEP CURVE

It is estimated that an infant experiencing neonatal abstinence syndrome is born every 15 minutes in the U.S. While these newborns are carefully monitored shortly after birth, much is unknown about longitudinal health outcomes once they transition home. For mothers with opioid use disorder, many challenges threaten engagement in pediatric primary care, including stigma, child custody concerns, housing instability and mental health issues. Gaps in knowledge persist as to the adequacy of well child care (WCC) for these children.

Neera Goyal, MD, general pediatrician and researcher at Nemours, has focused her research on optimizing pediatric primary care for mothers and infants affected by substance abuse disorders. Recently, Dr. Goyal was awarded an ACCEL pilot grant funded by the Delaware Center for Translational Research Program along with supplemental funding from the National Institutes of Health.

This study will review PEDSnet data from 35 Nemours primary care sites across three states for children born between 2011 and 2016. Specifically, the study will look at 1) the receipt of recommended WCC visits, frequency of visits and usage of opioids during primary care; 2) diagnoses during primary care, developmental delays or other conditions requiring specialty care; and 3) weight-gain patterns.

The results will be used to inform the design and implementation of a large scale, national study using PEDSnet data from all eight participating institutions. Further research may also focus on specific interventions to address barriers to primary care for these families.
A COMMUNITY-DRIVEN INVESTMENT

Emotional and behavioral health are critical components of a child’s development. Addressing these concerns as early as possible results in better adjustment and long-term outcomes. A 2016 Community Health Needs Assessment conducted by Nemours identified child mental health services as one of the biggest needs across the Delaware Valley. Committed to improving access, Nemours has hired more than 25 pediatric psychologists, psychiatrists and therapists during the last two years. These behavioral health professionals have integrated their services within all Nemours specialties, and a child psychologist is now embedded in every Nemours primary care location. Nemours is able to ensure that the mental, emotional and social needs of all children and families are being identified and addressed quickly.

The number of children on the autism spectrum has increased 100 percent in the last decade. Today, Nemours/ Alfred I. duPont Hospital for Children (N/AIDHC) cares for nearly 2,000 children and teens with autism, as well as conducts research, training and advocacy. During fall 2018, Nemours opened a new space dedicated to behavioral health, developmental medicine and its Swank Autism Center. The space, designed in partnership with families, houses the clinical specialists and features special therapy areas for eating and toileting, a family resources room, a variety of sensory-friendly waiting areas, observation galleries, a conference room for community collaborations, and an education suite for residents and fellows training in these specialties.

NEW PROMISE

Led by Allison Aguado, MD, Nemours interventional radiologist, a study published in the November 2018 issue of Pediatric Blood & Cancer finds the procedure known as TARE-Y90 (a novel, targeted radiation treatment) is a feasible option for children with liver cancer that is resistant to chemotherapy and cannot be removed surgically.

TARE-Y90 has been shown effective in treating the most challenging liver cancer. It is also less toxic than current options and could facilitate a cure. The multidisciplinary Liver Tumor Treatment Team at Nemours will be investigating how TARE-Y90 can be introduced earlier, with chemotherapy to help reduce tumor size, providing better surgical treatment options and improved prognosis.

HOPE INCHES CLOSER FOR CHILDREN WITH T1D

On average, children with type 1 diabetes (T1D) check their blood sugar 10 times a day. That means families have increased responsibility and usually less sleep. With the goal of dramatically changing the standard of care for diabetes, the Nemours endocrinology team in Jacksonville, Fla., has been deeply involved with clinical research.

Last summer, investigators at the Nemours Children’s Health System in Jacksonville, led by Dr. Nelly Mauras, local principal investigator, enrolled children in an NIH-funded clinical trial for the iLet® — a novel closed-loop insulin delivery system that delivers insulin based on the speed of rise and fall of blood sugars, i.e., an artificial pancreas. Nemours was just one of four trial sites in the U.S. and the only site for participants aged 6 to 11 with T1D. The iLet device, designed by Dr. Ed Damiano from Boston University, combines the functions of a continuous glucose monitor and insulin pump, and “learns” the patterns of the wearer’s blood sugar levels to continuously adjust and predict future fluctuations. The iLet operates autonomously, but shares data with children, parents and the clinical team via Bluetooth technology to ensure efficient monitoring. The Nemours study was conducted as a “mini-camp” so all participants had similar activity levels over two weeks. Children were randomized to use the iLet for one week and rely on their usual care for the other week, to determine if the iLet provided better management of their condition. The device will be further refined and studied before it becomes available commercially.

