# Nemours Research Annual Report

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Introduction

In 2016, the Nemours Children’s Health System embraced the promise of precision medicine. Children, after all, represent our future and should be the primary beneficiaries of scientific and medical breakthroughs. Precision medicine takes into account all the things that make us different – our genetic background, lifestyle and the environment in which we live – and uses those factors to create the most effective plan of care for the patient. More than a technique, precision medicine is a movement for understanding, diagnosing, managing and treating pediatric disease – throughout a child’s early life, and into adulthood.

Precision medicine is especially important when it comes to rare diseases, because it improves health care providers’ ability to reach a precise diagnosis, recommend the best plan of care and spare the child any unnecessary therapies. Treatment for diseases like pediatric cancer can also be greatly improved with precision medicine. The type of tumor or cancer each child has, along with their unique genetic makeup, not only guides treatment but also helps physicians to more accurately predict which cancers are likely to resurface in a patient, and which will go into remission.

Examples of bench-to-bedside precision medicine efforts abound throughout Nemours as our research teams find new diagnostic techniques, integrate clinical and genomic data to develop predictive modeling, and use next generation sequencing to help children with neuromuscular disorders, cerebral palsy, sickle cell disease, kidney disease and many other conditions.

Nemours Children’s Health System is one of the few organizations in the United States with the capability to collect genetic data from children and then use that data to guide treatment decisions. We believe that a personalized approach to treatment through precision medicine truly embodies our mission: involving the patient and the family in their care, for better health outcomes.

Vicky Funanage, PhD
Operational Vice President, Nemours Biomedical Research
The Gift of Research – Asher’s Journey
By Richard S. Finkel, MD

Asher stared back at me, unaware that he had a serious illness and was about to begin a journey of experimental treatment, the outcome of which I was unable to predict. What I did know was that, without treatment, he was destined to die young and that his life would be extended only by artificial means – external feeding and breathing support. This beautiful 6-month-old boy was full of emotional energy but so weak that he could not sit or hold his head steady, lift his legs or roll over. He was born in seemingly perfect health but at about the five-month mark had lost strength and head control.

Asher had been diagnosed with spinal muscular atrophy (SMA), a rare genetic disorder that leads to premature deterioration of nerve cells in the spinal cord and results in progressive muscle atrophy and eventual failure of the muscles necessary for feeding and breathing. SMA is a cruel disease. The brain is spared and these children mature normally in their cognition and emotional development as their muscles wither. As recently as 20 years ago, many neurologists sent these babies home with their distraught parents, with instructions only to keep them comfortable and await a certain death. More recent advances in medical management have enabled children with SMA to survive with feeding tubes and noninvasive ventilatory support. The home becomes a mini-ICU and the parents learn to provide sophisticated medical support. Even with prolonged survival, these children would have no chance of improvement in muscle function. Motor development rarely progressed beyond that present at the time of diagnosis.

The world of SMA changed in 1995 with the discovery of the causative Survival Motor Neuron 1 (SMN) gene. This allowed physicians to definitively diagnose SMA without resorting to painful EMG testing or muscle biopsy. Parents could then be counseled about the recurrence risk with a future pregnancy (25 percent) and babies at risk for SMA can be diagnosed even before symptoms arise. Further advances in the understanding of the genetic basis of SMA identified a “backup” copy of the SMN gene called SMN2, which is not quite identical to SMN1 and does not function as well. This gene is typically silent in the background, but in a patient with SMA, who lacks SMN1, there is total dependence upon SMN2 for survival. Scientists have labored the past two decades to devise strategies to replace SMN1 or modify SMN2 so that it functions more efficiently.

