

Nemours Children's Health Researchers to Present at American Society of Hematology Conference

Presentations will highlight latest discoveries in sickle cell disease

WILMINGTON, Del. (Dec. 5, 2023) — Researchers from Nemours Children's Health will present several studies at the American Society of Hematology (ASH) conference, Dec. 9-12 in San Diego. Nemours Children's researchers will focus primarily on sickle cell disease (SCD), a group of inherited red blood disorders marked by defective hemoglobin that causes pain and anemia.

"Nemours is relentlessly focused on improving outcomes for patients with sickle cell disease," said Matthew M. Davis, MD, MAPP, Executive Vice-President, Enterprise Physician-in-Chief and Chief Scientific Officer of Nemours Children's Health. "We are honored to share our recent discoveries with researchers and clinicians who share this important mission."

The studies that Nemours Children's researchers will present at ASH cover a wide spectrum of issues in SCD, from screening for complications to managing pain with non-pharmacologic treatments. The studies include:

Association Between Acute Pain Scores in Children With Sickle Cell Disease and Emergency Department

Disposition and Return Rates: David Brousseau, MD, MS, Chair of Pediatrics at Nemours Children's Health, Delaware and the Sidney Kimmel Medical College at Thomas Jefferson University will discuss how assessment of patients' pain during emergency department (ED) visits, and the administration of opioids during and after ED visits, are associated with the likelihood that a child returns with uncontrollable pain after being sent home from the ED. Research that will be discussed by Dr. Brousseau was supported by the National Heart, Lung, and Blood Institute of the National Institutes of Health under Award Number **U01HL159850**.

Hemoglobin Genotype, Hemolytic Activity, Fetal Hemoglobin and Retinal Changes on Optic Coherence Tomography in Children with Sickle Cell Disease: Jing Jin, MD, PhD, and Robin Miller, MD, will share results of a study in which 181 patients who have SCD were screened for sickle cell retinopathy using optic coherence tomography. The authors suggest that tracking fetal hemoglobin from an early age could help identify patients at risk of later complications like retinopathy. Miller will present the study. Research to be reported in this presentation was supported by the National Institute of General Medical Sciences of the National Institutes of Health under Award Number **P20GM109021**.

A pair of studies led by Katie Parisio, DO, and Corrina Schultz, MD, examine the use of non-pharmacologic treatments for patients experiencing pain from SCD. In a study titled **Utilization of Pharmacologic and Non-Pharmacologic Therapies for Pain in Sickle Cell Disease: A Cross-Sectional Study**, Parisio and Schultz assessed the use of opioids for pain management compared with non-pharmacologic strategies such as healing touch and child life therapy. In **Patient, Caregiver, and Healthcare Provider Perspectives on Pharmacologic and Non-Pharmacologic Therapies for Pain in Sickle Cell Disease**, the researchers identified a desire among adolescent and young adult patients and their caregivers for more information on non-pharmacologic treatments for pain related to SCD. Parisio will present both studies.

These research efforts were supported by the National Institute of General Medical Sciences of the National Institutes of Health under Award Number **P20GM109021**.

Aimee Hildenbrand, PhD, will present a pair of studies focused on decision-making in care for patients with SCD: **Taking Shared Decision Making from Concept to Clinical Practice: What Do Sickle Cell Providers Need?** and **Disease-Modifying Therapies for Sickle Cell Disease: Decisional Needs and Supports Among Adolescents and Young Adults**. Research reports in Dr. Hildenbrand's presentations were supported by the National Institute of General Medical Sciences of the National Institutes of Health under Award Number **P20GM109021**.

Davis noted that the broad range of talks and posters being presented at ASH highlight Nemours Children's ongoing commitment to improving the treatment and management of SCD among children, adolescents, and young adults. "At Nemours, we know that each patient's experience with their health condition is just as important as the disease process itself. That's why we focus our research attention holistically on the people themselves, as well as on the problems they face. By intervening early in a person's life to treat sickle cell disease, we can help improve their health for decades to come."

In March, Nemours Children's announced a \$78 million donation from the Lisa Dean Moseley Foundation of Wilmington, Del., to fund new and innovative research programs and dramatically expand Nemours Children's capacity to provide clinical care for children with cancer, SCD, and other blood disorders. The donation will fund a new inpatient unit to be known as the *Lisa Dean Moseley Foundation Institute for Cancer and Blood Disorders at Nemours Children's Health*. The unit is expected to open in the summer of 2025 at Nemours Children's Hospital, Delaware.

About Nemours Children's Health

Nemours Children's Health is one of the nation's largest multistate pediatric health systems, which includes two free-standing children's hospitals and a network of more than 70 primary and specialty care practices. Nemours Children's 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 Children's also powers the world's most-visited website for information on the health of children and teens, Nemours 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. For more information, visit Nemours.org.

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