NORTHERN CALIFORNIA **NETWORK OF CARE** FOR SICKLE CELL DISEASE









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747 52nd St. Oakland, Ca 94609 The Health Resources and Services Administration has funded nine programs around the country as the Sickle Cell Disease Treatment and Demonstration Project with the goals to:

- 1. Gather information about the health care experiences of people with sickle cell disease, and
- **2.** Evaluate different ways to improve those experiences.

The Northern California Network of Care for Sickle Cell Disease was funded in September of 2009 as one of the Sickle Cell Disease Treatment and Demonstration Projects. Our program also aims to learn more about the psychosocial experiences of people with sickle cell disease and we want to understand what problems people with sickle cell disease face in getting the health care that they need.

Services of the **Network of Care** include:

- 1. Support activities for people with sickle cell disease through intensive case management and peer education;
- 2. Increasing access to genetic counseling and subspecialty care for people with sickle cell disease and their families;
- 3. Educating health care providers, community organizations and the general public through presentations given by Children's Hospital & Research Center Oakland Sickle Cell Center staff and individuals living with sickle cell disease;
- **4.** Teaching people with sickle cell disease and their family members skills for positive disease management;
- **5.** Providing educational and recreational activities for children with sickle cell disease and their families.

We hope to find the best ways to teach youth and adults with sickle cell disease, their families and health care providers about positive, patient-centered health care.

The *Network of Care* partners currently include:

Children's Hospital & Research Center Oakland;

Alta Bates Summit Medical Center -

Alta Bates and Summit campuses;

Alameda County Medical Center- Highland Hospital;

Berkeley Clinic for Women and Men;

The Sickle Cell Community Advisory Council;

Sickle Cell Disease Foundation of California;

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