

MSU-Henry Ford Health Systems Health Sciences Center Sickle Cell Disease Center of Clinical and Research Excellence

Strategic Plan Theme: Sustainable Health

Funding Level: Between \$1-5 million

Facility Needs: New facilities will be needed

Submitting Unit: College of Human Medicine / Dept of Pediatrics and Human Development / Pediatric Hematology/Oncology

Collaborating colleges/departments/units involved with this proposal.

Institute of Quantitative Health Sciences and Engineering, College of Public Health, Henry Ford Health Systems

What is the proposal's big theme or idea?

Every single day that you get up out of bed, you're fighting a battle, and when you take that first breath ... it's a breath of pain. You assess mentally. Okay, where are all the places that are hurting right now ... and you actually have to take several deep breaths to push the circulation through your body (Tosin O., a person with sickle cell disease (SCD)) Sickle cell disease (SCD) refers to a group of inherited red blood cell disorders. SCD is a debilitating and painful multi-system condition that causes lifelong acute and chronic complications throughout the whole body. SCD affects approximately 3000 people in Michigan, 100,000 people in the United States (US) and millions globally. SCD is taught as the classic monogenic disease and in the US occurs primarily in Black individuals with homozygous inheritance of the gene for sickle hemoglobin (HbS). Heterozygous inheritance of HbS protects from Plasmodium falciparum malaria, an infection endemic to sub-Saharan Africa. The trans-Atlantic slave trade, intranational (The Great Migration), and international migration patterns account for the prevalence and distribution of SCD in the US today. The pathology of SCD results from a complex interplay of hemolysis (the destruction of red blood cells [RBCs]), chronic inflammation, and systemic vascular damage. Its main presenting symptom is unpredictable, recurrent, and excruciating episodes of acute pain—often referred to as “pain crises”. The various consequences of acute and often eventually unremitting chronic pain are primary drivers of the psychosocial devastation of SCD and are also the primary reason for the use of health care. SCD also has profound effects on every organ and system of the body with life expectancy for individuals with SCD remaining more than 20 years less than that of the general population despite advances in therapy. In the US, SCD disproportionately impacts Black individuals. Treatment of pain crises and chronic pain often necessitates the use of medical opioids. The stigma associated with SCD and opioid use, systemic racism, and unconscious bias synergize to exacerbate the inherent health burden of individuals with SCD. Significant gaps in the medical community's and public awareness of SCD remain, and the stigma and complications of SCD negatively impact educational and employment opportunities, mental health, and relationships.

What is the proposal's goal?

Build a premiere MSU-HFHS HSC Center of Excellence for comprehensive and lifespan SCD clinical care that will lead in cross-disciplinary translational and outcomes research. Major disparities in research funding, clinical resources and quality measurements have been repeatedly noted in comparison with other monogenic disorders that primarily affect other populations (e.g., cystic fibrosis and hemophilia). Now is the time to coalesce community, academic, and clinical partners in Michigan and address these disparities in care

and drive innovative and impactful change for individuals and families challenged and afflicted by SCD. In partnership with the community-based organization SCD Association of America – MI (SCDAA-MI) and leading SCD physicians in Detroit, the sponsors of this proposal are actively working with Henry Ford Health Systems (HFHS) leadership to build a SCD Center of Excellence that will provide comprehensive lifespan care to the ~1800 individuals with SCD in southeastern Michigan. Currently, individuals with SCD >21 yo receive a patchwork of acute medical care, which in many cases is primarily received through the emergency department. These efforts are focused on building a cutting-edge care center and health care team for lifespan care based at HFHS. We propose the recruitment of a physician-scientist leader in SCD and three to five research faculty who will leverage cross-disciplinary and interinstitutional collaborations to build a premiere SCD Center of Clinical AND Research Excellence under the auspices of the MSU-HFHS Health Sciences Center.

Define the significance, or impact of your big idea.

