

Life After BMT

Updates from the Blood or Marrow Transplant Survivor Study

BMTSS Progress



Institute for Cancer Outcomes and Survivorship

BMTSS is the Blood or Marrow Transplant Survivor Study. We are a group of researchers from the University of Alabama at Birmingham, City of Hope, and the University of Minnesota. Our goal is to better understand the health of individuals who have received a Blood or Marrow Transplant (BMT). You are receiving this newsletter because you participated in the BMTSS. Although we do not require any action in response to this newsletter, we encourage you to update your contact information with BMTSS staff if you have moved or changed your phone number or email address. That way, we can continue to send you this newsletter and keep you informed about the results of this study, and about future studies that may be of interest to you. If you would like to update your contact information, please email us at BMTStudy@peds.uab.edu or call us at 855-903-2136.

So far we have collected about 3500 questionnaires from survivors and over 1000

questionnaires from brothers and sisters of BMT survivors. In the past several months we have also reached out to the families of those who passed away several years after their BMT. While this is a difficult topic, participation by families of these BMT survivors helps bridge some of our gaps in knowledge, and will allow us to inform healthcare providers about risks and possible preventive methods for future patients. We are immensely fortunate to have supportive families in the BMTSS study. We would not be able to complete this study without the

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For More Information:
Call:
855-903-2136
Mail:
Blood or Marrow Transplant Long-Term
Follow-Up Study
1600 7th Ave South
Lowder 500
Birmingham, AL 35233
Email:
BMTStudy@peds.uab.edu

knowledge and dedication that all of our participants provide. Thank you so much for participating in BMTSS and helping with this important research!

BMT Survivors (3126)



Approximately 2 in 10 BMT Survivors are diagnosed with a new cancer. See **Ask the Researchers** on page 2 for more information on new cancers after BMT.

**Non-Skin
Cancer (189)**

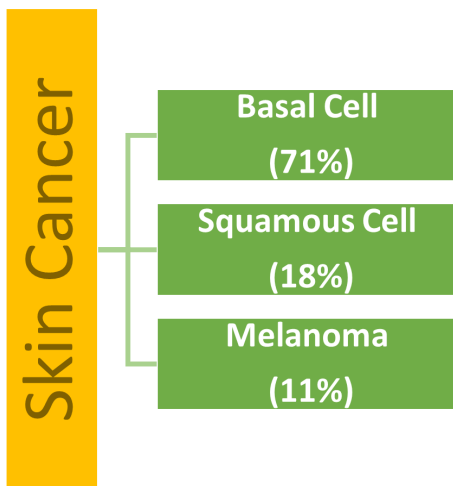
**Skin Cancer
(470)**



Ask the Researchers

After the last newsletter, we received a lot of great questions that we wanted to answer and share. Please send in your questions to the BMTSS Study Staff by emailing BMTStudy@peds.uab.edu. Although the study is still collecting data, we will do a preliminary analysis on 1 to 2 topics or questions that we receive, and publish the results in the next newsletter. In this newsletter, we are pleased to publish the answer to the following question, received in response to our last newsletter.

Question: What information is available about basal cell carcinoma after BMT?



Dr. Smita Bhatia (lead researcher) - Basal cell carcinoma is a type of skin cancer that is very common in BMT survivors treated with radiation – in fact, it is one of the most common “new cancers” that are experienced by BMT survivors. We do not have a clear sense of how long BMT survivors are at increased risk of developing basal cell carcinoma. In fact, this is one of the questions we are trying to address with BMTSS. Also, as people get older, the risk of basal cell cancer increases for everyone. It is for this reason that we advise that all patients who have received radiation see their dermatologist once a year, and more frequently, if there are suspicious skin lesions in between the annual visits.

Our Research - Looking at the data from BMTSS, we found that 659 participants out of 3126 (21%) had experienced a new cancer after their BMT. A new cancer is different from the original cancer diagnosis (not a relapse). Doctors may also call these new cancers “subsequent neoplasms.” These are important to study because they are not related to the original disease, and may be related to radiation or chemotherapy that was given during BMT or to treat the original cancer.

Looking only at the new cancers after BMT, we found that over 70% were some form of skin cancer. Based on participants’ responses we were able to classify skin cancer into three groups. Out of all of the skin cancers reported by our participants, 71% were basal cell carcinomas, 18% were squamous cell carcinomas, 11% were melanomas.

Hopefully this provides a rough idea of the frequency of basal cell carcinoma and other skin cancers in BMT survivors. Based on your responses to the BMTSS questionnaire, we found that most people (2467 out of 3126, 79%) did not report any new cancers after transplant. For those that did report a new cancer, most of these were some form of skin cancer. Some skin cancer can be prevented by using sunscreen. If you have any concerns about new growths, moles, open sores, or raised areas, please contact your primary care physician. Most skin cancers can be easily treated if caught early.



