

Transplant and Severe Combined Immunodeficiency (SCID)

Learning more about your child's (or your) treatment options can help you make informed medical decisions.

This fact sheet tells you:

- What SCID is
- What the transplant steps are
- When to see a transplant doctor
- Questions to ask your doctor

What is SCID?

SCID is a group of inherited immune system disorders. The immune system helps the body fight infections. With SCID, parts of the immune system are missing or don't work well. Babies born with SCID have many severe infections that keep coming back even after treatment. They also may have a hard time gaining weight or growing.

The 2 most common types of SCID are:

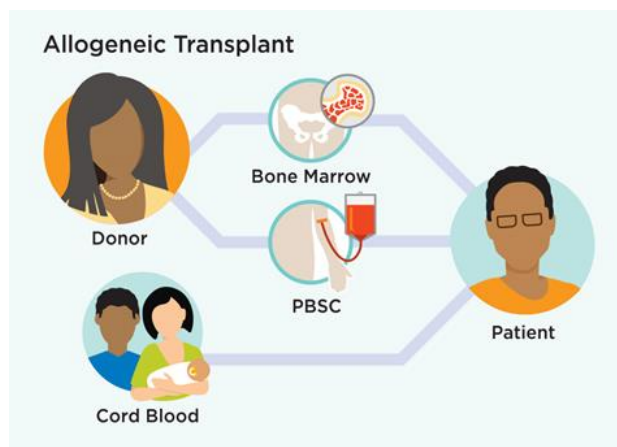
1. **Classical X-linked SCID** – This is sometimes called “bubble boy” disease. Only boys can have this type of SCID.
2. **ADA deficiency SCID** – Children with this type of SCID have low levels of an infection-fighting molecule called ADA. Boys and girls can have this type of SCID. This type of SCID may not cause problems until later in childhood, adolescence or even adulthood.

What is a blood or marrow transplant (BMT)?

BMT, also called bone marrow transplant, is the only known cure for SCID. It replaces the unhealthy immune system with a healthy one.

The type of BMT that treats SCID is called an **allogeneic transplant**. It uses healthy, blood-forming cells donated by someone else to replace the missing or unhealthy immune system. These

healthy cells can come from a family member, unrelated donor, or umbilical cord blood.



Allogeneic transplant steps

1. First, your child's doctor searches for their donor. This can take weeks to months.
2. Then, your child will get chemotherapy, and possibly radiation, to kill the unhealthy cells. This can take up to 2 weeks.
3. On transplant day the donated cells are given to your child through an intravenous (IV) infusion. The new cells travel to the inside of their bones.
4. After a few weeks, the donated cells begin to make healthy blood cells.
5. Then, your child will need many months to recover. Your child will spend some of this time in or near the hospital.

Doctors, nurses and social workers will closely care for your child during the entire process to prevent and treat any side effects or complications.

When to see a transplant doctor

Most children have a better chance of a cure if they have a transplant soon after diagnosis.

Your child should see a transplant doctor as soon as they're diagnosed.

Your first appointment with a transplant doctor

At the first appointment, the transplant doctor will:

- Review your child's medical history
- Talk with you about treatment options and their risks and benefits
- Recommend the best time for your child to get a transplant and prepare for treatment
- Start a donor search

Questions to ask your doctor

- What are my child's chances of a cure with transplant? Without transplant?

- What are the possible side effects of transplant? How can they be reduced?

- How might my child's quality of life change over time, with or without transplant?



AT EVERY STEP, WE'RE **HERE TO HELP**

Be The Match has a team dedicated to providing information and support to you before, during, and after transplant. You can contact our Patient Support Center to ask questions you may have about transplant, request professional or peer support, or receive free patient education materials.

CALL: **1 (888) 999-6743** | EMAIL: **patientinfo@nmdp.org** | WEB: **BeTheMatch.org/one-on-one**

Resources for you

Talk to someone who can help:

- Contact a BMT Patient Navigator:
 - Call: 1 (888) 999-6743
 - Email: patientinfo@nmdp.org

Order free resources to learn more. To see a full list, visit [BeTheMatch.org/request](https://www.bethematch.org/request).

Here are some that you might find helpful:

- VIDEO: *Basics of Blood and Marrow Transplant*
- VIDEO: *Super Sam Versus the Marrow Monsters*
- BOOKLET: *Transplant Basics*
- BROCHURE: *Transplant Outcomes and Treatment Decisions*



Every individual's medical situation, transplant experience, and recovery is unique. You should always consult with your own transplant team or family doctor regarding your situation. This information is not intended to replace, and should not replace, a doctor's medical judgment or advice.