Asher was fortunate to be born at a time and place where he was eligible to participate in a clinical trial of a new, experimental treatment for SMA. The drug, nusinersen, is unusual in that it is a small string of DNA that is designed to attach to a specific site on the SMN2 gene and render it more efficient in making the protein that is deficient in the nerve cells in SMA. This is termed a “splicing modifier” drug. Asher did not seem to care. His parents were understandably anxious and afraid yet eager to proceed with the one treatment that showed promise in SMA mouse models. The parents and I were both concerned about the multiple spinal taps necessary to administer the drug into the spinal fluid, where it then gets absorbed into the target nerve cells in the spinal cord. How would he tolerate the procedures? What can we expect as a response to the drug – stabilization, slowing of the rate of decline, or beyond all hope, the prospect of actually regaining lost strength and making gains in motor function? I did not have these answers and did not know how safe the drug would prove. But Asher looked back at me with his pure smile and intense gaze that he was ready to proceed as a pioneer in SMA research.
Asher’s journey with experimental treatment started three years ago. He is now a rambunctious little boy, full of mischief. He is sitting, rolling and beginning to walk with support. Feeding and breathing have remained secure; he has never needed supplemental support. Over the years, as Asher has returned to Nemours for his treatment, I have gotten to know the entire family and value their devotion to him. Nemours has become a second family of sorts to Asher, providing physical and occupational therapy, nutritional counseling, and pulmonary and orthopedic care.

Asher is one of just nine infants with SMA who were treated at Nemours Children’s Hospital, along with 11 others at three other hospitals, as part of the Ionis-sponsored study of nusinersen. The patients came from across Florida and from four neighboring states. The results of the study were striking and reported in the prestigious medical journal, *Lancet*, in January 2017. This brought welcome attention to SMA and to Nemours Children’s Hospital. The U.S. FDA approved nusinersen for the treatment of SMA on December 23, 2016 – the first drug approval ever for this devastating disease.

We have now conducted five clinical trials in SMA using nusinersen, one of which involved treating infants under 6 weeks of age before they show any signs of weakness. Help from our interventional radiology group has been instrumental in getting these lumbar punctures done safely and effectively in tiny newborns. The clinical trials office has been most supportive of the studies, keeping five research study coordinators quite busy. I am forever grateful for the innumerable other means of support given this program by my physician and nurse colleagues, research pharmacist, physical therapists and administrative staff.

Other clinical trials for SMA will begin shortly at Nemours Children’s Hospital, including the first gene therapy study to be done here. Asher and his family continue to give me rewards that I could never have anticipated and provide hope that the best is yet to come.

Richard S. Finkel, MD
Dr. Finkel is chief of the division of neurology at Nemours Children’s Hospital, Orlando, Fla. He directs the neuromuscular program at Nemours where comprehensive diagnostic and treatment services are provided to Florida children. The clinic is supported by a generous grant from the Muscular Dystrophy Association. There are currently 12 clinical trials in progress at Nemours, funded by NIH, industry or foundation grants, exploring new treatments for nerve and muscle disorders. Dr. Finkel has contributed more than 100 published articles and book chapters on these topics. He is professor of neurology at the University of Central Florida College of Medicine.
Nemours by the Numbers

Total External Funding by Location

Active Funding Types by Location
Research Education

In 2016, there were 90 educational visitors to Nemours Biomedical Research. The highly competitive Nemours Summer Undergraduate Research Program (NSURP) reviewed 118 applications for 10 slots, representing an eight percent acceptance rate. There were nine Journal Clubs held for graduate students and faculty.

**Rare Disease Day 2016**, cosponsored by Nemours and Delaware HOSA-Future Health Professionals, featured a competitive event designed to encourage student engagement in research and innovation, and better awareness and understanding of rare diseases. Nine student teams from area high schools walked judges and visitors through a visual display about a specific rare disease and answered questions. Topics ranged from congenital heart disease and sickle cell disease to Rett syndrome and primordial dwarfism.

To prepare, the students researched their topics, interviewed a patient/family, and interviewed researchers, physicians and other providers. This year’s theme, *Patient Voice*, recognized the role patients play in shaping research efforts to improve their lives and the lives of their families and caretakers.

Nemours participated in the day-long Junior Achievement **STEM Summit** at Ephrata High School in Lancaster County, Pa. The regional summit's focus is on helping students explore STEM careers. Nemours faculty also served as judges at the 2016 Delaware Technical and Community College Science Fair.

