

Title: Northern California Network of Care Evaluation Project - Sickle Cell Disease Treatment Demonstration Program (SCDTDP)

IRB# 2010-009

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Synopsis:

The estimated number of individuals with sickle cell disease (SCD) in the 10 counties served by the Northern California Network of Care for Sickle Cell Disease (Network of Care) is 1,574. Access to care for adults with SCD, particularly access to a medical home, is limited. Effective strategies for tracking outcomes across health care delivery systems do not exist. Factors known to affect access to care for children and adults enrolled in the sickle cell center at CHRCCO include: transportation difficulties; economic challenges; language barriers; stressors of urban living; low literacy; and lack of coordination of care. Access to and adherence with referrals for subspecialty care can be inadequate. Needs assessments support the importance of education about strategies for health promotion for those affected and about the medical home model for health care providers.

The Network of Care proposes to draw on the strengths of established collaborations within the Northern California region and develop new partnerships with the goals of 1) enhancing coordination of service delivery for individuals with SCD; 2) improving access to and follow up with comprehensive and subspecialty care, with particular focus on youth and adults with SCD; and 3) increasing knowledge about and participation in the medical home model for people with SCD across the lifespan. The Network of Care includes two federally qualified health centers and a public health system that provide primary care; a community based nonprofit medical center; the CSCC; the California Department of Public Health-Genetic Disease Screening Program; and three community based SCD organizations. The Network of Care will extend the clinical care provided by the sickle cell center by increasing access to subspecialty care for youth and adults and by outreaching to underserved adults in the community. Existing patient support activities will be enhanced by peer education about positive disease management and the medical home model. Genetic counseling and intensive case management will be added to available support services. The Network of Care will address gaps in the present system of care for SCD by educating hospitals, primary and emergency care physicians, patients, and their families about the need for and availability of comprehensive care to address the complexities of SCD. The Network of Care features partnerships between the sickle cell center staff and local community based organizations to educate health care providers about SCD, its management and patient perspectives, to improve their knowledge and attitudes. We will develop a system for tracking health care utilization and sickle cell related complications for youth and young adults with SCD throughout Northern California. Process evaluations will allow for replicability and outcome evaluations will demonstrate the effectiveness of the approaches.

The Network of Care targets populations in Northern California - the San Francisco Bay Area and immediately surrounding counties. The population includes over 600 children and adults with SCD across the lifespan followed for comprehensive care within the sickle cell center at CHRCCO and its satellites; close to an additional 1000 estimated individuals with SCD in the region; 600 emergency department and primary care providers and allied health professionals. The population reflects a range of economic and ethnic diversity. The Network of Care collaborative allows for the establishment of best practices and shared protocols for SCD within the region.