Creation of the MSU-HFHS SCD Center of Clinical and Research Excellence will have local, regional, and international cross-disciplinary impact. As most individuals with SCD in Michigan reside in southeastern Michigan, the primary “hub” is proposed in Detroit. A possible physical location for this hub could be within the proposed research MSU-HFHS research complex with “spokes” in this “hub and spoke” model of care and translational research proposed at sites of MSU statewide campuses in Flint, Lansing, and Grand Rapids to coincide with the location of individuals with SCD. This hub and spoke model is proposed as a platform for innovative efforts in digital health and community-based research. It is estimated that in collaboration with hospital partners in Detroit, Grand Rapids, and Flint (already engaged) that the center would engage ~2000 individuals with SCD throughout their lifespan. In collaboration with community partners (SCDAA-MI) and the SCD community, this cross-state network would provide a fertile seedbed for innovation and insight for a scientist in partnership with the MSU School of Public Health at Flint. SCD in the USA is primarily a Black disease. The complex interplay of the need for opioid pain management and its stigma, systemic and overt racism, and unconscious bias synergize to result in a shameful synergy of care disparity. Research at the SCD Center of Excellence on the socioeconomic underpinnings of these care disparities (MSU Public Health, Communications, Psychology, etc.) could lead in guiding governmental and philanthropic efforts towards addressing these care disparities. Disease-modifying therapies offer new opportunities for treatment and prevention of SCD complications. However, few, if any, relevant biomarkers of disease severity to guide clinical care and identify outcome measures have been identified. In partnership with the MSU Institute for Quantitative Health Sciences and Engineering (IQHSE), recruitment of a scientist with expertise in vascular medicine and its ex vivo analysis (e.g., microfluidic analysis) would push these efforts forward in collaboration with extensive phenotyping. A bioinformatics specialist would facilitate analysis of the complex data sets of disease and ‘omic’ phenotypes that are expected to be generated. Finally, clinical research into the efficacy of new therapies, including disease-modifying therapies, novel approaches to pain management, and gene therapy will require guidance of expert clinical scientists and physicians. To summarize, we propose a MSU-HFHS Center of [transdisciplinary] Clinical and Research Excellence. The underlying theme of scientific recruits will be to bring diverse ideas and skillsets that will recombine to innovate and spark new energy to improve the lives of individuals with SCD and their families.

Who will be impacted?

Families and patients with SCD - Immediate and long-term impacts are expected. Immediately, creation of the SCD Center of Excellence will address disparities in access to care and cutting-edge innovative translational, clinical, and public health research. This will increase the immediate quality and value of the care that is given. Long-term, we expect that the Center will serve as a nidus for research that will change the paradigms of outpatient monitoring and digital health. The SCD Center will drive excellence and innovation in the next generation of education and research addressing health disparities across Michigan’s urban and underserved communities.

Healthcare providers and the hematology community - increasing diversity of the health care community and training of Black individuals with an interest in Sickle Cell Disease. The SCD Center of Excellence will Increase proactive engagement with historically underrepresented and underserved communities based

on partnerships informed by shared goals and mutual learning. There will be active engagement of Black individuals in the community with the SCD Center of Excellence at all stages of life with the clinical and research enterprise of the Center.

MSU Colleges and Students - The Center and recruited faculty will spark interest and collaboration across Colleges at MSU. While the College of Public Health and IQHSE are emphasized here, the broad impact of SCD across academic disciplines is expected to serve as a catalyst for new collaboration and interaction focused on addressing this health care disparity.

What does sustainability for your proposal look like?

We propose the investment of the provost's office and MSU in the ground-up assembly of SCD Center of Clinical and Research Excellence in collaboration with already engaged partners at Henry Ford Health Systems and Sickle Cell Disease Association of America-Michigan. The vision presented here will succeed in collaboration with an effort to build a cross-state collaborative clinical and research-enabling facility with clinical and community partners. The recruited faculty are expected to identify synergies and increase the community and academic reach.