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Types of Skin Cancer:

Basal Cell Carcinoma- the most common type of skin cancer. Basal cell carcinoma can appear in a variety of forms, such as an open sore, a reddish area, a shiny bump (in several colors such as pink, tan, or black), a growth with raised and “rolled” borders, or a scar-like patch. These can be diagnosed and removed by a trained dermatologist or skin doctor.

Squamous Cell Carcinoma- the second most common form of skin cancer. Squamous cell carcinoma may look like a scaly red area, open sore, raised growth with a sunken middle, or wart. These areas may crust or bleed frequently. These can be diagnosed and removed by a trained dermatologist.

Melanoma- a rarer form of skin cancer that can be dangerous if left untreated. Melanomas look similar to moles, but may come in a variety of colors, such as brown, black, pink, red, purple, blue, or white. If you are worried that you may have a melanoma use the “ABCDE rule” from the American Cancer Society.

ABCDE Rule:

A- Asymmetry, the growth may appear uneven in color or size

B- Border, the edges may not be circular and might appear jagged or blurred

C- Color, there may be multiple colors in the growth

D- Diameter, the area appears larger than ¼ inch (the size of a pencil eraser)

E- Evolving, the mole is changing in size, shape, or color

Recent BMTSS Publications

Using data published from the BMTSS cohort, researchers examined the survivorship stories of children who received a blood or marrow transplant (BMT). BMTs are used to treat several types of childhood cancers. Previous research included childhood survivors with adult survivors, or only included certain diseases, or focused on short-term survivorship. We wanted to provide a more comprehensive outlook for childhood BMT survivors. We used data from patients transplanted at age 21 or younger, between 1974-2010, who survived two or more years after their transplant at one of the participating transplant centers. We found that over 75% of our participants were alive 10 years after their transplants. The biggest hurdles for survivors to overcome are relapse of primary disease, additional cancers, and heart conditions. Through advances in medical science, there has been a significant improvement in childhood BMT survival over the past three decades. With studies like the BMTSS, we are able to identify risks, so that doctors can take steps to improve outcomes before late complications occur.

References:

Late Mortality after Autologous Blood or Marrow Transplantation in Childhood – a BMTSS-2 Report

Holmqvist AS, Chen Y, Wu J, Battles K, Bhatia R, Francisco L, Hageman L, Kung M, Ness E, Parman M, Salzman D, Winther JF, Rosenthal J, Forman SJ, Weisdorf DJ, Arora M, Armenian SH, Bhatia S.

Late Mortality after Allogeneic Blood or Marrow Transplantation in Childhood for Leukemia – a report from the Blood or Marrow Transplant Survivor Study-2 (BMTSS-2)

Holmqvist AS, Chen Y, Wu J, Kung M, Ness E, Parman M, Francisco L, Hageman L, Battles K, Bhatia R, Salzman D, Winther JF, Rosenthal J, Forman SJ, Weisdorf DJ, Armenian SH, Arora M, Bhatia S.

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Preventive Health

After a transplant or other intensive medical procedure, many patients try to develop healthier habits. But as the years go by, it can be hard to maintain these changes. Scientific research has shown that sticking with healthier lifestyle choices can have dramatic effects. In this newsletter, we are focusing on Oral Health after BMT.

The most common oral health problems after transplant are dry mouth, oral cancer, and periodontitis.

Dry Mouth- happens when your mouth does not produce enough saliva. This may change your sense of taste (especially for foods you ate before treatment), and it can also make chewing and swallowing difficult. If you have dry mouth, talk to your doctor about artificial saliva or oral rinses. These may reduce some of the symptoms associated with dry mouth.

Oral Cancer- may appear as a persistent growth or sore in the mouth. Oral cancer may be caused by head or neck radiation, and is more likely in individuals who have graft-versus-host disease. If you have a sore in your mouth that is not healing, you should contact your dentist.

Periodontitis- an infection of the gums that may result in loosening or loss of teeth. Gum diseases, like periodontitis, can often be prevented by proper brushing and flossing.

BMT survivors who were transplanted as children may also have damage to the enamel in their teeth, resulting in discoloration or stained patches. Tooth enamel is the hardest substance in the human body, and is the outermost visible layer of our teeth. If you have tooth enamel damage, check with your dentist to find out what options may be available to minimize any discoloration of your teeth.

Here are some healthy lifestyle tips to maintain good oral hygiene and reduce oral problems:

- Find a regular dentist you feel comfortable with, and have regular appointments with them, at least once every six months. Make sure they know your health history and the treatment you received during your transplant.
- Floss your teeth at least once a day.
- Avoid smoking and chewing tobacco. Tobacco is one of the main causes of oral cancer in United States. Complications from radiation or chemotherapy may be worsened by tobacco use.
- Avoid piercings in the mouth, because this can increase your risk of infection.
- Limit the amount of sugar in your food and beverages.

