Life After BMT



The University of Alabama at Birmingham

Updates from the Blood or Marrow Transplant Survivor Study

BMTSS Progress

We hope this summer 2022 newsletter finds you well and that you and your families are staying safe and healthy. BMTSS is the Blood or Marrow Transplant Survivor Study. The BMTSS is currently ongoing at the University of Minnesota, the University of Alabama at Birmingham, and City of Hope. You are receiving this newsletter because you are a BMTSS participant. In this newsletter, we will provide information on two topics (1) COVID-19 Study Results and (2) Sun Safety. As a reminder, all of our older newsletters are available on our website: https://www.uab.edu/medicine/icos/icos-research/bmt-study.

This newsletter will give you an update on the study's progress and let you know how your information is helping us to make further progress in understanding life after BMT. We do not require any action in response to this newsletter unless you have moved or changed your phone number.

[Summer 2022]

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@uabmc.edu

We encourage you to update your contact information by sending us an email at bmtstudy@uabmc.edu or calling us at 855-903-2136. Thank you so much for participating in BMTSS and helping us with this important research!

Recent BMTSS Publications

Blood or marrow transplants (BMTs) are used to treat a variety of hematologic malignancies and other life-threatening illnesses. In preparation for transplant, patients receive "conditioning" regimens that contain chemotherapy and/or radiation. These conditioning regimens differ in intensity, with some regimens containing very high doses of chemotherapy and full doses of total body irradiation (TBI), known as "high intensity" conditioning; while other regimens contain reduced chemotherapy doses and no or lower doses of TBI, known as "reduced intensity" conditioning. A recently published research paper, which used data collected from the BMT Survivor Study (BMTSS), evaluated the association between conditioning intensity and the probability of live birth after a BMT.

The cohort consisted of 1,330 BMT survivors, and 1,039 siblings. Additionally, 172 BMT survivors and their closest in age and same sex siblings were included in a matched-pair comparison. The researchers found that BMT survivors were twice as likely to report no live births when compared with their biologic same-sex siblings. The researchers also found that among BMT survivors, the risk of not reporting a live birth after BMT was significantly higher among those who were older at BMT, those who received high-intensity conditioning that included TBI doses of more than 800 cGy, and those who did not undergo medical interventions to facilitate pregnancy. Importantly, there was no difference in the live birth status between BMT survivors who received high-intensity conditioning without TBI, and those who received low-intensity conditioning with or without low-dose TBI.

The findings from this study that full-dose TBI is associated with a lower chance of live birth after BMT are similar to findings from previous studies. However, this study was the first to evaluate the impact of conditioning intensity on live births after BMT, and the first to report that the probability of live birth among BMT survivors who received low-dose TBI is similar to BMT survivors who received conditioning with chemotherapy alone.

For more information: Nora Balas, Lindsey Hageman, Jessica Wu, Liton Francisco, Elizabeth Schlichting, Alysia Bosworth, Hok Sreng Te, Lennie Wong, Wendy Landier, Donna Salzman, Daniel J. Weisdorf, Stephen J Forman, Mukta Arora, Saro H. Armenian, Smita Bhatia; Conditioning Intensity and Probability of Live Birth after Blood or Marrow Transplantation (BMT) - a Report from the BMT Survivor Study (BMTSS). Blood 2021; 138 (Supplement 1): 2905. doi: https://doi.org/10.1182/blood-2021-146191



Ask the Researchers

We received several great questions since our last newsletter. Here we share some answers with you. Please send your questions to the BMTSS Study Staff by emailing bmtstudy@uabmc.edu .Although the study is still collecting data, we will do a preliminary analysis regarding 1 to 2 topics or questions that we receive, and publish the results in the next newsletter.

Question: How did COVID-19 affect BMT survivors?

The emergence of COVID-19 in late 2019 led to many questions about the virus, infection rates, symptoms, and vaccines. Thanks to so many of you who participated in our most recent survey, our research staff was able to examine the risk of infection with COVID-19 as well as the financial effects of the COVID-19 pandemic on BMT survivors.

Our researchers found that overall, the risk of COVID-19 infection in BMT survivors who participated in our study when compared to their siblings who did not receive a BMT. However, similar to the siblings, the risk was increased for those who were exposed to COVID-19 infection. Importantly, wearing a mask provided the greatest protection.

However, our researchers found that during the pandemic, BMT survivors reported higher out-of-pocket medical costs than their siblings. These high out-of-pocket costs for survivors were found to be significantly associated with the following:

- problems paying medical bills
- deferring care for a medical problem
- taking smaller dose of medication than prescribed
- considering filing for bankruptcy

The financial hardships caused by high out-of-pocket medical costs could affect the health of BMT survivors, for example, if medical care is deferred or omitted due to financial difficulties.

COVID-19 Financial Resources

- Family Reach COVID-19 Emergency Fund: Telephone: 973-394-1411 Website: https://familyreach.org/family-reach-covid-19-letter/
- Patient Advocate Foundation COVID Care: Telephone: 866-316-7263 Website: https://www.patientadvocate.org/covidcare/help/
- Cancer Support Community Helpline: Telephone: 1-888-793-9355 Website: https://www.cancersupportcommunity.org/coronavirus



Medication and Treatment Cost Assistance Programs

- Assist Fund provides financial support to chronically ill patients with high-cost medications: https://tafcares.org/
- Good Days provides financial support by covering co-pays for those with life-altering conditions: https://www.mygooddays.org/
- Patient Advocate Foundation's Co-Pay Relief (CPR), this program provides direct financial
 assistance to qualified individuals for out-of-pocket medication copayment and coinsurance expenses: https://copays.org/
- **Medicine Assistance Tool (MAT)** helps qualifying patients who lack prescription drug coverage obtain the medications they need: https://medicineassistancetool.org/
- Patient Access Network Foundation assists patients with out-of-pocket costs associated with their treatment: https://www.panfoundation.org/
- **Patient Services**, **Inc**. provides assistance with insurance premiums and co-payments for people with chronic diseases: https://www.patientservicesinc.org/

