

California Newborn Screening

Hemoglobin Trait Follow-up Program



By: Marlene Espinoza, MPH, Certified Hemoglobin Trait Counselor
Director of Special Projects, Sickle Cell Disease Foundation

History of CA Newborn Screening Program: SCT and SCD

- ◆ Since February 1990, the California NBS Program has been testing newborns for sickle cell disease and related hemoglobin disorders.
- ◆ Babies identified with a hemoglobin disorder are referred to a Sickle Cell Disease Center for treatment. (ASC)
- ◆ The screening also identifies babies with certain hemoglobin traits. (Hb: AS, AC, AD)

Hemoglobin Trait Follow-up Program

- ◆ Parents of infants identified with sickle cell trait, hgb C trait and hgb D trait receive a letter by mail notifying them of their babies trait status.
- ◆ Letter gives parents general trait information, states that trait is NOT a disease and encourages parents to call toll free 800 number to speak to a trait counselor.
- ◆ Parents call the toll free 800 number speak to a hgb counselor about their baby's trait.

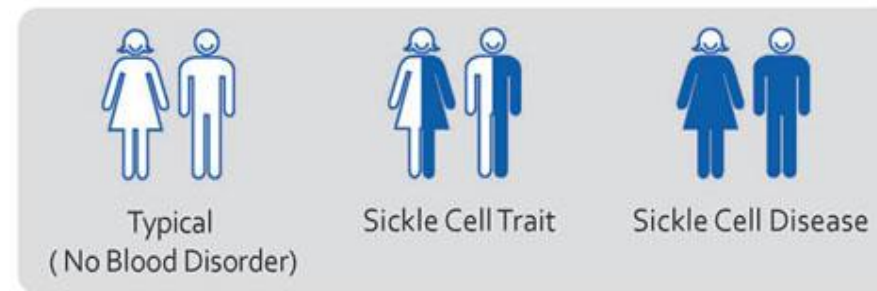
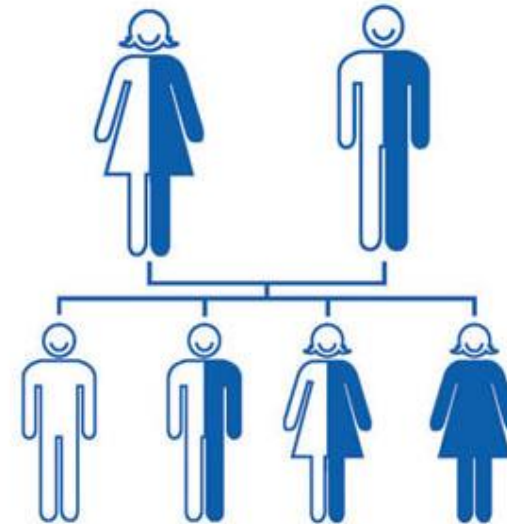
NBS Trait Counseling Process



- ◆ A free phone or face-to-face counseling session is provided to parents.
- ◆ Paperwork and consents are sent to parents via email or regular mail.
- ◆ Parents respond with signed consent forms and lab authorization paperwork is sent to parents.
- ◆ Parents take paperwork to a designated Quest Diagnostics location near them.
- ◆ Quest Diagnostic performs blood draw, bills state of CA NBSP
- ◆ Results sent via fax to NBS counselor and CDPH-NBSP program coordinator.
- ◆ Results counseling provided and copies of lab results sent to parents.

Prevalence of SCT & SCD among Latinx in the U.S.

- ◆ SCT: 1 in 180 Hispanic births (Hb: AS)
- ◆ SCD: 1 in 16,300 Hispanic births (Hb: SS, SC, SD, SE)



(CDC, 2016)

Latinx families and NBS Counselin



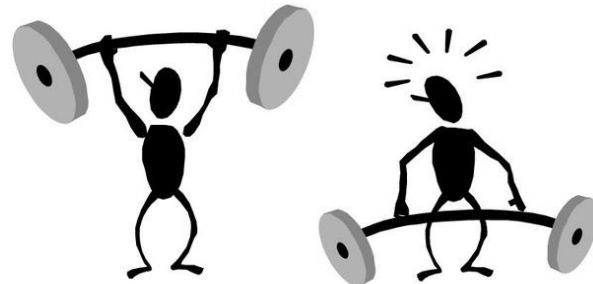
- ◆ Approximately 20% of NBS calls are Spanish speaking families.
- ◆ Mostly Hb: AS (90%), Hb: AD (6%), Hb: AC (4%)
- ◆ Have limited knowledge on how SCD/SCT is inherited, have never heard of it
- ◆ SCT: often willing to participate in the CA NBS Hb trait testing

(SCDFC, 2018)

Strengths & Gaps of CA NBS Trait Program

Strengths

- ◆ Offers FREE counseling and testing for parents and other children born outside of CA or US.
- ◆ Parents born in CA after 1990 can request copies of their NBS results anytime.



Gaps

- ▶ Lacking personnel and staff:
 - Continue to provide training modules and certify more hb trait educator/counselors.
 - No in house genetic counselors (in Richmond, CA)
 - No mechanism in place to reach out to families once counseling and testing is completed as newborns. (Follow-up with NBS as teenagers)

Benefits to Enhancing the CA NBSP



- Ability to train and certify more hb trait educator/counselors.
- Expand the number of trained individuals working in previous identified high risk communities.
- Work with CA NBS to develop and create an online tool for teens and parents to access for trait counseling “refresher” course.
- Reach out to middle school kids and their parents through school system to inform them about online trait counseling “refresher” course.

Resources and Contacts



CA Newborn Screening Program

Counseling Line: 1-866-954-2229



Sickle Cell Disease Foundation (SCDF)

909-743-5226 or info@scdfc.org

Certified Counselors:

Marlene Espinoza, MPH and Deborah Green