



bone marrow transplant in primary HLH

AN OVERVIEW OF WHAT TO EXPECT

Once primary hemophagocytic lymphohistiocytosis (HLH) is highly suspected or diagnosed, treatment usually begins right away. The first step is to get symptoms under control. This is often done to prepare for a bone marrow transplant. The official name for this procedure is hematopoietic stem cell transplantation, or HSCT.

what is HSCT?

HSCT is a medical procedure that is done at a transplant center. It puts healthy blood stem cells from a donor into the body to replace damaged or diseased bone marrow.

what are blood stem cells and bone marrow?

Blood stem cells live in the bone marrow, which is the spongy tissue inside our bones. Blood stem cells help our bodies produce:

- White blood cells that fight infection
- Red blood cells that carry oxygen and remove cell waste
- Platelets that help blood clot

when is HSCT needed?

Sometimes a disease causes the blood stem cells in bone marrow to stop working properly. A transplant may be necessary if this happens in primary HLH. HSCT is the only cure for most patients who have primary HLH. Not everyone who has primary HLH will need a transplant. You and your doctors will discuss if transplant is right for you or your child.

who will do the procedure?

If you or your child needs a transplant, a team of specialists will guide you through the process. Your team will be led by a **hematologist/oncologist**. It will also include a transplant coordinator, surgeons, nurses, counselors, and medical insurance experts.

what is the process for HSCT?



1 Prepare for transplant

Before transplant, the transplant team will make sure the patient's condition is stable.



2 Locate a donor

The transplant team will work with the patient's family to identify a stem cell donor. If the patient has no genetic match in their family, a search will be done through an organization that specializes in finding donors, such as Be The Match, which is run by the National Marrow Donor Program.



3 Stem cell collection

The donor's blood will be circulated through a machine to gather stem cells and store them for transplant.



4 Conditioning treatment

Before transplant the patient will receive chemotherapy to calm their immune system. This will lower the chance of the body rejecting the new stem cells.



5 Transplant

The transplant team will use an intravenous, or IV, line to infuse donor stem cells into the patient, similar to a blood transfusion.



6 Follow-up

After the procedure, the patient's immune system will be very weak. The transplant team will keep close watch to make sure the new stem cells are accepted. They will also look out for infections and other complications.

You can get more information about transplant from these helpful resource groups

It's normal to feel uncertain about HSCT. Ask questions along the way to help you understand the process. And hold onto hope. Many patients with primary HLH have been cured by transplant.

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