

TRANSPLANT AND SICKLE CELL DISEASE (SCD)

Learning more about treatment options for sickle cell disease (SCD) can help you make decisions that are best for you. Be The Match® can help you understand how transplant may be used to treat SCD.

READ ON TO **LEARN ABOUT:**

- How transplant treats SCD
- Questions to ask your doctor

ABOUT **SICKLE CELL DISEASE (SCD)**

SCD is a blood disorder you're born with. It's caused by a change in **hemoglobin**. Hemoglobin is in the red blood cells and helps carry oxygen to all parts of your body. The change causes the red blood cells to become stiff and form a sickle shape. This blocks the blood flow in small vessels which can cause severe pain. Severe pain is an emergency called an acute sickle cell pain crisis. It can also damage your lungs, brain, kidneys and other organs.

SCD is passed on from parents to children through **genes**. Genes are instructions that tell the body how to make all the different substances the body needs to work properly. Defective genes cause the blood-forming cells (stem cells) in the **bone marrow** to make faulty hemoglobin. The bone marrow is the soft, spongy tissue inside bones.

ABOUT **BLOOD OR MARROW TRANSPLANT (BMT)**

BMT, also called a bone marrow transplant, replaces the defective blood-forming cells with healthy cells. Transplant is the only known cure for SCD. However, transplant is only used in patients with severe SCD.

For SCD, the type of transplant is an **allogeneic transplant**. This type uses healthy blood-forming cells donated by someone else to replace the cells that make faulty hemoglobin. First, you get chemotherapy, with or without radiation, to kill the cells that make faulty hemoglobin. Then, the healthy donated cells are put into the bloodstream

through an intravenous (IV) catheter. The new cells travel to the inside of your bones and begin to make healthy blood cells.

The entire transplant process, from the start of chemotherapy or radiation until hospital discharge, can last weeks to months. This is followed by many months of recovery near the transplant center and at home. Doctors, nurses and social workers closely care for patients to prevent and treat any side effects or complications. Transplant doesn't reverse any organ damage that has already happened, but it can stop more damage from happening.

Key points:

- Transplant is the only cure for SCD at this time.
- All transplants for SCD are allogeneic.
- Transplant is only used for patients with severe SCD.
- Transplant doesn't reverse organ damage that already happened.

WHEN TO **SEE A TRANSPLANT DOCTOR**

Doctors recommend that patients with severe SCD see a transplant doctor. This means, patients who have had a stroke, organ damage or frequent pain crises should see a transplant doctor right away.

A transplant doctor can explain the risks and benefits of transplant. Whether transplant is the best treatment option depends on several things, such as the patient's age, how much organ damage the patient has and how much pain a patient has.

Key points:

- Ask to see a transplant doctor if you or your child have SCD with a stroke, organ damage or frequent pain crises.
- A transplant doctor will weigh the risks and benefits of transplant and help you decide if transplant is the best treatment option.

YOUR FIRST APPOINTMENT WITH A TRANSPLANT DOCTOR

At your first appointment, the transplant doctor will:

- Review your medical history.
- Talk with you about your treatment options.
- Discuss the risks and benefits of transplant.
- Make recommendations for you and your other doctors.
- Start a donor search even if you don't need a transplant right away. This can help you get a transplant faster if it's needed later.

QUESTIONS TO ASK YOUR DOCTOR

It's important to ask questions so that you can make informed decisions about your or your child's treatment plan. Questions you may want to ask include:

- What are the risks of waiting or trying other treatments before a transplant?
- Do I (or my child) have any risk factors that might affect how well transplant will work?
- Does my age (or my child's age) affect the risks of transplant?
- What are the possible side effects of transplant? How can they be reduced?
- How might my (or my child's) quality of life change over time, with or without transplant?

OTHER RESOURCES TO HELP YOU LEARN MORE

Be The Match has free resources to help you learn about transplant.

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

Here are just a few that you might find helpful:

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

Most recent medical review completed March 2016.



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

LEARN: BeTheMatch.org/patient EMAIL: patientinfo@nmdp.org

ORDER: BeTheMatch.org/request CALL: 1 (888) 999-6743

TRANSLATED RESOURCES: BeTheMatch.org/translations



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.