Life After BMT

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

BMTSS Progress

INSTITUTE FOR CANCER OUTCOMES & SURVIVORSHIP
The University of Alabama at Birmingham

BMTSS is the Blood or Marrow Transplant Survivor Study. The BMTSS is currently in progress at the University of Minnesota, University of Alabama at Birmingham, and City of Hope. You are receiving this newsletter because you are a BMTSS participant. We have now collected over 4000 questionnaires from patients who have received a BMT and their families. As we collect more information, we are better able to understand issues related to health and wellbeing after BMT. We continue to publish this information in scientific journals (see "Recent Publications" for more information). We are also continuing to ask for health information from BMT families. We have been inspired to hear stories of survivors and their families and would like to thank everyone who has reached out to tell us about their loved ones.

We are sending you this newsletter to keep you updated on our progress, and to let you know about how your information is helping researchers continue to make progress. We do not require any action in response to this newsletter, except, if you have moved or changed your phone number, we encourage you to update your contact information by sending us an email at BMTStudy@peds.uab.edu or calling us at 855-903-2136. Thank you so much for participating in BMTSS and helping us with this important research!

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For More Information:

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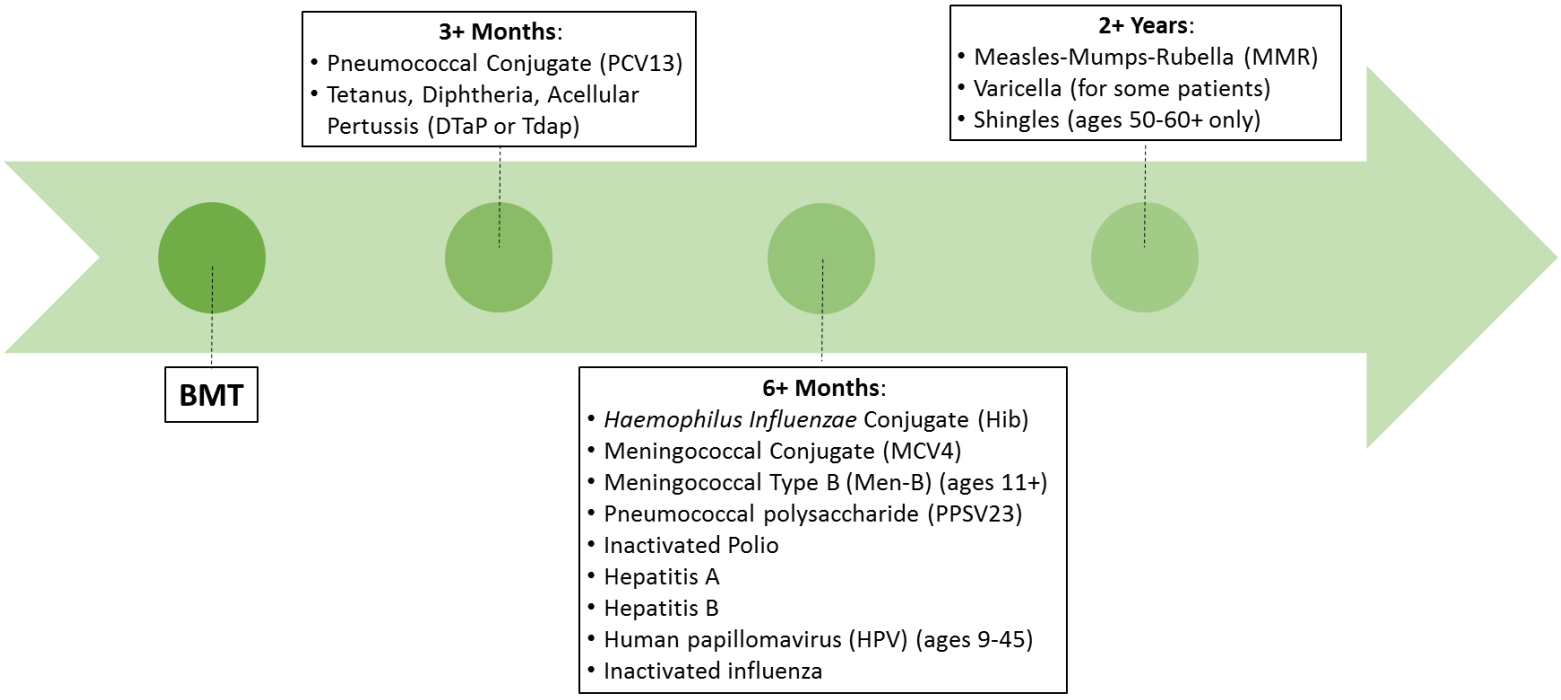
Recent BMTSS Publications

In March 2019 "Late mortality in blood or marrow transplant survivors with venous thromboembolism: report from the Blood or Marrow Transplant Survivor Study" was published in the *British Journal of Haematology*. This article describes the experience of BMT survivors who developed venous thromboembolism, which is a blood clot (thrombus) that starts in the veins, typically in the lower leg, thigh, or pelvis. The blood clot can break loose and travel through the bloodstream (embolus) to the lungs. People who have had cancer treatment, especially those who received BMT, are more likely to have these blood clots. Fortunately, the number of BMT survivors who have this condition is still small. Only 7% of our original BMTSS group reported having been diagnosed with one of these blood clots. Although only a small percentage of patients will be diagnosed with venous thromboembolism, it is important to identify those at highest risk because blood clots can be associated with other serious health conditions. We are still working to identify exactly what health factors put people at risk for these blood clots. Once it is possible to identify the highest risk patients, it may be feasible to use medications to prevent clots before complications occurs.

