

TRANSPLANT AND SEVERE COMBINED IMMUNODEFICIENCY (SCID)

Learning more about treatment options for severe combined immunodeficiency (SCID) can help you make decisions that are best for your child. Be The Match® can help you understand how transplant may be used to treat SCID.

READ ON TO LEARN ABOUT:

- Transplant as a treatment option
- Questions to ask your doctor

ABOUT SEVERE COMBINED IMMUNODEFICIENCY (SCID)

SCID is a group of inherited immune system disorders. The immune system helps the body fight infections. In these disorders, 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. Babies with SCID have a hard time gaining weight or growing at a healthy rate.

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.

ABOUT BLOOD OR MARROW TRANSPLANT (BMT)

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

Allogeneic transplant is used for SCID. This type of transplant uses healthy, blood-forming cells (blood stem cells) donated by someone else to replace the unhealthy ones. These healthy cells can come from a family member, unrelated donor, or umbilical cord blood. The cells create a working immune system for a child with SCID. First, the child gets chemotherapy (chemo) to kill the unhealthy cells. Then, the healthy, donated cells are put into the bloodstream through an intravenous (IV) catheter. The new cells travel to the marrow inside of the bones and begin to make healthy cells.

The entire transplant process, from the start of chemo until hospital discharge, can last weeks to months. This is followed by many months of recovery near the transplant center and at home. The transplant team will closely watch your child to prevent and treat 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 your child is diagnosed.**

YOUR CHILD'S FIRST APPOINTMENT WITH A TRANSPLANT DOCTOR

At the first appointment, the transplant doctor will:

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

QUESTIONS TO ASK YOUR DOCTOR

Ask questions so you understand your treatment options and can make decisions that are best for your child. Questions you may want to ask include:

- 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?

OTHER RESOURCES TO HELP YOU LEARN MORE

The Be The Match **Patient Support Center** provides support, information and resources for transplant patients, caregivers and families.

Visit: **BeTheMatch.org/patient-before**

Here are just a few resources that you might find helpful:

- Videos: *BeTheMatch.org/LearnTheBasics*
- Video: *BeTheMatch.org/SuperSam*
- Booklet: *Transplant Basics*
- Brochure: *Transplant Outcomes & Treatment Decisions*

Most recent medical review completed March 2017.



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 us 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/patient-after**



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.