The **Nemours lecture series on pediatric research** is a shared venture across the enterprise with each site hosting lectures, and all programs broadcast throughout Nemours and Thomas Jefferson University via webex. In 2016, 30 lectures were delivered by 23 invited speakers and seven Nemours speakers.
Grant Awards

Thao-Ly Phan, MD, Division of Weight Management, and assistant research scientist, Center for Healthcare Delivery Science, secured a five-year NIH K23 Mentored Patient-Oriented Research Award. Her study, “Integrating Parenting Interventions into Pediatric Obesity Care,” aims to develop innovative obesity approaches that address health care disparities and leverage the use of health information technology. Dr. Phan will develop a series of brief, tailored, culturally sensitive videos to provide guidance on the use of evidence-based parenting techniques for managing a child's obesity-related behaviors, incorporating qualitative feedback from parents during the development process.

Melissa Alderfer, PhD, senior research scientist and her co-investigators, Matthew E. R. Butchbach, PhD, head of the Motor Neuron Diseases Research Laboratory, and Mena Scavina, DO, pediatric neurologist, received a one-year Clinical Care Pilot Award from Cure SMA for the research project, “Screening for Psychosocial Risk Among Families of Children with Spinal Muscular Atrophy.” Spinal muscular atrophy (SMA) poses significant challenges to families. Research documents that the burden of the disease is high and escalates throughout the child’s life as functional abilities decline and complications increase. The psychosocial needs of these families, however, are not systematically assessed, leading to gaps in the delivery of psychosocial care. The purpose of the funded research project is to develop a brief, standardized measure of family psychosocial risks and resources, tailored to the challenges and demands associated with SMA. This tool will eventually provide a way to screen families in an effective and inclusive manner, systematically identifying those in need so that appropriate psychosocial care can be provided.

Robert Olney, MD, Nemours Children’s Specialty Care, Jacksonville, Fla., and Michael Bober, MD, PhD, Nemours/Alfred I. duPont Hospital for Children, Wilmington, Del., co-principal investigators, received a $50,000 award from Growing Stronger, an organization affiliated with Little People of America. The award funds their project entitled “Survey of C-Type Natriuretic Peptide Levels in People with Skeletal Dysplasia.” C-type natriuretic peptide (CNP) stimulates chondrocyte differentiation and linear growth in growth plates. The research group led by Drs. Olney and Bober has previously shown that people with achondroplasia (the most common form of dwarfism) have an elevated blood level of CNP and its more easily detectable amino-terminal propeptide, NTproCNP, indicating CNP resistance. They are now interested in looking at other forms of dwarfism. Drs. Olney, Bober and their co-investigators are studying a cohort of patients with various skeletal dysplasias to determine whether there is any evidence of “alterations of the CNP regulatory pathway.” If there is, it suggests that CNP-analogs might be an option for treatment for these patients.
Nemours has been a participating center of the American Lung Association (ALA) Airways Clinical Research Centers network since 1999. These trials, funded by NIH and the pharmaceutical industry, have been published in many high-impact journals. The ALA had always been focused on asthma, but in 2015 decided to expand the scope of research to include other airway diseases beyond asthma, such as chronic obstructive lung disease (COPD), chronic airway diseases in children, and lung diseases as manifestations of other diseases such as sickle cell disease and AIDS. Kathryn Blake, PharmD, submitted a project on the treatment of asthma in children with co-incident sickle cell disease, and Dr. Jason Lang submitted a project focused on treatment of children who have a pediatric form of the asthma-COPD overlap syndrome known as ACOS. In 2016, Nemours was awarded $100,000 per year for five years to do this critical research. Nemours was the only site selected that does not also conduct research in adults, which is a testament to the recognition by the ALA and the external reviewers of the excellent scientific contributions that Nemours has made to the network over the past 16 years.

