Duke’s Sickle Cell Disease Research Is a Vital Resource for Federal Policymakers

What is Sickle Cell Disease?
Sickle Cell Disease (SCD) is a devastating and painful disease impacting individuals and families in communities across the United States. According to the Centers for Disease Control and Prevention (CDC), it is estimated that SCD affects about 100,000 Americans, with a disproportionate impact on racial and ethnic minorities. SCD is not only painful, but those who suffer from it are more susceptible to other infections and complications that result in a severely shortened lifespan, frequently in the mid 40’s vs. 70-80’s compared with the US population.

How is Duke responding?
Managing SCD is a life-long struggle. Researchers at the Duke University School of Nursing (DUSON) and the Duke University School of Medicine (DUSOM) are working diligently to improve the quality of life, quality of health services provided, and clinical outcomes for both adults and children with SCD in North Carolina and throughout the United States. DUSOM’s Sickle Cell Center provides medical services, comprehensive care, and acute management for over 850 children and adults in the Sickle Cell Day Hospital, in addition to basic and clinical research, screening and testing, social services, educational services, and community outreach. Clinics are located in Durham, Raleigh, and Fayetteville, and telehealth visits are available to patients throughout the state. DUSOM conducts research to help understand the prevalence and impact of SCD and on how to better treat and care for patients.

Federal funding is critical to Duke’s important SCD work. Funding for this research is supported by the CDC, Health Resources and Services Administration (HRSA), the National Institutes of Health (NIH), and the Agency for Healthcare Research and Quality (AHRQ).

Meet Duke’s SCD research team
Below are some of the Duke experts on the frontlines of research and care, who are resources for policymakers to improve the response to SCD.

Dr. Nirmish Ramesh Shah: Leveraging Technology to Improve Patient Care

Dr. Shah is an Associate Professor in both Pediatrics and Medicine. He is the Director of the SCD Transition Program and Director of Clinical Research in Benign Hematology. He is currently involved in three main areas of research: 1) novel therapeutic options for patients with sickle cell disease; 2) the transition from pediatric to adult care for sickle cell disease; and 3) the use of mobile technology to advance patient care for sickle cell disease.

Dr. Shah is most excited about the progress made in developing apps and leveraging technology to improve patient care. He currently has several studies using self-developed mobile apps to help patients with SCD. Understanding the subjective nature of symptoms and the intermittent data that comes through manual entries, he has added wearable devices (like Apple Watches) to passively acquire objective data such as heart rate, activity, and sleep. He has recently been focusing on
developing predictive algorithms through various machine learning techniques and has been able to accurately predict pain. He continues to work on refining and improving these algorithms through collaborations with multiple institutions and studies using the same platform.

Dr. Paula Tanabe: Advancing Care of Individuals with Sickle Cell

Dr. Tanabe is the Laurel B. Chadwick Distinguished Professor in the Schools of Nursing and Medicine at Duke, and Vice Dean for Research at the Duke University School of Nursing. Dr. Tanabe’s research focuses on improving systems of healthcare and patient outcomes for persons with SCD. She has been instrumental in disseminating evidence-based guidelines and education on sickle cell treatment, including pain management, to all emergency departments (EDs) across the United States. She is currently leading two trials to improve pain management in 14 different EDs in the US. This work is important as SCD causes painful episodes called vaso-occlusive crisis, which can lead to individuals seeking treatment in EDs and pain is frequently poorly managed; patients are often assumed to be drug addicts seeking opioids instead of patients seeking care for their pain control. Dr. Tanabe also co-leads the Duke site with Dr. Shah, in the Sickle Cell Disease Implementation Consortium project, funded by the National Heart, Lung, and Blood Institute.

Dr. Tanabe has received funding from AHRQ, NHLBI, National Institute of Minority Health and Health Disparities, and the National Institute of Nursing Research. She is an excellent resource for policymakers on the care and treatment for individuals with SCD, especially pain management for patients seeking care in EDs and decision support tools for the treatment of SCD.

Dr. John Strouse: Enhancing Access to Comprehensive, State of the Art SCD Care for Patients

Dr. Strouse and his team are the Duke grant recipients for the HRSA SCD Regional Collaborative, which focuses on enhancing access to comprehensive, state of the art SCD care for patients living with the disease by providing educational programs and assistance to providers to assure that patients have access to the most current treatments and advances in SCD care. The grant program brings together both community providers and hematologists, who specialize in the disease. In our region, funds have been used for weekly online educational sessions for physicians, nurse practitioners, physician assistants, and other health professionals providing care to people with SCD and to increase access by expanding telemedicine consults. Each state partner also collaborates with a community based organization that serves families with SCD.
**Dr. Mariam Kayle: Understanding the Prevalence and Impact of Sickle Cell Disease in N.C. and the U.S.**

Due to the lack of national surveillance data, the epidemiology, healthcare needs, and financial impact of SCD in the United States are unknown. The NC Sickle Cell Data Collection Program, under an award from the CDC, is a close partnership between Duke University and the NC Department of Health and Human Services. The DUSON lead for this vital project is Dr. Mariam Kayle, Assistant Professor in the Duke University School of Nursing. This program aims to implement a high-quality, state-wide, population-based SCD surveillance program in NC. A state-wide SCD surveillance program allows for the collection and analysis of health data to accurately describe the epidemiology of SCD, identify population healthcare needs, and inform healthcare practices and health policy for SCD in the state, as well as help inform the prevalence of SCD across the U.S.

**Dr. Nancy Crego: Increasing Knowledge Relating to the Prevalence of Opioid Prescribing for Children with SCD**

Dr. Nancy Crego’s work examines an important knowledge gap relating to SCD in children and the management of this chronic disease. Specifically, Dr. Crego’s research focuses on the prevalence of opioid usage for this population, who are exposed to opioids at an early age to manage SCD. Using NC Medicaid data, Dr. Crego has identified that one in five preschoolers has had an opioid prescribed and filled for them. She examines pharmacologic and non-pharmacologic pain interventions for children with SCD, as well as how parents decide to administer opioids: “What did they see in their child that would prompt them to give an opioid versus giving another type of analgesic?” Her work was featured in an MDedge article, “In sickle cell disease, opioid prescribing starts early, study finds.” Dr. Crego also examines the quality of life as children with SCD transition to adulthood.

**Dr. Mitchell Knisely: Improving the Understanding of Pain Management and Sickle Cell Disease**

Dr. Mitchell Knisely is an Assistant Professor in the Healthcare in Adult Populations Division of the Duke University School of Nursing, whose research focuses on the use of precision health approaches to understand and ameliorate pain and associated symptoms in individuals with chronic conditions. His goals include identifying patients at increased risk for development of chronic pain and/or poor pain control and personalizing strategies for pain management. Currently he is exploring biopsychosocial markers (including genetic markers) associated with pain profiles in SCD. The knowledge generated through this line of research can advance nursing science and practice through improving the ability to identify patients at greater risk for high pain burden and potential new targets for non-opioid interventions for pain relief in people with SCD. He is currently co-leading a study assessing the implementation and effectiveness of acupuncture and guided relaxation on people with chronic SCD pain.