

Executive Summary

Sickle Cell Disease (SCD) is a serious genetic disorder that causes painful conditions and affects people globally. Approximately 100,000 Americans live with sickle cell disease. Usually, this blood-related health disorder is inherited from one member of a family to another, whereby an individual produces excess hemoglobin, thus causing the development of rigid sickle shaped red blood cells. Particularly, the main problem caused by the disease revolves around the lifespan of these cells, as they tend to die early. This short lifespan does not match the constant generation of new cells, and hence, attracts health problems associated with the shortage of red blood cells. Sickle Cell disease causes severe pain to patients as it drastically affects the oxygen flow in the body system. Some of the common complications caused by sickle cell disease include damage to organs, acute chest syndrome, stroke, and premature deaths.

Although people with SCD are living longer, there is still much to be done. First, the disease results in a series of health complications that inflict pain to patients. Second, the complex system that seeks to provide care for the patients does not achieve the expected results. These challenges often lead to premature deaths among patients, thus contributing to an additional burden of the healthcare system. The costs and demands for sickle cell disease treatment are high and often unaffordable to patients. Patients are normally forced to access a wide range of medications, as the illness affects multiple organs. Therefore, it necessitates the cooperation of different partners to address the problem. Donations from companies, individuals, and governmental agencies will play a key role in ensuring that patients impacted by SCD receive the necessary medical attention that would extend their lifespan. These critically needed resources will also be utilized to provide facilities that will improve access to care and research concerning sickle cell disease.

Project HOPE (Health, Opportunities, Prevention, and Education)

Since July 1987, in South Carolina, all newborns are screened for sickle cell before leaving the hospital. The Louvenia D. Barksdale Sickle Cell Anemia Foundation, founded in 1974, serves fifteen counties in the Upstate of South Carolina. The mission of the organization is *"To optimize the quality of health care and quality of life for individuals and families impacted by the presence of Sickle Cell Anemia disease."* Through the implementation of Project Hope, we have increased awareness through sickle cell disease research with our collaboration with the Comprehensive Sickle Cell Disease Center at Prisma Upstate. We have increased our visibility as community advocates, through education and awareness activities for the patients and families we serve. We have outlined a plan for sustainability and developed a continuum of care for our patients in both clinical and non-clinical settings. The additional funds will continue our efforts to expand our reach by providing resources and supportive services to more underserved communities. We will be able to continue with the services of a Registered Nurse (RN), Community Engagement Specialist, Community Outreach Coordinator, and our collaboration with the Community Advisory Board. Additionally, the funds will be used to develop educational and materials and resources that will allow us to raise awareness about the disease. Through *Project Hope*, the LD Barksdale Sickle Cell Anemia Foundation will be able to continue to provide much-needed support and resources to those affected by the disease and make a significant impact in the fight to eradicate this life-threatening disease.