Divya Moodalbail, MD, Division of Nephrology, received a Young Investigator Grant Award from the National Kidney Foundation. The one-year, $40K grant supports her research on kidney disease in youth with sickle cell disease (SCD). Sickle cell disease is a chronic, debilitating, hereditary blood disorder seen in one in 300 African-Americans, associated with a variety of acute and chronic health problems, including increased risk for kidney disease, usually by the mid-20s. Early identification of youth with SCD at high risk for kidney disease is critical because available interventions can promote kidney health and reduce advanced kidney disease requiring dialysis or kidney transplant. Dr. Moodalbail is testing African-American youth with SCD for the presence of known variants of the apolipoprotein L1 (APOL1) gene that puts children at risk for kidney disease. Her hypothesis is that patients who have the APOL1 variants will also have elevated genetic laboratory markers for kidney disease. Those markers could then be used to develop more readily available early identification screening.

Judith L. Ross, MD, director of the duPont Hospital for Children EXtraordinarY Kids Clinic, was awarded a two-year R21 grant from the NIH for her project, “Structural and Functional Characteristics of XYY – Relationship to Autism Spectrum Disorder (ASD).” The study will evaluate boys from six to 16 years of age who have XYY syndrome, a genetic condition associated with an increased risk of ASD. There is a male preponderance in ASD, and this condition may be a contributing factor. Dr. Ross and colleagues will look specifically at the influence of the extra Y chromosome on cognitive-behavioral function and will compare the findings with reference data from children on the autism spectrum and from their neurotypical peers.

Meghan M. Lines, PhD, clinical director, psychology, duPont Hospital for Children, received grant renewal from the Health Research and Services Administration for her project, “Clinical Psychology Internship Training in Integrated Pediatric Primary Care.” The project seeks to give children in vulnerable populations more immediate access to psychological services by expanding psychologist diversity and workforce. The project places additional emphasis on training medical students and residents to identify pediatric emotional and behavioral issues so that they may give families advice about behavioral health and make referrals to behavioral health services.
Dr. Tariq Rahman, PhD, director, Center for Orthopedic Research and Development, duPont Hospital for Children, and co-principal investigator Thomas H. Shaffer, MSE, PhD, associate director, Nemours Biomedical Research, received funding from the Delaware Bioscience Center for Advanced Technology (CAT) for their proposal, “Noninvasive Respiratory Monitor.” The grant funds a clinical study using their prototype pneuRIP respiratory inductance plethysmography (RIP) system. The current RIP test uses outdated hardware, which does not provide real-time feedback, such as in the case of an asthma attack. Drs. Rahman and Shaffer, in collaboration with an electronics company, developed the pneuRIP unit as a compact, wireless alternative to the currently used hardware. It is capable of delivering RIP parameters wirelessly to an iPad. The ability to use a noninvasive, safe, low-energy, and real-time device in a clinical setting offers great advantages, such as securely transmitting data to the electronic medical record and immediate feedback. The study will assess breathing in patients in the muscle clinic under the supervision of Robert Heinle, MD, and Abigail Strang, MD, clinical collaborators on the project.

Erin L. Crowgey, PhD, associate director of bioinformatics, duPont Hospital for Children, has received CAT funding for her proposal, “Assessment of Epigenetic Signatures Associated with Cerebral Palsy,” with co-investigator Robert E. Akins, PhD, principal scientist and director, Center for Pediatric Clinical Research and Development, duPont Hospital for Children. Cerebral palsy (CP) refers to a group of movement disorders that occur as the result of an insult to the developing brain, generally between 24 weeks gestation and full term. As such, the disorder is present at birth, but often goes undiagnosed until a few years later, when movement problems are noted. Data have suggested that early intervention could allow individuals to overcome developmental disabilities associated with CP, but imaging techniques, including CT, MRI and ultrasound, have been unreliable for early diagnosis of CP. There are currently no assays for detecting biomarkers of CP for neonatal screening and early diagnosis. Drs. Crowgey and Akins are collaborating with others to analyze DNA methylation patterns in patients with CP with the goal of discovering novel epigenetic biomarkers that could be used for early detection of CP and/or in the design of new therapeutic and regenerative strategies.

