SCID Compass

An educational program of the Immune Deficiency Foundation

SCID Compass, an educational program of the Immune Deficiency Foundation (IDF), seeks to improve outcomes for infants with severe combined immunodeficiency (SCID), a set of genetic disorders which results in a lack of an immune system. SCID Compass enhances access to and use of educational resources, provides linkages to critical services for patients and families, and develops protocols and mechanisms for long-term follow-up for infants identified with SCID through newborn screening.

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Program Purpose

SCID Compass serves as a hub of information and resources for parents, caregivers, and professionals as they navigate next steps after being diagnosed with SCID, with the goals of:

- Increasing awareness and knowledge about SCID
- Supporting state newborn screening programs
- Linking families with children with SCID, especially those in rural and underserved areas, to clinical centers with expertise in treatment and management
- Developing strategies for long-term follow-up

Program Offerings

- A centralized website, www.scidcompass.org, containing all new and edited materials, resources, and information pertaining to SCID
- Hardcopy resources for parents and healthcare providers
- Links to SCID support groups, such as SCID, Angels for Life
- Access to SCID conferences and workshops
- SCID information sessions to the medical community

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SCID: Frequently Asked Questions

What is SCID?

SCID, or severe combined immunodeficiency, is a set of genetic disorders which results in a lack of an immune system. Most babies born with SCID produce no T cells, resulting in no B cell function. With no operating T or B cells, the baby lacks natural defenses against germs, and is highly susceptible to pathogens including bacteria, viruses, and fungi. The condition is fatal if not treated within the first year or two of life. There are close to 20 different genetic mutations that cause SCID.

What are the symptoms of SCID?

Often, when the baby is first born, there are no outward symptoms. Sometimes a baby with SCID is born with an infection, or presents with one quickly after birth. As the baby develops, common symptoms of SCID, are respiratory infections, yeast infections, meningitis, sepsis, failure to thrive, diarrhea, ear and sinus infections, skin rashes, and liver infections.

How is SCID diagnosed?

SCID is diagnosed through a TREC test performed on blood obtained during the newborn screening. A TREC, or T cell excision circle, assay that yields low or no TRECs means there are few or no T cells and is a strong indicator of SCID. Further testing for SCID includes a complete blood count and a flow cytometry. Infants with SCID are referred to an immunologist.

How is SCID treated?

The most common treatment for SCID is a bone marrow transplant, which provides the baby with an immune system through donor cells. Gene therapy, a treatment option still in clinical trials, uses the baby's own corrected cells to build an immune system. Babies with ADA-SCID may benefit from enzyme replacement therapy, but that treatment is only temporary. Almost all babies with SCID will receive antibiotics and immunoglobulin therapy. Early treatment for SCID, within the first few months of life, is essential before infection develops in the baby and compromises their chances of recovery.

What's the best way to protect a baby with SCID?

Babies with SCID should be kept in isolation and come into contact with as few people as possible in order to reduce exposure to germs. The best way to prevent spread of germs is to wash or sanitize hands every time before touching the baby.

How prevalent is SCID?

It's currently estimated that SCID occurs in 1 out of 58,000 births, or 76 cases annually. SCID occurs in babies of all races and ethnicities, however, higher numbers of cases do occur in certain populations such as the Navajo Nation and among Amish and Mennonite communities. SCID affects both boys and girls, but the most common type, X-linked, only occurs in boys.

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SCID Facts

- SCID, or severe combined immunodeficiency, is a life-threatening genetic condition diagnosed through newborn screening when blood is taken and tested.
- Babies with SCID have no functioning immune system.
- SCID is caused by genetic mutations in the genes of cells responsible for the functioning of the immune system cells and close to 20 mutations have been identified so far.
- Most types of SCID are hereditary, though some develop spontaneously.
- Babies with SCID have few or no T cells, which prevents B cell function — T cells activate B cells and kill virus-infected cells; B cells provide antibodies to fight infection.
- A child with SCID is extremely susceptible to serious illnesses such as severe viral respiratory infection, meningitis, bloodstream infections, skin infections, intestinal tract infections, chicken pox, cytomegalovirus, cold sore virus, adenovirus, rhinovirus, parainfluenza virus, mononucleosis, polio, measles, and rotavirus.
- Infections in babies with SCID are fatal within the first year of life if the child is not treated.
- Babies with SCID must be kept in isolation to reduce exposure to germs. The main way to control germs is to wash or sanitize hands before touching a baby with SCID.
- Treatment for SCID is a bone marrow transplant, or gene therapy through clinical trials. In bone marrow transplant, the child with SCID receives stem cells from a donor, which create an immune system; in gene therapy, the child's own cells are altered to create an immune system.
- A treatment for SCID does not "cure" the condition; it simply provides the child with a working immune system that may or may not continue to function in the future.
- Babies with SCID receive immunoglobulin, or Ig, therapy, which is plasma from blood provided by donors. Plasma contains antibodies the child needs to fight infection.
- The Ig therapy is administered either intravenously or subcutaneously on a regular basis, such as weekly or monthly, depending on the child's condition.
- The incidence of SCID is 1 in about 58,000 children, or 76 children, annually.
- To learn more, visit www.scidcompass.org.

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