PEDIATRIC MONEYBALL

In October 2018, Nemours convened more than 125 attendees from 70 leading organizations, including Abbott, Aetna, Reebok International, Child Care Aware, Kellogg Foundation, The Pew Charitable Trusts and The Urban Institute, for the inaugural Pediatric Moneyball conference in Washington, D.C.

• Keynote speakers Walter Isaacson and General Colin Powell, USA (Ret.) headlined the day-long conference that focused on the relationship between children’s health and America’s future as a global leader.
• Attendees explored the economics of pediatrics, effecting change through population health, and the challenges and opportunities for innovation in children’s health.

In addition to boosting PRESENT OUTCOMES for child health, we must anticipate FUTURE DEMANDS for care, services and capabilities if we are to REALIZE the potential for GENERATIONAL IMPACT.
2018 MILESTONES

Leukemia Research Foundation of Delaware pledges $1 million to Nemours Research

Nemours Achieves HIMSS Stage 7 Revalidation

NCH Begins Integrated Facility Design for 6th Floor Cardiac Center

Becker’s Hospital Review Names Nemours Among “150 Top Places to Work in Healthcare”

Nemours Institute for Clinical Excellence at N/AIDHC Receives 5-Year Accreditation by the Society for simulation in Healthcare

Nemours Children’s Specialty Care, Pensacola opens its new 33,000 SF facility at West Florida Healthcare

The Toy Foundation Awards Nemours a Second Grant of $425,000 for Trauma-Informed Care Research

N/AIDHC Ranks in Seven Specialties by U.S. News & World Report Including #6 in Orthopedics and #16 in Cancer

Nemours Joins NEURONext NIH Clinical Trial Network

Nemours Receives U.S. Surgeon General’s “Angels of Maria” Award for its Post-Hurricane Relief Efforts

Nemours Neuroscience Center at N/AIDHC Achieves Level 4 Status from the National Association of Epilepsy Centers

Nemours KidsHealth and the Michael Phelps Foundation Kick off a New Emotional Health Campaign

The Toy Foundation Awards Nemours a Second Grant of $425,000 for Trauma-Informed Care Research

N/AIDHC Ranks in Seven Specialties by U.S. News & World Report Including #6 in Orthopedics and #16 in Cancer

Nemours Joins NEURONext NIH Clinical Trial Network

Nemours Receives U.S. Surgeon General’s “Angels of Maria” Award for its Post-Hurricane Relief Efforts

Nemours Neuroscience Center at N/AIDHC Achieves Level 4 Status from the National Association of Epilepsy Centers

Nemours KidsHealth and the Michael Phelps Foundation Kick off a New Emotional Health Campaign

Nemours Study on Blood Test to Predict Spastic Cerebral Palsy Published in Peer-Reviewed Journal BMC Bioinformatics

NCH Scores “Top of Class” in The Joint Commission Survey/On-Site Visit

Nemours-LED PEDSnet Study Shows Link Between Obesitv and Asthma in Children

Study Shows Nemours-Developed Model Helps Kids on Autism Spectrum Avoid Behavioral Drugs in the ER

R. Lawrence Moss, MD, Begins Tenure as President & CEO of Nemours Children’s Health System

Nemours-Led PEDSnet Study Shows Link Between Obesitv and Asthma in Children

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Study Shows Nemours-Developed Model Helps Kids on Autism Spectrum Avoid Behavioral Drugs in the ER
2018 COMMUNITY BENEFIT

$195.9 MILLION

$149.0 MILLION

UNCOMPENSATED MEDICAL CARE

SUBSIDIZED HEALTH SERVICES

RESEARCH

EDUCATION & TRAINING OF HEALTH PROFESSIONALS

PREVENTION & INFLUENCING CHILDREN'S HEALTH

$4.3 MILLION

$23.6 MILLION

$4.0 MILLION

$15.0 MILLION

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.

