Nemours Children's Health Secures $10.5 Million NIH Grant for Sickle Cell Research

Study Will Examine Effects of Stigma/Racism on SCD Care and Explore Ways to Help Patients Better Manage Their Condition

WILMINGTON, Del. (September 21, 2021) – Researchers at Nemours Children's Health, Delaware have received a $10.5 million National Institutes of Health (NIH) grant to support the Delaware Comprehensive Sickle Cell Research Program. The five-year award from the NIH Center of Biomedical Research Excellence (COBRE) will support clinical, translational, and psychosocial research in sickle cell disease (SCD).

The work will be led by a diverse team of clinician-scientists from Nemours, Christiana Care Health System, University of Delaware, and Delaware State University, with support from the Delaware IDeA network – a collaborative of Delaware academic, health care, and research institutions. The program will primarily focus on pediatric, adolescent and young adult patients with sickle cell disease.

Sickle cell (SCD) is a life-long disease. It is one of the most common inherited conditions in Black populations and is also more prevalent in Afro-Caribbean and Middle Eastern populations. Symptoms can include pain due to occlusion and damage of small blood vessels by sickle-shaped cells, as well as organ damage, stroke, fatigue, frequent infections, and slower-than-normal growth.

"Sickle cell disease begins manifesting at birth, so how we manage a two-year-old impacts their life when they're 40," said principal investigator Anders Kolb, MD, director of the Nemours Center for Cancer and Blood Disorders.

> *" One reason that sickle cell care has struggled relative to other pediatric diseases is in part because pain is one of its top symptoms, which can elicit a bias related to opioid seeking," said principal investigator Anders Kolb, MD, director of the Nemours Center for Cancer and Blood Disorders. "In addition, a sickle cell patient may describe their pain as severe, but their doctor may not know how to assess pain in a patient with sickle cell who has pain frequently, and the result is often undertreatment of the pain. If a patient thinks a provider is minimizing their symptoms, they may become reluctant to seek timely care and to trust their provider's recommendations."* "

The grant will support a comprehensive SCD program comprised of four research projects. Two of these will engage patients and families in identifying and addressing barriers to good SCD care – including racism and stigma associated with the disease, as well as patients' understanding of SCD and self-efficacy in managing symptoms of the condition. The research team will develop a technology-enhanced, shared decision-making toolkit to improve patients' use of and adherence to SCD treatments – and provision of these treatments by clinicians. The team will also test a peer-mediated group intervention for chronic pain and self-efficacy in adult SCD patients to assess the contribution of racial identity and stigma on the efficacy of chronic pain management.

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Another project will test innovative ophthalmologic exam techniques as a noninvasive way to identify stroke risk, to aid in diagnosis of sickle cell retinal damage, and to seek ways to incorporate newborn screening results and sickle cell trait carrier status into electronic health records. The fourth project will evaluate physician and patient perceptions of sickle cell carrier status identified in newborn screening programs to improve awareness of and counseling on sickle cell inheritance.

This grant builds on an earlier NIH grant to Nemours that helped build an active program to advance sickle cell treatment and research. The initial grant helped researchers build partnerships with Nemours' SCD patient population, ultimately facilitating more than 800 enrollments in SCD studies.

"Because of earlier NIH funding in this area, we have local SCD patients participating in nationally funded trials, ensuring that our communities are part of large studies pursuing important questions about SCD," said Mary Lee, MD, FAAP, Enterprise Chief Scientific Officer for Nemours. "With this new grant, these communities play a central role, with each project incorporating patient and family feedback – even engaging them in how we design and conduct the research – which is essential to understand their experience of systemic and/or healthcare-associated racism and its effects on SCD outcomes."

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About Nemours Children’s Health

Nemours Children’s Health is one of the nation’s largest multistate pediatric health systems, including two free-standing children's hospitals and a network of nearly 80 primary and specialty care practices across five states. Nemours seeks to transform the health of children by adopting a holistic health model that utilizes innovative, safe, and high quality care, while also caring for the health of the whole child beyond medicine. Nemours also powers the world’s most-visited website for information on the health of children and teens, KidsHealth.org.

The Nemours Foundation, established through the legacy and philanthropy of Alfred I. duPont, provides pediatric clinical care, research, education, advocacy, and prevention programs to the children, families and communities it serves.

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