

# Provider action sheet for severe combined immunodeficiency (SCID)

If the California Newborn Screening (NBS) Program has identified an infant in your care who has a screen-positive result for severe combined immunodeficiency (SCID):

## What steps do I need to take?

- 1. Consult** with a California Children's Services Special Care Center (SCC) immunology specialist. They will ask for your assessment of the infant's current health status and if the infant has any signs of the disorder. The Area Service Center may assist the Immunology Center with confirmatory test orders (complete blood count with flow cytometry). The immunologist may schedule a clinic visit or hospital admission. They will provide confirmatory result interpretation and follow-up instructions.
- 2. Contact** the family to explain the positive newborn screening test result. For information on how best to communicate, consult the [Health Resources & Services Administration Newborn Communication Guide](https://bit.ly/HRSAGuide) (<https://bit.ly/HRSAGuide> search online for "HRSA" "heritable" "communication").
- 3. Inform** the family that their infant was positive on a screen, and it is not diagnostic. Emphasize that you, with the help of the SCC specialist, will guide them through the next steps of confirmatory testing and follow-up services.
- 4. Review** the accompanying "Family Action Sheet" for severe combined immune deficiency (SCID) with the family and ensure that they understand.

**5. Advise** parents to (1) isolate the infant from exposure to any illness (2) follow the plan for confirmatory testing right away, and (3) keep their infant's appointments with SCC specialists.

## Clinical information

SCID includes a group of rare, sometimes fatal, congenital disorders that cause a child to be born with little or no immune response.

Until the confirmatory results are available, continue with the following:

- The infant must be isolated from exposure to infection including avoiding crowds and limiting visitors.
- Do not administer live attenuated rotavirus vaccine or other live virus vaccines.
- Do not transfuse with blood products unless leukoreduced, irradiated, and free of cytomegalovirus (CMV).

Treatments include stem cell or bone marrow transplant or gene therapy.

**Please visit these sites.** Search for the site name and "SCID" if needed.

[National Human Genome Research Institute](http://www.genome.gov/13014325)  
([www.genome.gov/13014325](http://www.genome.gov/13014325))

[Baby's First Test](https://www.babysfirsttest.org/)  
(<https://www.babysfirsttest.org/>)

## Questions?

For follow-up questions, please call your NBS Program Area Service Center.

For program questions, please email NBS Program staff at [NBS@cdph.ca.gov](mailto:NBS@cdph.ca.gov) or visit the [NBS Program website](http://www.cdph.ca.gov/NBS) ([www.cdph.ca.gov/NBS](http://www.cdph.ca.gov/NBS)).