UNCOMPENSATED MEDICAL CARE: $149.0 MILLION

Uncompensated medical care includes health care services without a direct source of payment. In 2018, total uncompensated medical care provided by Nemours included:

- $13.2 million in services classified as "charity care" where the recipient could not afford services or lacked adequate health insurance
- $97.4 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
- $38.4 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: $4.3 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 2018, Nemours SeniorCare provided outpatient services to 6,431 Delaware seniors. The program also completed its fifth year of partnership with the St. Francis LIFE program. Nemours SeniorCare made progress on the planning and construction of a new facility in southern Delaware. Services will relocate to that site by early 2020.

RESEARCH: $23.6 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:

- 620 funded research projects and clinical trials
- 100+ Nemours physician-scientists
- 28 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: $4.0 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 2018, Nemours hosted:

- 798 residents
- 1,042 medical students
- 92 physician fellows
- 2,318 allied health professionals

The online presence of Nemours Continuing Medical Education continues to grow through NemoursEducation.org, with more than 100,000 registered users.
2018 VOLUNTEER IMPACT

Across Nemours Children’s Health System, more than 1,500 volunteers provided support to nearly every pediatric specialty during 2018. These dedicated individuals shared their time and talent in excess of 109,000 hours. Nemours extends a sincere thank you to all volunteers for bringing joy, comfort, laughter and entertainment to children and families receiving care at Nemours.

CENTRAL FLORIDA VOLUNTEERS
465 volunteers | 45,000 hours of service | $1,111,050 monetary equivalent
30 animal-assisted activity teams | 408 infants comforted in our NICU/CICU by volunteer cuddlers
3,800 escorts from the surgical suites provided by Parental Presence volunteers

DELWARE VALLEY VOLUNTEERS
888 volunteers | 59,392 hours of service | $1,466,389 monetary equivalent
3,938 children read to in our waiting areas by Read Aloud volunteers
40 pet therapy teams | 2,856 NICU babies read to by Baby Bookworm volunteer readers | 6 clowns

NORTH FLORIDA VOLUNTEERS (JACKSONVILLE & PENSACOLA)
188 volunteers | 4,918 hours of service | $121,426 monetary equivalent
7 animal-assisted activity teams | 1,054 faces painted by 2 volunteer clowns

2018 DONOR IMPACT

$11.3 MILLION

Philanthropic gifts have a profound impact on the children and families Nemours serves. Donations help Nemours stay on the leading edge of patient care, research and education. In 2018, Nemours Fund for Children’s Health received nearly $11.3 million in gifts from 6,532 generous donors across the U.S.

Where 2018 Donations Came From

How Funds Were Distributed in 2018

<table>
<thead>
<tr>
<th>PURPOSE</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>CAPITAL</td>
<td>61.3%</td>
</tr>
<tr>
<td>EDUCATION</td>
<td>1.7%</td>
</tr>
<tr>
<td>HEALTH CARE</td>
<td>9.8%</td>
</tr>
<tr>
<td>OPERATIONAL</td>
<td>14.5%</td>
</tr>
<tr>
<td>RESEARCH</td>
<td>12.7%</td>
</tr>
</tbody>
</table>
ACCELERATING NEMOURS’ EFFORTS TO HELP KIDS WITH CANCER

Across Nemours, the Center for Cancer & Blood Disorders (NCCBD) is experiencing tremendous strides in supporting children and families dealing with a diagnosis of pediatric cancer and continuously working toward a future without childhood cancer. From venture philanthropists and corporate and foundation partners to individual and community support — these investments are helping Nemours make rapid advances toward finding new treatments, minimizing side effects and improving quality of life through:

- pediatric cancer research
- advanced clinical care and therapies
- integrated psychosocial support
- family and supportive services

SO MUCH TO CELEBRATE, SO MUCH TO SUPPORT

The NCCBD is one of the nation’s largest pediatric hematology/oncology practices in the United States. With its membership in the Children’s Oncology Group, Nemours patients have access to the latest clinical trials and drug therapies. Strong investment from donors has helped Nemours acquire equipment and funded studies that are advancing testing, treatment and care for children battling cancer.

