California Newborn Screening Cystic Fibrosis Carrier Follow-up Program

Information for Primary Care Providers

The California Newborn Screening (NBS) Program screens for cystic fibrosis (CF) in newborns, as well as identifies those who are CF carriers.

Approximately 1 in 30 Americans is a CF carrier, and CF affects individuals of **all races and ethnicities.**

The NBS Program provides comprehensive education and genetic counseling to parents of newborns shown to be CF carriers through the California Newborn Screening Cystic Fibrosis (NBS CF) Carrier Follow-up Program. This voluntary program is provided at no cost to families and plays a crucial role in addressing the risk of future pregnancies affected by CF. The NBS program provides information directly to families, but some do not receive it.

Provider responsibilities

1. **Encourage parents** of newborns identified as CF carriers to contact the NBS CF Carrier Follow-up Program at 1 (800) 793-1313. The program offers education and genetic counseling by phone, at no cost to families, regarding their NBS CF results.
2. **Refer parents** to genetic counseling, if preferred over the NBS CF Carrier Follow-up Program.
3. **Document** that the newborn is identified as a CF carrier in medical records.
4. **Monitor child.** California's newborn screening for CF is accurate. However, in rare cases, even sequencing may not detect all CF-causing variants. Any child who exhibits signs or symptoms of CF, such as chronic cough, chronic respiratory infection, or poor weight gain may need more testing, even if their newborn screening results did not identify two CF-causing variants.

The NBS Cystic Fibrosis Carrier Follow-up Program will provide the following information to parents:

Regarding the newborn

- Explain the differences between being a CF carrier and having CF.
- Describe the CF gene variant their infant's screening result identified and explain the inheritance pattern and implications for future pregnancies.
- Advise that their child's CF carrier status should be shared with them and that reproductive implications should be discussed before they reach child-bearing age.
- Share information about the limitations of screening tests. Parents will be advised to contact their child's health care provider if they have specific concerns about their health.

Regarding the parent

- Explain that parents should be offered and should consider genetic testing to determine if both parents are CF carriers, as this would raise the risk of having a child with CF in future pregnancies.

See CDC's Cystic Fibrosis page (www.cdc.gov/cystic-fibrosis/about/index.html)

CDPH California Department of Public Health

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Newborn Screening Program (www.cdph.ca.gov/NBS)