



# March of Dimes: Health Literacy, Advocacy, and Quality Improvement

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# March of Dimes Mission

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- To improve the health of babies by preventing birth defects, premature birth, and infant mortality
- NBS fits into the categories related to
  - Birth Defects
  - Infant Mortality



# Health Literacy

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Education and Health Promotion (EHP) helps women become healthy so they can have healthy pregnancies and healthy babies



# Reaching Our Audiences

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- March of Dimes health messages focus on preconception, pregnancy and newborn care.
- We also provide information on bereavement and birth defects.
- We target our content to consumers and professionals using a variety of strategies and media.

# Education and Outreach

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## ■ Media

- Print – Flyers, booklets, magazines, organizers, curriculum
- Web – [marchofdimes.org](http://marchofdimes.org), [nacersano.org](http://nacersano.org)
- Email – Ask Us: Personal responses from trained health education specialists to consumer questions in English and Spanish
- Social media – Blogs, Twitter, Facebook, Pinterest, live chats
- Videos - YouTube

# Consumer Print Initiatives

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- All pieces are created in English and Spanish - Many are bilingual, with both languages in a single piece.
- Easy-to-read (ETR) pieces champion efforts to address the problem of low health literacy in our target population.
  - Written at a 5<sup>th</sup>- to 7<sup>th</sup>-grade reading level to accommodate the nearly half of all American adults who have trouble understanding and using health information.

# Newborn Screening (NBS)

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<p>Newborn screening</p>  <p>march of dimes pregnancy &amp; newborn health education center</p> <p>flip it!</p> <p>marchofdimes.com</p>	<p>Pruebas de detección para recién nacidos</p>  <p>march of dimes el centro de enseñanza del embarazo*</p> <p>ncersano.org</p>
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select a category ▼

Search

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[Home](#) > [Baby](#) > [Newborn screening](#) > **Biotinidase deficiency and other disorders**

### What is severe combined immunodeficiency?

Babies with severe combined immunodeficiency (also called SCID) have trouble making white blood cells that work normally. These blood cells help fight off infection, so babies with SCID get sick easily and often. Babies with SCID can't get vaccines that contain live viruses because the vaccine itself can make them sick. About 1 in 100,000 babies is born with SCID each year in the United States. Most are diagnosed by about 6 months of age. Without treatment, most babies with SCID die before age 2.

Signs and symptoms of SCID include:

- **Bronchitis.** This is inflammation (irritation) of the lining of the tubes that connect the trachea (windpipe) to the lungs.
- **Ear and sinus infections**
- **Diarrhea**
- **Meningitis,** inflammation of the lining of the brain and spinal cord
- **Pneumonia,** an infection of the lungs
- **Sepsis,** an infection in the blood
- **Thrush,** a yeast infection in a baby's mouth or throat that can cause cracks in the corners of the mouth and white patches on the tongue, lips, insides of the cheeks and the roof of the mouth

Treatment for babies with SCID may include:

- **Antibiotics.** These are medicines that kill infections caused by bacteria.
- **Stem cell transplant.** Stem cells can develop into many different kinds of cells in the body and can help the body repair itself. They are found in bone marrow, the spongy tissue inside some bones (like hip and thigh bones). They're also in **umbilical cord blood**, the blood left in the umbilical cord and placenta after a baby is born. In a stem cell transplant, stem cells from a healthy person are put into the baby through a tube into a vein. The new stem cells travel through the blood to the baby's bone marrow. Once these cells reach the bone marrow, they can help the baby build up a healthy immune system. The immune system is what helps the body fight off infection. Identification of SCID through newborn screening allows for early stem cell transplants and improved survival.





# March of Dimes Advocacy

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The March of Dimes engages in advocacy at the federal level and in all 50 states on a wide range of maternal and child health issues:

Access to Health Care: Health insurance, Affordable Care Act, Medicaid, CHIP, quality measures

Research and Surveillance: NIH, CDC and other research funding, birth defects surveillance, vital statistics and records collection

Education and Prevention: NBS, tobacco cessation, immunizations, health equity, environmental health, nutrition and obesity,

Nonprofit Issues: Tax issues, postal rates, nonprofit governance

# SCID Advocacy in States


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March of Dimes chapters have advocated successfully for SCID screening in various states since its addition to the RUSP, including:

**2012: Texas, Washington**

**2013: Alabama, Maryland, Ohio, Pennsylvania**

**2014: Arizona, Nebraska, Oregon, Rhode Island**



**fact sheet**

**march of dimes**  
Georgia

**Support Screening for Severe Combined Immunodeficiency (SCID) as part of Georgia's newborn screening panel.**

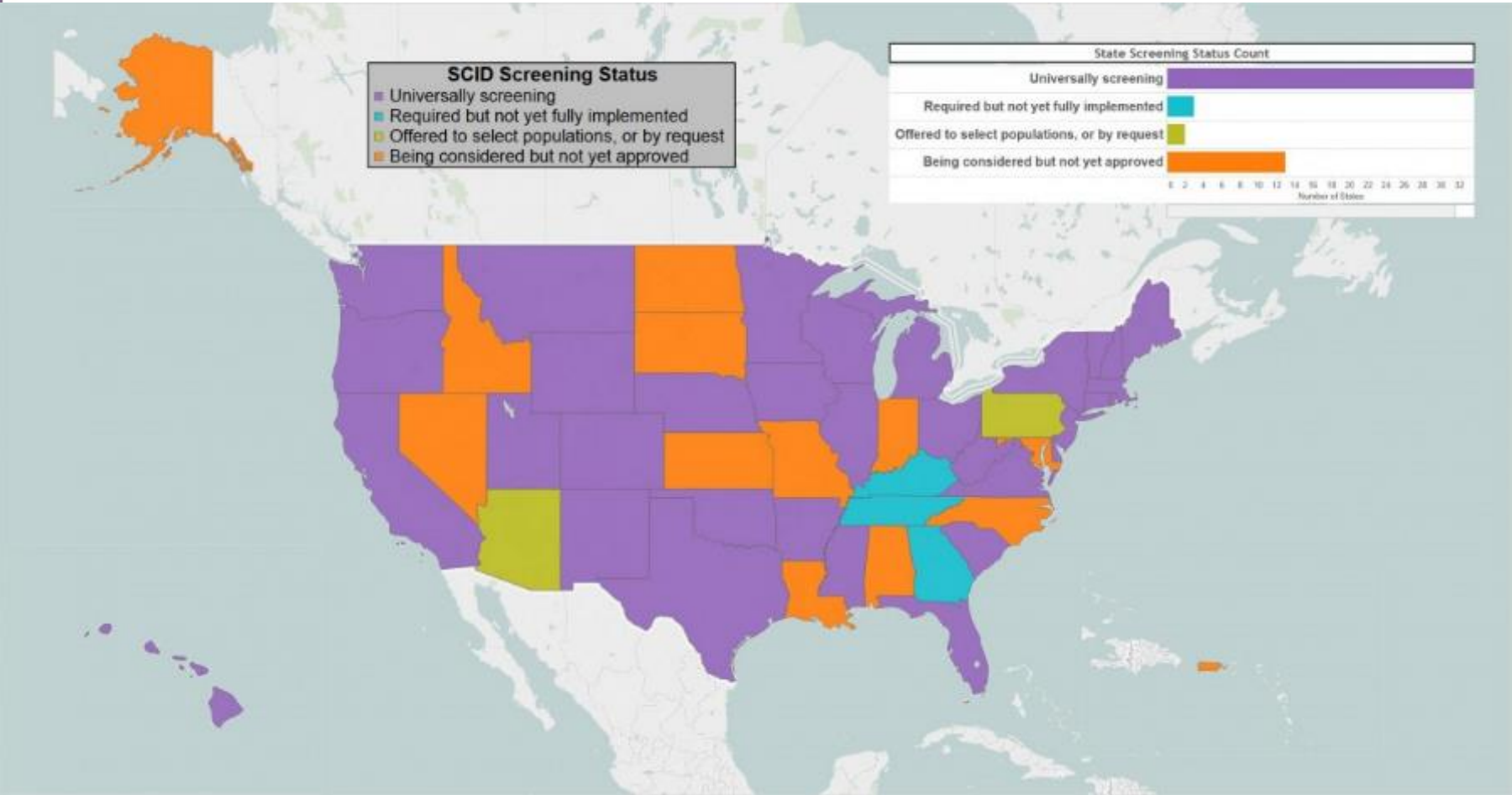
Screening newborns for SCID saves lives.

**What is SCID?**  
Severe Combined Immunodeficiency (SCID) is a term that describes a group of rare inherited disorders characterized by defects in two critical immune system cells that are normally mobilized by the body to combat infections. SCID has been referred to in the popular media as the "bubble boy disease." SCID is not very common and experts estimate approximately 40-100 infants are diagnosed with SCID in the United States every year. The Secretary of the U.S. Department of Health and Human Services added screening for SCID to the Recommended Uniform Screening Panel (RUSP) in May 2010.

**Why Screen for SCID?**  
Without treatment, infants with SCID are more susceptible to and can develop recurrent infections, leading to failure to thrive and oftentimes death. Treatments are available to significantly enhance the health outcomes of infants with SCID who are pre-symptomatic or early symptomatic. Based on several large studies, hematopoietic stem cell transplant from either umbilical cord blood or bone marrow appears to be effective in significantly decreasing the morbidity and mortality associated with SCID.

**Key Points**

- SCID, or "bubble boy disease," is a term that describes a group of rare inherited disorders characterized by defects in two critical immune system cells that are normally mobilized by the body to combat infections.
- Without treatment, infants with SCID are more susceptible to and can develop recurrent infections, leading to failure to thrive and oftentimes death.
- Evidence suggests that the earlier a newborn can receive treatments



Map courtesy of NewSteps, <https://www.newsteps.org/scid>

# Quality Improvement in the NBS System

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- Problems identified by *MJS*
  - Delays in testing led to deaths
- March of Dimes proposed solution
  - Op Ed: Baby Tests Require Culture of Safety
  - Convened NBS QI Workgroup
    - Currently 16 organizations, including AACC, AAP, ACHDNC, ACOG, AHA, AMCHP, APHL, ASTHO, AWHONN, CDC, HRSA, MOD, NICHD, NNSGRC, NSGC, SBTSF

# Summary

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- MOD is a consumer-facing organization with a mission that includes NBS, in which we are focused on
  - Health Education
  - Advocacy and Government Affairs
  - Quality Improvement