National Financial Service Organizations for Survivors

- Cancer Financial Assistance Coalition (CFAC) is a group of national organizations that provide financial help to patients. CFAC provides a searchable database of financial resources: https://www.cancerfac.org
- **CancerCare** provides limited financial assistance for co-pays, transportation, home care, and child care: https://www.cancercare.org/
- **Family Reach** is a national organization dedicated to eradicating the financial barriers that accompany a cancer diagnosis: https://familyreach.org/ftp/
- **Healthwell Foundation** helps patients with a chronic, life-altering disease afford their medications when health insurance is not enough: https://www.healthwellfoundation.org/
- **Triage Cancer** offers an online tool called Cancer Finances to help guide you through some key topics that may impact your financial situation: https://triagecancer.org/cancer-finances
- Patient Advocate Foundation provides education, legal counseling, and referrals for people with cancer who need assistance managing insurance, financial, debt crisis, and job discrimination issues: https://www.patientadvocate.org/



Preventive Health

During the summer, days are longer and hotter, and many people spend more quality time outdoors. It's important to keep in mind that although the sun may make you feel bright and energetic, the sun's energy can also pose a danger to your health. This energy, called UV radiation, can damage skin and is the cause of most skin cancers.



There are three types of UV radiation:

- * **UVA:** the most common and dangerous type of UV radiation; causes premature skin aging (wrinkles, sun spots), skin cancers, and eye damage
- * **UVB:** does not penetrate as deeply as UVA radiation, but can also cause sunburns, skin cancer, and eye damage
- * **UVC:** stopped from reaching us by the ozone layer, this type of radiation can be quite harmful but is only emitted from artificial

Sunlight is the main way we expose ourselves to UV radiation. There are many factors that determine the strength of the UV rays: time of day, season, distance from the equator, altitude, cloud cover, surface reflections, and contents of the air. However, UV rays and all of the associated risks are still present on cloudy days and in the winter months.

UV Index

Exposure Category	UV Range
Low	< 2
Moderate	3 to 5
High	6 to 7
Very High	8 to 10
Extreme	11 +

The UV Index is a scale that can help you understand exposure to UV radiation. A UV index rating of 3 to 7 indicates that sun protection is needed. A UV index or 8 or above indicates very high to extreme levels of UV radiation. Extra caution is advised, and sun exposure should be avoided if at all possible when the UV index is at 8 or above. You can find the current daily and hourly UV index for your area by entering your zip code at this link: https://www.epa.gov/enviro/uv-index-search

Skin cancer is the most commonly diagnosed cancer in the United States, with an estimated 9,500 people diagnosed every day. There are two main types of skin cancer: melanoma and non-melanoma, which includes basal and squamous cell carcinomas. There are also rarer types of skin cancer, including cutaneous T-cell lymphoma (CTCL), Merkel cell carcinoma, and Kaposi sarcoma.

There is a long list of risk factors for skin cancer, including high lifetime UV exposure, frequent sunburns, blistering sunburns in childhood, use of tanning beds, working outside for prolonged periods, very pale skin, light colored eyes, blonde or red hair, freckles, and number of moles. People who have a family history of skin cancer, have a weakened immune system, have received radiation (including TBI), have received an allogeneic BMT, have received an organ transplant, or are currently taking certain medications, including immunosuppressants, are also at a higher risk of skin cancer. Skin cancer is more common in people who live at higher altitudes or who live in tropical or sub-tropical climates.

Fortunately, most skin cancers can be cured if caught early. This underscores the importance of performing monthly self-checks and seeing a health care provider if you notice any changes or causes for concern. A skin specialist (dermatologist) can perform a biopsy of any concerning skin lesions. Treatment for skin cancer, especially when caught early, most often consists of removal (excision) of the skin lesion.



Preventive Health Continued...

There are several ways that you can protect yourself against sun damage and skin cancer this summer:

- Always use sunscreen when outdoors (SPF 15 or higher, reapplied every 2 hours)
- Try not to spend time outdoors between 10 am and 4 pm (when the sun's rays are strongest)
- Pay attention to the forecasted UV index
- Find shade, but keep in mind that umbrellas, trees, and tents do not provide full protection
- Wear protective clothing (wide-brimmed hats, sunglasses, tightly-woven, loose-fitting clothing)
- · Avoid reflective surfaces, including water, snow, and sand
- Do not tan or use tanning beds
- Conduct a monthly self-check for any skin abnormalities or changes and follow-up with a healthcare provider or dermatologist if needed
 - Be vigilant for new or changing spots, sores that bleed and don't heal for several weeks, a rough or scaly red patch that crusts or bleeds, wart-like growths, a mole changing in size, shape or color, or a mole with an odd shape, irregular border or with more than one color.
 - ♦ Contact your health care provider if you notice any of these potential signs of skin cancer.





Wear long-sleeved shirt and pants



Use sunscreen that is SPF15 or higher



Wear sunglasses and a hat with a wide brim



Seek shade



CDC.GOV/CANCER

Sources

- https://www.epa.gov/radtown/ultraviolet-uv-radiation-and-sun-exposure
- https://www.yalemedicine.org/conditions/skin-cancer
- https://www.cancer.org/healthy/cancer-causes/radiation-exposure/uv-radiation.html
- https://www.cancer.org/healthy/be-safe-in-sun.html