

## Adult Sickle Cell Quality of Life Measurement Information System (ASCQ-ME) Project

IRB# 2008-075

Principal Investigator: Marsha Treadwell, MD

### Synopsis:

Instruments to assess health-related quality of life for other conditions are not ideally suited to capture the unique, multi-faceted impact of sickle cell disease. NHLBI, the American Institutes for Research (AIR) and CHRCO are developing the Adult Sickle Cell Quality of Life Measurement Information System (ASCQ-Me). The project was designed as a multi-phase project. In the first two phases, qualitative strategies were used to develop the measurement system for health related quality of life for adults with SCD. In this third phase, the tool that was developed is being field tested in seven sites around the country - in Connecticut, Maryland, Florida, Missouri, Virginia and in California, Los Angeles and Oakland. We are developing a state-of-the-art computerized version and a paper version of ASCQ-Me.

The goal of the field test is to evaluate the reliability and validity of ASCQ-Me questions. The specific aims of the field test are to (i) calculate statistical analyses of the questions to be used in the computer adaptive version of ASCQ-Me; and to (ii) evaluate the measurement properties (reliability and validity) of items and summary scores for both versions.

In addition, the field test will determine if ASCQ-Me data will be enhanced by incorporating other health-related quality of life items from the NIH Patient-Reported Outcomes Measurement Information System (PROMIS).

ASCQ-Me will collect responses across the 7 sites from a total of 500 adults with sickle cell disease (> 18 years of age) on the following topics:

- Health-related quality of life,
- Case-mix-related demographic information,
- Condition-severity, and
- Quality of care.