The Center for Pharmacogenomics and Translational Research (John Lima, PharmD, Jim Franciosi, MD, and Kathryn Blake, PharmD, co-investigators) received funding in partnership with the University of Florida (UF) Health Personalized Medicine Program (lead site) from the National Institutes of Health National Human Genome Research Institute. The project will use longitudinal electronic health record (EHR) data to add to the body of evidence on PPI efficacy and safety by CYP2C19 genotype and to document the feasibility and potential clinical benefits of CYP2C19 genotype-supported PPI dosing. Nemours began using pharmacogenomics in 2016 to guide PPI dosing in children at Nemours Children’s Hospital in the project “Implementation of Pharmacogenomic Testing in Nemours Children’s Health System.” This funding expands the program within the Nemours Children’s Health System.
Laura Dewey, PhD, earned a DE-CTR ACCEL Community Engaged Research (ACE) award for her proposal, “Increasing Access to Empirically-Validated Interventions for Autism Spectrum Disorder: Dissemination of PEERS into Community Health Settings.” Dr. Dewey’s project aims to increase access to empirically-validated interventions for autism spectrum disorder in the community by disseminating a social skills group intervention called Program for the Education and Enrichment of Relational Skills (PEERS) — a 14-week manualized intervention — to community partners. The project will enable clinicians from DGS to receive training in PEERS and to hold two rounds of PEERS social skills groups in the community. The team will be measuring clinicians’ perception of receiving training and using PEERS, as well as measuring family outcomes regarding the child’s social skills, family quality of life, and caregiver stress.

Cheyenne Hughes-Reid, PhD, secured the 2016 Behavioral Health Workforce Education and Training (BHWET) for Paraprofessionals and Professionals award from the Health Resources and Services Administration’s (HRSA) Division of Nursing and Public Health. As a part of the U.S. Department of Health and Human Services, HRSA funds 34 new programs with trainees from multiple behavioral health disciplines, including paraprofessional certificate programs, master-level counseling programs, marriage and family therapy programs, and doctoral-level psychology internship programs. Their goal is to guarantee that Americans have access to quality mental health services. Dr. Hughes-Reid’s grant will be used to support this effort and to make advancements in the field of clinical psychology. The grant allows two new interns to join the already-existing APA-accredited Predoctoral Psychology Internship Program within the Division of Behavioral Health. The program provides training for students who wish to pursue careers in clinical practice and applied research. It offers broad-based training, exposing interns to a wide range of patients in pediatric psychology.
Judith Ross, MD, secured a $1.7M, four-year grant from the Eunice Kennedy Shriver National Institute of Child Health and Development to serve as PI for the duPont Hospital for Children site for the IDeA States Pediatric Clinical Trials Network (ISPCTN).

The ISPCTN represents a transformational opportunity to recruit more underserved children to participate in state-of-the-art clinical trials, facilitate implementation of well-designed pediatric clinical trials, and enhance pediatric clinical trial capacity within Delaware with the goal of improving public health in the state and the nation. Funding will also support professional development of faculty-level pediatricians and their support teams in the conduct of clinical trials research. Nemours/duPont Hospital for Children was one of 17 IDeA state sites selected to participate in this NIH Environmental Children’s Health Outcomes (ECHO) Initiative with a focus on factors that may influence health outcomes around the time of birth, as well as into later childhood and adolescence, including upper and lower airway health and development, obesity, and brain and nervous system development.
Vanessa Short, PhD, received a loan repayment award from the National Institutes of Health, one of only five extramural award recipients in 2016. The awards are based on an applicant’s potential to build and sustain a research career. The extramural award categories are clinical research, health disparities research, clinical research for individuals from disadvantaged backgrounds, pediatric research, and contraception and infertility research. Dr. Short applied for and received the pediatric research award, with the help of her mentor Diane J. Abatemarco, PhD, MSW.

