

Provider action sheet for severe combined immunodeficiency (SCID)

The California Newborn Screening (NBS) Program has identified a baby in your care who has a screen-positive result for severe combined immunodeficiency (SCID).

The NBS Program screens for SCID by measurement of T-cell Receptor Excision Circles (TRECs) using the baby's NBS dried blood spot sample. The possibility of SCID or a serious T cell disorder has been identified in your patient; please see the attached/enclosed test results.

What steps do I need to take?

- **Consult** with the chosen Special Care Center (SCC) immunologist. They will ask for your assessment of the child's current health status and whether the newborn has any signs of the disorder as they formulate a diagnostic follow-up plan. The immunologist will order confirmatory tests (CBC/Flow Cytometry) and, depending on the result, may schedule a clinic visit or hospital admission for the child. If the baby has a diagnosed condition, the specialty care center will provide clinical follow-up care.
- **Contact** the family to explain the positive newborn screening test result. Underline the importance of keeping the baby away from crowds, ill contacts, or exposure to infections. If the TREC value is in the "Urgent Positive" category (0-3 TRECs per microliter of blood), advise that breast feeding be suspended until further tests are done.
- **Inform the family that their baby was positive on a screen. This is not diagnostic.** Emphasize that you are there to help guide them through the next steps of confirmatory testing and follow-up services. Use the follow-up plan provided by the NBS Area Service Center (ASC) staff. The plan includes the need for immediate confirmatory testing and, if necessary, referral to a California Children's Services (CCS) approved Special Care Center. ASC staff will provide a family information sheet, *Family action for Severe Combined Immunodeficiency (SCID)*. You should give this information to the family.
- **Encourage** parents to do the following: (1) isolate the child from exposure to infections, (2) follow the plan for confirmatory testing right away, and (3) keep their child's appointments with the Special Care Center specialists. The family should receive services from a multidisciplinary team of specialists, including genetic counseling services. Review the family action sheet with parents.

Questions?

For questions about the next steps, please contact the NBS ASC staff at the number provided when notified of the screening test result. This telephone number can also be found on the bottom of the patient result mailer. You can contact NBS program staff at NBS@cdph.ca.gov.

The NBS website address is www.cdph.ca.gov/nbs, or you can do an internet search for CDPH Newborn Screening Program.

For information about how to communicate screen-positive NBS results to parents, go to: [Health Resources & Services Administration Newborn Communication Guide](http://www.hrsa.gov/sites/default/files/hrsa/advisory-committees/heritable-disorders/Resources/achdnc-communication-guide-newborn.pdf) (www.hrsa.gov/sites/default/files/hrsa/advisory-committees/heritable-disorders/Resources/achdnc-communication-guide-newborn.pdf).

Clinical information about the disorder is in the *Provider Fact Sheet for SCID*, provided by ASC staff contact, which also includes links for further information.

