

# California Newborn Screening Hemoglobin Trait Follow-up Program

## Information for Primary Care Providers



The California Newborn Screening (NBS) Program screens newborns for hemoglobinopathies. The screening test also identifies infants who are hemoglobin trait carriers.

Carrier follow-up is provided to parents of infants identified with sickle cell or hemoglobin C or D traits. This follow up is important because of the **potential risk for couples who are both trait carriers to have a future child with sickle cell disease**, or another hemoglobinopathy.

One out of every 95 newborns in California is identified with S, C, or D trait. Hemoglobin trait and disease can present in anyone of any race or ethnicity, not just in Black and Hispanic/Latinx populations.

### Provider responsibilities

- 1. Encourage** parents of a newborn with sickle cell or hemoglobin C or D traits to contact the California Newborn Screening Hemoglobin Trait Follow-up Program at **1 (866) 954-2229 or [info@scdfc.org](mailto:info@scdfc.org)**. The program offers education and counseling, along with free, voluntary, and confidential parent trait testing. The NBS Program sends parents a mailer about this, but many do not receive it.
- 2. Note** newborn trait status in medical records.
- 3. Refer** parents, if they may have more children, to genetic counseling if preferred over the Trait Follow-up Program.

### The Hemoglobin Trait Follow-up Program will provide the following information to parents:

#### Regarding the newborn

- ▶ Which hemoglobin trait the infant's newborn screening test showed
- ▶ The newborn screening test is highly accurate; the infant does not need to be retested for trait
- ▶ Trait and disease are different, with explanations of each
- ▶ The child's trait status should be shared and discussed with the child before they reach child-bearing age

#### Regarding the parent

- ▶ Parents are offered testing for hemoglobin traits because of the possibility of sickle cell disease or another hemoglobinopathy for each pregnancy if both parents have a hemoglobin trait.

See Hemoglobin Trait Carrier Rate by Race/Ethnicity in CA Newborns, 2013-2022, Table



See [CDC sickle cell toolkit](https://www.cdc.gov/ncbddd/sicklecell/toolkit.html) (<https://www.cdc.gov/ncbddd/sicklecell/toolkit.html>)