The National Institutes of Health awarded the Delaware IDEA Network of Biomedical Research Excellence (INBRE) $522,000 to coordinate services between Delaware and Vermont core facilities. The funds will be used to purchase and implement iLab Solutions software in core facilities at Nemours/Alfred I. duPont Hospital for Children, University of Delaware, Delaware State University and the Christiana Care Health System. The effort will be headed by Katia Sol-Church, PhD, senior research scientist and director of the Biomolecular Core Laboratory and Central Research Instrumentation Core, in collaboration with Sean McSorley, core facility financial program manager, on iLab implementation across the network. The software will allow networking between Delaware and Vermont cores, linking three facilities in the Vermont Genetics Network with 13 facilities in the Delaware INBRE. Nemours sites that will be part of the new network include the Bioinformatics Core, directed by H. Timothy Bunnell, PhD; Cell Science Core, directed by Robert W. Mason, PhD; High-Throughput Screening/Drug Discovery Laboratory, directed by Andrew Napper, PhD; and the Histochemistry and Tissue Processing Laboratory, directed by Heather Hardy. The shared data will allow the cores to search for trends in operating expenses, funding support, revenue and services used.

AnneMarie Brescia, MD, Meg Simonds and Amanda Schleman, DO, of the Rheumatology Research Lab at duPont Hospital for Children received a two-year renewal grant from The Nancy Taylor Foundation for Chronic Diseases. The lab was approved for a project entitled “Prognostic Synovial Biomarkers in Juvenile Idiopathic Arthritis.” The lab has received continuous support for this work since 2010, first through The Arthritis Foundation, and then directly from The Nancy Taylor Foundation. The current grant for $200,000, in conjunction with Dr. Brescia’s NIH K23 career development award, will fund the ongoing project. The lab’s main focus is identifying synovial fluid biomarkers which will predict extension to polyarticular juvenile idiopathic arthritis (JIA). Though JIA is the most common pediatric rheumatic disease, reliable predictors of the disease course have yet to be identified. Early aggressive therapy may allow patients to achieve remission and avoid joint damage from the difficult course of JIA.
Honors and Recognition

Andrea Wrightson, RN, BSN, CPON, hematology/oncology clinical research nurse coordinator at duPont Hospital for Children, has been selected as study clinical research associate (CRA) on a national project, “Improving the Use of Evidence-Based Supportive Care Clinical Practice Guidelines in Pediatric Oncology.” This honor follows her work that established duPont Hospital for Children as a top accruing site for Cancer Control and Supportive Care (CCL) studies, presentations to the Children’s Oncology Group (COG), and contributions to Cancer Care Delivery Research (CCDR). Wrightson’s selection to oversee this first CCDR study concept enables Nemours’ participation in COG pediatric cancer research trials and expands treatment options for children in our care.

Christina Calamaro, PhD, CRNP, director of clinical and nursing research at duPont Hospital for Children, was appointed by the secretary of Health and Human Services (HHS) to the National Advisory Council for the Agency of Healthcare Research and Quality (AHRQ). The National Advisory Council provides advice and recommendations to AHRQ’s director and to the secretary of HHS on priorities for a national health services research agenda. Dr. Calamaro will serve on this 21-member panel for a three-year term. This panel is comprised of private-sector experts who contribute a diverse perspective on the health care system and the most important questions that AHRQ’s research should address to promote improvements in the quality, outcomes and cost-effectiveness of clinical practice. The members represent health care plans, providers, purchasers, consumers and researchers. Dr. Calamaro’s area of funded research is pediatric sleep, with a focus on the relationship between sleep and obesity. Additional research includes health outcomes in the primary care setting. She has published on issues related to obesity, sleep, cultural proficiency in research and quality, and safety of APRN care in the pediatric setting.

