

Life After BMT

Updates from the Blood or Marrow Transplant Long-Term Follow-Up Study

Welcome to BMTSS!

UAB SCHOOL OF MEDICINE

Institute for Cancer Outcomes and Survivorship

BMTSS is the **B**lood or **M**arrow **T**ransplant **S**urvivor **S**tudy. This newsletter is for people like you who have had a blood or marrow transplant (BMT) and have agreed to participate in the BMTSS. Brothers and sisters of some BMT survivors are also part of the study. Researchers at the City of Hope in Southern California, the University of Minnesota, and the University of Alabama at Birmingham are working together to better understand the long-term health of patients who have received a BMT. Your participation helps us to reach this important goal!

As part of the BMTSS, you will be asked to complete a questionnaire about your health. Your answers help the researchers to better understand the BMT recovery process, and any health problems that may occur after BMT. Ultimately the



Dr. Smita Bhatia is head of the Institute for Cancer Outcomes and Survivorship in Birmingham, AL where the BMTSS coordinating center is located.

information from the BMTSS participants will be used to help future BMT patients and to guide their doctors and nurses in providing the best care possible after BMT.

The BMTSS started over 15 years ago, and more than 1,500 BMT patients from City of Hope and the University of Minnesota have already participated. We are now expanding the study to follow BMT survivors over time, so that we can better

understand their health as time goes by, and so that we can include patients who have received more recent transplants that use newer types of treatment. The University of Alabama at Birmingham has joined with City of Hope and the University of Minnesota for the expanded BMTSS study. The BMTSS Coordinating Center is now located on the campus of the University of Alabama in Birmingham, Alabama.

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For More Information:

Email:
BMTStudy@ped.s.uab.edu

Call:
855-903-2136 (BMTSS)

Mail:
Blood or Marrow Transplant
Long-Term Follow-Up Study
1600 7th Ave South
Lowder 500
Birmingham, AL 35233

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Introduction to BMT

Blood or Bone Marrow Transplant (BMT), also known as **Hematopoietic Cell Transplant** (HCT), is used to treat certain **hematologic disorders** (diseases that affect the blood). The BMT procedure involves using stem cells to help repair the patient's bone marrow from the effects of chemotherapy and/or radiation given during the transplant. There are two types of BMT: **autologous** and **allogeneic**.

Autologous transplants use the patient's own stem cells, while **allogeneic transplants** use cells from a donor (a family member or an unrelated donor). There are different reasons why a doctor may recommend an autologous or allogeneic transplant, including the patient's diagnosis and health, and the availability of a donor. Stem cells can

be collected from the donor's **blood or bone marrow**; stem cells can also be collected from the **umbilical cord blood** of a newborn baby. In the past, bone marrow was the most common type of stem cell transplant. Today, transplants using stem cells collected from blood are becoming more common.

People who receive an allogeneic transplant are at risk for **Graft-versus-Host Disease**, commonly known as **GvHD**. GvHD happens when the transplanted donor stem cells (the graft) recognize differences between the patient (the host) and the donor. The graft's response to these differences can cause problems with the liver, skin, bowel, and other tissues and organs.

BTSS – Five Primary Aims:

- 1.) Determine the health status of BMT survivors
- 2.) Determine how the health habits of BMT survivors and the treatments given before or during BMT may affect the risk of developing health problems after BMT
- 3.) Examine how the BMT survivors are receiving healthcare many years after BMT
- 4.) Determine the long-term survival experience of BMT patients
- 5.) Develop a bank of DNA samples from BMT patients and their siblings that can be used to help researchers understand why some people may develop health problems after BMT while other people do not develop these health problems

Key Terms

- ◆ **Blood or Bone Marrow Transplantation**— Transplantation of stem cells from yourself or a donor to replace diseased or damaged stem cells
- ◆ **Hematologic Disease**— A disease that affects the blood cells, such as leukemia, lymphoma, or severe aplastic anemia
- ◆ **Autologous Transplantation**— Transplant that uses the patient's own stem cells
- ◆ **Allogeneic Transplantation**— Transplant that uses stem cells from a donor
- ◆ **Graft-versus-Host Disease**— A condition that may occur after allogeneic transplant in which the donor cells cause problems with the liver, skin, bowel, and other tissues and organs
- ◆ **Bone Marrow**— tissue inside of the bones that produces blood cells
- ◆ **Cord Blood**— Blood taken from a newborn baby's umbilical cord that contains a high number of stem cells.

