Sickle Cell Disease (SCD) is a non-communicable, genetic blood disorder that leads to the production of atypical, “sickle” hemoglobin that causes red blood cells to form a characteristic “sickle” shape. These sickle cells cause vascular occlusion and impair oxygen delivery, and as a result, the disease carries a high mortality and morbidity rate if left undiagnosed and untreated. Interestingly, SCD confers an evolutionary advantage against malaria, and as a result, the sickle hemoglobin gene is most often found in populations who live in malaria-endemic areas. The Terai region in southern Nepal, where the indigenous Tharu population has lived for centuries, has an extensive history of malaria. However, the first case of sickle cell anemia in Nepal was only formally reported in 2003, and more recent reports suggest a large and longstanding burden of SCD, especially in underserved Tharu communities in rural Nepal. Diagnosis and management of SCD and associated sequelae is only available at a limited number of institutions, inaccessible for most rural and remote Tharu communities. Knowledge of SCD is poor in these populations and most cases go unrecognized.

In 2015, our team set out to estimate the prevalence of SCD in the Tharu population in the rural district of Dang, located in the Western Terai region of Nepal. The 2016, 2017 and 2018 teams have since focused on conducting needs assessments and delivering community-based training and educational sessions to raise awareness and improve access to healthcare resources in a sustainable manner.