Michelle Littlefield, RN, BSN, clinical research nurse coordinator in the Center for Pharmacogenomics and Translational Research, was presented with a DAISY Award for Extraordinary Nurses in Jacksonville. She was nominated for the award by two colleagues. Littlefield was instrumental in the start-up of the AsthmaNet program, now conducting five studies in Jacksonville and Orlando. In her role as research coordinator, Littlefield recruits and enrolls study participants, schedules and conducts research visits, and manages large data sets. She is the primary coordinator contact for both Nemours sites. Littlefield has also been active in the leadership of Nemours Nursing Shared Governance as the research council chair. Michelle participated in planning the first two Nemours Pediatric Nursing Conferences for area nurses and organized the volunteers for the events. She is also involved in the preceptor program for nursing students. DAISY is an acronym for Diseases Attacking the Immune System. The DAISY Foundation was formed in 1999 and the DAISY Award for Extraordinary Nurses honors the superhuman work nurses do for patients and families every day.
Anne E. Kazak, PhD, ABPP, co-director of the Center of Healthcare Delivery Science, was presented the American Psychological Association (APA)’s Presidential Citation award for her prominent roles as a clinician, editor, researcher, educator and administrator. Her contributions to the medical field have helped to advance behavioral care for children and families. As co-director of the Center for Healthcare Delivery Science, Dr. Kazak studies what can affect a child’s health, including care, outcomes, quality, cost, safety and value. By learning how to more efficiently deliver treatment, the center strives to improve the health of both the child and the family. Dr. Kazak is a professor of pediatrics at Thomas Jefferson University’s Sidney Kimmel Medical College and an adjunct professor of psychology at the University of Delaware. Dr. Kazak serves as editor-in-chief of the APA publication *American Psychologist*. With her passion for psychology and health care delivery, Dr. Kazak is working to make this publication a platform for the betterment of public policy and human welfare.

Roger Berkow, MD, a pediatric hematologist/oncologist, was elected to serve on the editorial board of *Florida Pediatrician*, the official journal of the Florida Chapter of the American Academy of Pediatrics. Dr. Berkow assists in writing and reviewing articles to be published in the educational quarterly journal, which helps pediatricians improve the health and welfare of Florida’s children. Dr. Berkow joined Nemours Children’s Clinic, Pensacola (now Nemours Children’s Specialty Care, Pensacola), in 2014, where he serves as chair of medicine and as a pediatric hematology/oncology specialist.

Jessica S. Pierce, PhD, was appointed co-chair of the Diabetes Special Interest Group of the Society of Pediatric Psychology, serving from 2016 through 2018. Dr. Pierce is a psychologist with Nemours Children’s Specialty Care in Orlando, Fla. Her primary field of study concerns the interplay of psychology and medicine in order to help children and teens living with a chronic medical condition.

Stephen Lawless, MD, MBA, senior vice president and chief clinical officer, was named to *Becker’s Hospital Review’s* 2016 list of 50 Experts Leading the Field of Patient Safety. Dr. Lawless is recognized among clinicians, advocates and legislators who work to eliminate medical errors and improve safety in the industry. Experts were selected for the list based on editorial research and discretion.

Nelly Mauras, MD, was featured on *Healio.com* for her research on growth increase in boys with idiopathic short stature who were in puberty. Her work was presented at the Endocrine Society’s “ENDO2016” Meetings in Boston, Mass. Dr. Mauras’ study looked at the effects of intervention with either growth hormone (GH) alone, an aromatase inhibitor alone, or combination GH/aromatase inhibitor on linear growth in a group of 76 pubertal adolescent boys with significant short stature and no other pathology or hormone disorder. She and her colleagues found that the combination GH/aromatase inhibitor group had significantly more growth than the other two groups (P = 0.0002). This work was done in collaboration with Judith Ross, MD, in the Delaware Valley, Miles Yu, MD, in Orlando, and others.
Judith Ross, MD, accepted an invitation from the NIH Center for Scientific Review to serve on the Developmental Brain Disorders Study Section from 2016 through 2020. Study section members have demonstrated achievement in their field and are chosen on the merits of their scientific publications, activities and honors. They are charged with reviewing NIH grant applications and making recommendations on whether to fund those projects. The Developmental Brain Disorder Study Section is concerned with the genetic, metabolic, infectious, environmental and behavioral factors in the fetal, neonatal or pediatric brain that lead to abnormal brain development and function.

Matthew E. R. Butchbach, PhD, who heads the Motor Neuron Diseases Research Laboratory (MNDRL), received a highly competitive Young Investigator Award to attend the 6th Biennial National IDeA Symposium of Biomedical Research Excellence (NISBRE) in Washington, D.C. He gave an invited platform presentation on his group’s latest work on a drug discovery project with AurimMed Pharma, Inc., entitled “Identification of Novel Inducers of SMN2 Expression.” The project is supported by AurimMed Pharma, Inc., as well as the Center for Pediatric Research COBRE program (P30GM114736), in which Dr. Butchbach is a pilot investigator.