Working alongside other specialists throughout the Nemours health system, such as Nemours’ interventional radiology group, members of the NCCBD have been able to defeat cancerous tumors once indomitable. New procedures, such as the TARE-Y90 liver tumor treatment (see p. 23), that combine the expertise of these Nemours specialists are literally saving lives.

Finally, through its access to PEDSnet data, Nemours Bioinformatics teams and cancer researchers are working on exciting sequencing research to identify mutations and prevent relapses for survivors of certain types of cancer.

PRECISION MEDICINE

In 2018, the Lisa Dean Mossley Foundation announced two grants to two NCCBD research scientists in the amount of $2 million over five years. Both awards will support pediatric cancer research, in particular the use of stem cell therapy in the treatment of childhood leukemia.

“Precision medicine is reshaping the way we think about health, enabling us to tailor treatment to individual patients. At Nemours, we combine scientific discovery with studies to advance new approaches to care, and this very generous donation helps to accelerate our efforts,” says Nemours EVP and Chief Scientific Officer Mary M. Lee, MD.

RUNWAY TO HOPE: PROVIDING LIFTOFF

During the dedication ceremony (see right), co-founders of Runway to Hope Mark and Josie Nefjame announced a new $500,000 pledge to continue the fight against pediatric cancer. The funds will support Nemours’ efforts in precision medicine and the development of a Cancer Survivorship Program of Excellence — the first comprehensive program of its kind in the state of Florida. Additionally, funds will enable the purchase of new equipment and training for use of microwave ablation as a part of the Nemours pediatric interventional radiology program.

“Nemours leads all programs in the country in terms of the number of children we are enrolling in trials that are designed to reduce the symptoms and side effects of treatment. In looking at all that goes on behind the scenes to develop these trials, we could not do that without donor support. The supportive services that families need when children are going through treatment, including trials, cannot be provided without donor support.”

— E. Anders Kolb, MD, Director, Nemours Center for Cancer & Blood Disorders

Donors provide much-needed financial support for programming not typically covered by insurance. This includes programs such as music and art therapy, mental health counseling, support groups and child life services that help patients cope with their disease and are crucial to the healing process for the whole family.

At Nemours Children’s Specialty Care, Jacksonville, the Kent Lindsay Music Therapy Program and Child Cancer Fund child life specialist benefit 150 hematology/oncology patients each week. Each year, 85 child cancer patients receive psychology services thanks to support from the Tom Coughlin Jay Fund.

During the dedication ceremony (see right), co-founders of Runway to Hope Mark and Josie Nefjame announced a new $500,000 pledge to continue the fight against pediatric cancer. The funds will support Nemours’ efforts in precision medicine and the development of a Cancer Survivorship Program of Excellence — the first comprehensive program of its kind in the state of Florida. Additionally, funds will enable the purchase of new equipment and training for use of microwave ablation as a part of the Nemours pediatric interventional radiology program.

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During 2018, Nemours provided direct care and services to 470,000 children during 1.8 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 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, 2018* AND 2017

(Dollars in thousands)

<table>
<thead>
<tr>
<th></th>
<th>2018</th>
<th>2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>Net patient service revenue</td>
<td>$1,141,716</td>
<td>$1,054,919</td>
</tr>
<tr>
<td>Contributions from the Alfred I. duPont Charitable Trust</td>
<td>176,709</td>
<td>162,040</td>
</tr>
<tr>
<td>Other income</td>
<td>96,099</td>
<td>100,198</td>
</tr>
<tr>
<td>Total revenue and other support</td>
<td>1,414,524</td>
<td>1,317,157</td>
</tr>
<tr>
<td>Total operating expenses</td>
<td>1,347,262</td>
<td>1,258,392</td>
</tr>
<tr>
<td>Operating income</td>
<td>67,262</td>
<td>58,765</td>
</tr>
<tr>
<td>Nonoperating gains (losses), net</td>
<td>4,596</td>
<td>—</td>
</tr>
<tr>
<td>Gain on bond defeasance</td>
<td>7,454</td>
<td>(1,967)</td>
</tr>
<tr>
<td>Net periodic benefit cost, net of service cost</td>
<td>79,312</td>
<td>56,798</td>
</tr>
<tr>
<td>Excess of revenues and gains over expenses</td>
<td>79,312</td>
<td>56,798</td>
</tr>
<tr>
<td>Net assets released from restrictions used for capital purchases</td>
<td>3,512</td>
<td>3,059</td>
</tr>
<tr>
<td>Pension-related changes other than net periodic pension cost</td>
<td>4,833</td>
<td>(38,991)</td>
</tr>
<tr>
<td>Increase in assets without donor restrictions</td>
<td>$87,657</td>
<td>$20,866</td>
</tr>
</tbody>
</table>