Graft-versus-Host Disease

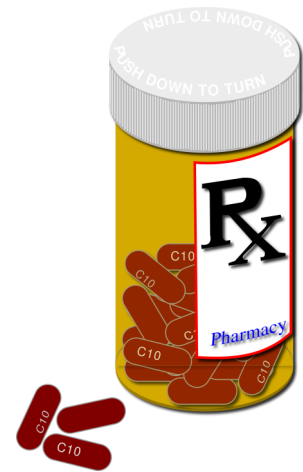
Graft-versus-Host Disease (GvHD) is a common complication that occurs after allogeneic transplantation. GvHD occurs when the donor’s cells respond to differences between the graft (donor) and the host (patient), causing damage to tissues and organs. There are two primary forms of GvHD, known as **acute** and **chronic**. Acute GvHD occurs within 100 days of transplantation, while chronic GvHD occurs more than 100 days after transplantation.

In acute GvHD, the skin is most commonly affected. The liver and intestinal tract may also be affected. Chronic GvHD affects the same areas as acute GvHD. Additionally, the nails, mouth, eyes, muscles, and

female genitalia may be affected by chronic GvHD. Nails may become weak or brittle. The mouth may be dry, and there may be mouth sores or difficulty opening the mouth. The eyes may become very dry. The muscles may become inflamed and there may be muscle loss, especially around the joints. Finally, female genitalia may be affected by dryness and scarring.

Over half of allogeneic BMT survivors will experience chronic GvHD, which may resolve over time. While chronic GvHD can be treated, those who have active chronic GvHD are more likely to develop other medical complications. It is therefore very important for patients with active chronic GvHD to remain under the care of their

transplant center and follow directions for GvHD management



Graft-versus-Host Disease can be a serious condition for those that have received an allogeneic transplant. However, with proper medication and treatment GvHD may resolve.

Acute vs Chronic Graft-versus-Host Disease

Acute

- ◆ Within 100 days of transplant
- ◆ Most Commonly Affected Areas:
 - ◆ Skin-rash
 - ◆ Intestinal tract– Diarrhea, vomiting, loss of appetite, abdominal pain
 - ◆ Liver– Yellowing of eyes and skin

Chronic

- ◆ 100+ days after transplant
- ◆ Most Commonly Affected Areas:
 - ◆ Skin/Intestinal Tract/Liver (see acute GvHD)
 - ◆ Nails– Weak or brittle
 - ◆ Mouth– Dry mouth, sores, difficulty opening
 - ◆ Eye– Dryness
 - ◆ Muscle– Inflammation or loss
 - ◆ Female Genitalia– Dryness or scarring





Contact us!

Institute for Cancer Outcomes and Survivorship

1600 7th Ave S, Lowder 500
Birmingham, AL
35233

Phone:

Institute for Cancer Outcomes or Survivorship: 205-638-2124
Blood or Marrow Transplant Survivor Study: 855-903-2136

Fax: 205-638-2121

Email: BMTStudy@peds.uab.edu



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Recent Publications

“Physiologic Frailty in Nonelderly Hematopoietic Cell Transplantation Patients”

Published in JAMA Oncology in 2016, “Physiologic Frailty in Nonelderly Hematopoietic Cell Transplantation Patients” examines frailty in the BMT survivor population. Frailty is when a person has a group of symptoms such as feeling exhausted, being underweight, and having muscle weakness. While frailty is present in about 10% of elderly people, it is not commonly seen in younger people. BMTSS researchers found that frailty was present in 8% of BMT survivors who were between the ages of 18-64 years. Survivors with active chronic GvHD were at highest risk for frailty. Frailty is linked to an increased risk for illness, so findings from this research have important implications. Since the rate of frailty

seen in BMT survivors is close to that seen in the elderly, this paper stresses the importance of proper monitoring and management of the health of BMT survivors.

Citation: Arora M, Sun CL, Ness KK, Teh JB, Wu J, Francisco L, Armenian SH, Schad A, Namdar G, Bosworth A, Kuo L, Weisdorf DJ, Forman SJ, Bhatia S. **Physiologic Frailty in Nonelderly Hematopoietic Cell Transplantation Patients: Results From the Bone Marrow Transplant Survivor Study.** *JAMA Oncology.* E-published ahead of print Jun 2 2016.

Meet the Staff



The Institute for Cancer Outcomes and Survivorship was founded at the University of Alabama at Birmingham School of Medicine in January of 2015. The Institute focuses on research that will

improve outcomes for cancer and BMT survivors. It houses multiple studies that research a variety of topics including: Long-term outcomes for BMT survivors, improving medication adherence in pediatric patients with leukemia, understanding the risk for developing complications following treatment for childhood cancer, chemoprevention of breast cancer in women who have received chest radiation, HPV vaccination in cancer survivors, hearing loss after cancer treatment, understanding the burden of illness in older cancer survivors, understanding the best way to care for older patients after major abdominal surgery, the health and wellbeing of adoles-

cents and young adults with cancer, and development of ways to determine which elderly patients will tolerate cancer treatment without major complications.



The Institute for Cancer Outcomes and Survivorship (ICOS) is a group of researchers dedicated to improving survivor outcomes through advancement of knowledge and increased follow-up.

