Project Title: SIERRA LEONE SICKLE CELL DISEASE RESEARCH AND CLINICAL PROGRAM

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Project Description

Sickle cell disease (SCD) is the most common hemoglobinopathy worldwide. It is estimated that more than 300,000 babies worldwide are born with SCD every year, with 75% of the births occurring in sub-Saharan Africa. Unlike the United States where early mortality has been reduced significantly over the past decades with more than 90% of people with SCD surviving beyond 20 years of age, SCD remains an under-recognized, but important contributor to the mortality of children under 5 years in sub-Saharan Africa. SCD patients have a multitude of complications, including pain, infections, stroke, sepsis, acute chest syndrome, multi-organ damage, and early death. Lack of structured care and absence of early diagnosis and preventive care contribute to high mortality among these patients [4-6]. Also, lack of public knowledge of SCD perpetuates social stigma and myths about SCD causation resulting in fewer patients seeking appropriate treatment.

In Sierra Leone, a West African nation, recovering from a major Ebola epidemic and a decade of civil war, SCD remains an important but largely neglected risk to child survival. The probability of early death among children born with SCD in Sierra Leone might be as high as 50%-to-90%. Published estimates of the disease prevalence and burden are imprecise. Two reports, one in the mid-1950s and the other in 1996, which examined the prevalence of the sickle cell traits in blood samples constituted the bulk of the available published literature. Universal newborn screening program which provides accurate estimates of live SCD births is currently lacking in Sierra Leone. Based on dated sickle cell trait frequencies of between 22-25%, and a birth rate of about 45 per thousand and a population of about 6 million people, it is estimated that approximately 3500-5000 babies born with SCD annually are in need of preventive care, close health supervision, and advocacy.
The study described in this proposal is foundational for a comprehensive long-term health capacity building initiative for SCD screening, health maintenance, and research programs in Sierra Leone. The initiative is based on collaboration between the University of Cincinnati, Jericho Road Community Health Center, Sickle Cell Carers Awareness Network (public university, US-based nongovernmental agency, and a local advocacy group respectively). Undergirding this collaboration are World Health Organization (WHO) pronouncements for the necessity of early SCD diagnosis, preventive care, training, public awareness based on north-south institutional collaborations in regions with the highest disease burden.