

NORTHERN CALIFORNIA
NETWORK OF CARE
FOR SICKLE CELL DISEASE

Network of Care Evaluation Project



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What is the Network of Care Evaluation Project?

Children and adults with sickle cell disease have limited access to healthcare. We need to understand why, and to find ways to improve healthcare for those with sickle cell disease.

The Health Resources and Services Administration has teamed up with programs around the country to:

1. Gather information about the healthcare experiences of people with sickle cell disease, and
2. Test different ways to improve those experiences.

In September 2009, the Health Resources and Services Administration funded the Northern California Network of Care for Sickle Cell Disease as one of its demonstration sickle cell disease programs.

Our program would like to learn more about the psychosocial experiences of people with sickle cell disease. What problems do people with sickle cell disease face in getting the healthcare they need?

With your help, we hope to find the best ways to teach youth and adults with sickle cell disease, their families and healthcare providers about positive, patient-centered healthcare.

We are interested in enrolling children and adults with sickle cell disease of all ages, and their primary caregivers.



We will reimburse you for your travel expenses. You will also receive a gift as a thank-you for your time.

What will happen?

We ask for two visits to gather your information, one year apart. We will try to schedule these visits during a regular clinic visit.

Visit 1

We will ask adults and children with sickle cell disease, and the children's primary caregivers, to fill out a few questionnaires about the health, healthcare, quality of life, and psychological well-being of the person with sickle cell disease. Some of the questionnaires are just for the project; others you have already seen as part of your healthcare assessments.

Questions may also be answered during an interview. It will take about 30 to 45 minutes to answer the questions on all the forms. You can fill them out in the waiting area or while waiting for your doctor or nurse.

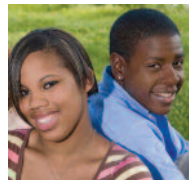
Visit 2

One year later, the adults and children with sickle cell disease, and the children's primary caregivers, will be asked to fill out the same questionnaires. Again, it will take about 45 minutes to answer all of the questions, and you can fill the forms out while you are waiting. It is usual practice for the forms to be filled out again in one year.

Why participate?

Your answers to the questions will help us find and fill gaps in healthcare for those with sickle cell disease. With your help we can improve the care that sickle cell disease patients receive and help them have a better quality of life.

We hope your two visits answering questions related to your healthcare, or your child's healthcare, will help us improve medical and other services for people with sickle cell disease. Thank you.



To apply

To sign up for the Network of Care Evaluation Project, please fill out this form or call:

Marsha Treadwell, PhD
510-428-3356

Fernando Barreda
510-428-3885,
ext. 5354

APPLICATION FORM

Name of person with sickle cell disease:

Age: _____

Parent or Guardian (if applicable):

Street address: _____

City: _____

State: _____ Zip: _____

Cell Phone: (_____) _____

Home Phone: (_____) _____

Best time to reach you: _____ a.m. _____ p.m.

Comments or questions? _____

Please mail this form to:

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