THE NEMOURS FOUNDATION
CONDENSED COMBINED BALANCE SHEETS
DECEMBER 31, 2018* AND 2017

(Dollars in thousands)

<table>
<thead>
<tr>
<th></th>
<th>2018</th>
<th>2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>Current assets</td>
<td>$562,333</td>
<td>$536,308</td>
</tr>
<tr>
<td>Non-current assets</td>
<td>1,292,467</td>
<td>1,263,219</td>
</tr>
<tr>
<td><strong>Total assets without donor restrictions</strong></td>
<td><strong>1,854,800</strong></td>
<td><strong>1,799,527</strong></td>
</tr>
<tr>
<td>Restricted assets</td>
<td>222,906</td>
<td>240,734</td>
</tr>
<tr>
<td><strong>Total assets</strong></td>
<td><strong>2,077,706</strong></td>
<td><strong>2,040,261</strong></td>
</tr>
<tr>
<td><strong>Liabilities and Net Assets</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Current liabilities</td>
<td>$200,830</td>
<td>$190,762</td>
</tr>
<tr>
<td>Non-current liabilities</td>
<td>638,913</td>
<td>681,365</td>
</tr>
<tr>
<td><strong>Total liabilities</strong></td>
<td><strong>839,743</strong></td>
<td><strong>872,127</strong></td>
</tr>
<tr>
<td>Net assets:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Without donor restrictions</td>
<td>$1,015,057</td>
<td>$927,400</td>
</tr>
<tr>
<td>With donor restrictions</td>
<td>222,906</td>
<td>240,734</td>
</tr>
<tr>
<td><strong>Total net assets</strong></td>
<td><strong>1,237,963</strong></td>
<td><strong>1,168,134</strong></td>
</tr>
<tr>
<td></td>
<td><strong>$2,077,706</strong></td>
<td><strong>$2,040,261</strong></td>
</tr>
</tbody>
</table>

*Unaudited
2018 GOVERNANCE

Governance for The Nemours Foundation is composed of a group 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.

THE NEMOURS FOUNDATION BOARD OF DIRECTORS

BOARD OF DIRECTORS
Brian P. Anderson
Chair
Jane Cavalier
Richard T. Christopher
Claire M. DeMatteis, Esq.
Rosa B. Hekala
Robert G. Riney
Vice Chair
James S. Hunt
Toni Jennings
Terri L. Kelly
J. Michael McGinnis, MD, MPP
Valerie Montgomery Rice, MD*
Linda D. Norman, DSN, RN, FAAN
Marcus F. Probst*
*Not pictured

THE NEMOURS FOUNDATION BOARDS OF MANAGERS

BOARD OF MANAGERS, DELAWARE
Richard T. Christopher
Chair
Catherine M. Bonuccelli, MD
William Dugdale
Hinton J. Lucas, Jr.
Gina F. Ward

BOARD OF MANAGERS, FLORIDA
Matthew Certo
Chair
Hugh M. Brown*
Catherine Brown-Butler*
David A. Disney
J. Malcolm Jones, Jr.*
Toni Jennings*
(Board Liaison)
Andrea Massey-Farrell
Joseph Terry
Dora Canasova Toro
Judy Wall, MD
Richard J. Walsh
Robert K. Wilson, Jr., MD
*(Not pictured)

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Wherever Nemours is, all of Nemours is. The spirit of our promise: to do whatever it takes to help each child grow up healthy and reach his or her full potential extends beyond the walls of our physical locations. Our promise addresses all factors affecting health — physical, emotional, educational and social. And the dedication to our promise by more than 8,000 Nemours Associates is what will connect today’s children to a healthier tomorrow.