J. Atilio Canas, MD, Nemours Children’s Health System, Jacksonville, was promoted to associate professor of pediatrics at The Mayo Clinic College of Medicine. Dr. Canas is certified by the American Board of Pediatrics with a subspecialty certification in pediatric endocrinology. He is also medical director of the Adolescent Bariatric Center at Nemours Children’s Specialty Care and is part of the multidisciplinary Nemours/Wolfson Cardiometabolic and Bariatric Surgery Center. Dr. Canas has served as principal investigator for several studies. Published in Pediatric Diabetes, his multicenter clinical trial, “A Randomized, Double Blind, Placebo-Controlled Pilot Trial of the Safety and Efficacy of Atorvastatin in Children with Elevated Low-Density Lipoprotein Cholesterol (LDL-C) and Type 1 Diabetes,” evaluated 60 children with type 1 diabetes. The authors demonstrated that low-dose atorvastatin “lowered LDL-C, apoB, and atherogenic lipoprotein subparticles in children with [type 1 diabetes] and elevated LDL-C without worsening insulin resistance.”
Philanthropy

Piper’s Kidney Beans Foundation, started by Chris and Erin Lee of Wilmington, held its first BEANefit gala in May, raising more than $15,000 to enhance genetic testing capabilities at Nemours/Alfred I. duPont Hospital for Children. Piper Lee, whose father Chris donated a kidney to his daughter, represents the best of “bench to bedside” at Nemours. Piper’s rare form of kidney disease was diagnosed via genetic testing not easily available or affordable in the United States. The BEANefit and the Foundation are dedicated to advancing our work by bringing more laboratory testing resources related to kidney disease to Nemours.

Kathryn Blake, PharmD, and Robin Miller, MD, received the 2016 Unsung Hero Award from the William E. Proudford Sickle Cell Fund on behalf of “Clinical Research Teams” for the project “Molecular Phenotyping of Asthma in Sickle Cell Disease.” The William E. Proudford Sickle Cell Fund supports sickle cell awareness, education, state-of-the-art treatment and research to bring hope to families affected by sickle cell disease in Delaware and Maryland. Results of the project indicate that children with both asthma and sickle cell disease have a distinct molecular phenotype compared to children with sickle cell disease only and African-American children with asthma. The team is planning additional studies for this population of children with asthma and sickle cell disease. The Nemours sites in Jacksonville, Wilmington and Orlando contributed to the success of this project. The Nemours sickle cell team in Delaware has had a long-standing relationship with the William E. Proudford Sickle Cell Fund. The fund has contributed a $100,000 endowment in support of the Sickle Cell Center at Nemours/Alfred I. duPont Hospital for Children.

Nemours received a one-year grant from the Toy Industry Foundation for the project, “Trauma-Informed Care for Children and Families in Pediatric Health Care.” The project will explore the impact of trauma-informed patient care and the role of play in helping children and families heal and cope. Research findings will be used to develop an innovative, high-quality program using play materials and related resources designed to support and comfort children experiencing stress reactions due to life-threatening illness, injury or painful medical procedures. Anne Kazak, PhD, ABPP, co-director of the Nemours Center for Healthcare Delivery Science (CHDS), leads the project, in collaboration with Jen Sciolla, MS, of Child Life and Melissa Alderfer, PhD, of CHDS. The multiphase research will gather perspectives of patients and their families of diverse backgrounds as well as health care providers regarding the need for, and best ways to deliver, trauma-informed pediatric patient care — an approach that incorporates awareness of the potentially traumatic nature of medical events and aims to reduce or prevent traumatic stress reactions in children.
# Staff List

**RESEARCH FACULTY AND STAFF – DELAWARE VALLEY**

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<td>Sheeja Abraham, MD</td>
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Publications


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