

SICKLE CELL DISEASE TRAINING CENTER

- Sickle cell population: 100,000 people USA, > 7,000-10,000 CA.
- 1 in 400 African Americans and 1 in 15,000 Latinos.
- Most patients lack of access to the NIH minimum standard of care
- The lack of access, results in morbidity, mortality and ↓ survival in adults.
- The major factor is the lack of trained, available adult sickle cell providers with ongoing access to multidisciplinary care.
- There is an urgent need for access to trained health professionals.
- The training and ongoing educational support of adult providers including primary care physicians, hematologists, nurse practitioners, case managers, social workers, and counselors is critical to improving the survival of adult SCD patients.

NATIONAL SICKLE CELL CENTER GOALS AND GOAL OF THE PILOT PROGRAM

- A National Sickle Cell Center will serve as a resource to train physicians, healthcare providers, case managers, social workers, and clinical scientists. The multidisciplinary graduates of these training programs, recruited from all regions of the country, will apply what they have learned in their community.
- The goal of the project is to pilot a small training program utilizing multidisciplinary techniques designed to improve participants' education and enable them to be an anchor in the development of a sickle cell care program.

NATIONAL SICKLE CELL CENTER GOALS AND GOAL OF THE PILOT PROGRAM

1. Training of physicians (Primary Providers and hematologists with individualized design for each candidate)

- The pathology of SCD results in widespread organ injury. The prevention of the complications and management of the disease requires educational expertise beyond any one specialty discipline.
- a rigorous training program for physicians. Includes financial incentives for their institution to support. The program will include multiple training pathways including didactic lectures, patient interviews, online curricula, case conferences, and participation in project ECHO.
- Project ECHO is an approach that utilizes video technology for monthly telementoring clinics consisting of didactic and case-based presentations focused on the National Heart, Lung and

2. Training Program for non-physician specialty

- Multidisciplinary teaching staff will consist of multiple specialties.
- The trainee will undergo a one-two week intensive training program. A six-month integrated telemedicine education curriculum.
- Genetic counseling
- Nursing
- Community Health Worker

TELEMEDICINE PROGRAM

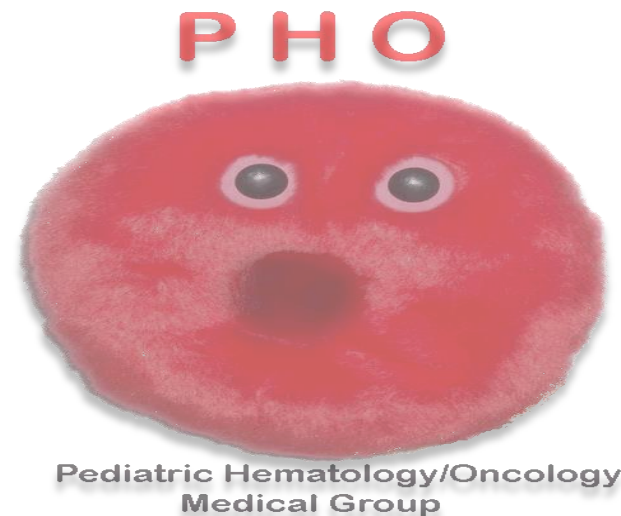
- Designed for interaction with personnel, laboratory imaging.
- Each person participating in the training program will have access to the telemedicine sessions.
- Monthly presentations on a specific subject preceded by a short case and reading list.

REVIEW, CERTIFICATION, AND ONGOING SUPPORT OF GRADUATES

- Critical review and determination of success of the education program in meeting goals: key areas to be tracked as indicators of a successful pilot training program.
- Certification of the Project by State, GHPP, and regional hospital networks.
- 24-hour back-up coverage and hotline for ongoing case management support by the Sickle Cell Center case managers, social workers, nurses, and mental health team.

HELP - SC

**HEALTH EDUCATION AND LIAISON FOR SICKLE CELL
SATURDAY, JANUARY 27, 2018**



BIG PICTURE

- Improve community and hospital provider care for persons with sickle cell
- Improve the knowledge, skills, and comfort of providers caring for persons with sickle cell
- Develop a network of community-based physicians caring for persons with sickle cell
- Create SOPs for Sickle Cell Disease testing

SMALL PICTURE

1. Developing a Sickle Cell “Boot Camp” for intensive provider training over a week
 - Will start with Physicians
 - Hoping to add NPs, nurses, and Social Workers over time
2. Small Group and one-on-one didactic, case-based mentoring
3. Standardized patients using persons with sickle cell for social, organ specific, and quality of life teaching
4. Discussions of institutional support for providers
5. Follow up by remote conferences or telemedicine to review ongoing support and educational needs

BOOT CAMP

Curriculum will include:

- Understanding the psychosocial impact of sickle cell disease
- Approach to the adult with sickle cell disease
- Sickle cell emergencies, urgencies, and their treatment
- Sickle cell specific history and physical exam
- Organ specific evaluation and treatment
- Iron overload and its management
- Acute, chronic, and neuropathic pain evaluation and management
- Neurologic evaluation, conditions, and treatments
- Impact of sickle cell on adult medical conditions
- Pitfalls and pearls in sickle cell care
- NIH guidelines for sickle cell care

SESSIONS

- Format will be based on key skills, knowledge, and attitudes for each topic.
- Patients who have volunteered will be part of the educational session.
- We will use these sessions to develop SOPs.

FIRST CAMP

- Our first camp will be from April 30th to May 4th.
- We have two UCSF physicians and a Southern California physician for the first camp.