Ask the Researchers

We have received some questions about vaccinations after BMT. Receiving vaccinations after BMT is important for survivors, so that they can regain immunity that may have been lost during treatment. All survivors need to get re-vaccinated after BMT to protect them from infection. Most BMT survivors begin to receive inactivated vaccines (such as the flu vaccine) about 3 to 6 months after BMT, and live vaccines (such as Measles, Mumps and Rubella [MMR] vaccine) about 2 years after BMT. However, some BMT survivors, such as those with active graft vs host disease, may need to wait longer to receive certain vaccines. The timeline below outlines a typical schedule for vaccination following BMT. It is likely that you may have already received some or all of these vaccinations, since vaccination is typically part of standard follow-up care after BMT. However, if you do not remember receiving these vaccinations after BMT, please talk to your healthcare provider.



Vaccine	Protects Against	Number of Doses	Months after Transplant
Pneumococcal Conjugate (PCV13)	*Streptococcus pneumonia,* a type of bacteria that can cause infections in the lungs (pneumonia), bloodstream (bacteremia or sepsis), or the brain and spinal cord (meningitis)	3 to 4	3+ months
Pneumococcal Polysaccharide (PPSV23)	*Streptococcus pneumonia* (the PPSV23 vaccine should be given 6-12 months after the last dose of PCV13)	1	6+ months
Tetanus, Diphtheria, Acellular Pertussis (DTaP or Tdap)	Tetanus (lockjaw), diphtheria (infection involving the back of the throat that makes it difficult to breathe), and pertussis (whooping cough)	3	3+ months
Haemophilus Influenzae Conjugate (Hib)	*Haemophilus influenza type b,* a type of bacteria that can cause many types of serious infections, including pneumonia, bacteremia, sepsis, meningitis, and epiglottitis (blockage of the throat and windpipe)	3	6+ months
Meningococcal Conjugate (MCV4)	Four types of meningococcal infection (serogroups A, C, W and Y), which can cause infection in the brain and spinal cord (meningitis)	2	6+ months
Meningococcal Type B (Men-B)	Serogroup B meningococcal infection, which can cause infection in the brain and spinal cord (meningitis), for ages 11+	2 to 3	6+ months
Inactivated Polio	Poliovirus, a type of virus that can attack the brain and spinal cord, and may cause paralysis	3	6+ months
Hepatitis A	Hepatitis A, a viral infection of the liver that can cause scarring and liver failure	2	6+ months
Hepatitis B	Hepatitis B, a viral infection of the liver that can cause scarring and liver failure	3	6+ months
Human Papillomavirus (HPV)	Human papillomavirus, a viral infection that can cause certain types of cancer (such as cervical and oropharyngeal cancer), for ages 9-45 years	3	6+ months
Inactivated Influenza	Influenza, a virus commonly known as the “flu”, which can cause serious infections in people with weakened immune systems. The survivor and all family members should receive the flu vaccine yearly.	1 yearly	6+ months
Measles-Mumps-Rubella (MMR)	Measles, mumps, and rubella are viral infections that can cause serious complications in people with weakened immune systems	1 (adults) or 2 (children)	2+ years
Varicella	Chickenpox, a virus that can cause serious complications in people with weakened immune systems (only for survivors who have not previously had chickenpox or the varicella vaccine)	2	2+ years
Shingles	Shingles, an infection that can cause a painful rash and other serious complications in people with weakened immune systems, for ages 50-60+	1 to 2	2+ years

Preventive Health

Since Spring has arrived and fresh vegetables are around the corner, it's a good time to talk about nutrition. Good nutrition is one of the most important ways to keep yourself healthy. While the data is sparse regarding dietary recommendations after BMT, we know that many survivors struggle with eating a healthy diet. Several health conditions that are more common after BMT, such as cardiovascular disease and diabetes, can be helped by healthy diets.

What is a healthy diet after BMT?

The foundation of our dietary intake is made up proteins, carbohydrates, and fats, known as *macronutrients*. A healthy diet should generally have a balance of macronutrients, which supply energy to the body (in the form of calories). In some cases, a physician or nutritionist may recommend a diet enriched or restricted in a certain macronutrient, such as a high-protein diet or a low-fat diet. Another component of a healthy diet is *micronutrients*, which include vitamins and minerals. Although micronutrients do not provide calories, they allow your body to function properly. A healthy diet will have plenty of fruit and vegetables, along with some grains, meat, nuts, and dairy products. Ideally, you should be eating a diet that contains a variety of different foods.

Macronutrients:

Carbohydrates: Should typically provide 45-65% of daily calories. Important for energy, waste elimination, and keeping vital organs and muscles functioning.

Foods rich in carbohydrates: Vegetables, fruits, grains

Proteins: Should typically provide 10-35% of daily calories. Protein is important for energy, tissue repair, and immune system function, and for growth in children. Survivors who are taking steroids, such as prednisone, may need a high-protein diet. Check with your healthcare provider if you are taking steroids.

Foods rich in protein: Meats, cheese, milk, nuts, eggs

Fats: Should typically provide 20-30% of daily calories. Fats are important for energy, cellular maintenance, and allowing you to absorb vitamins properly. They are also important for body growth and development in children. Unsaturated fats (fats that are liquid at room temperature and are often plant-based) are typically healthier than saturated or trans-fats.

Foods rich in fat: Meats, milk products, oils

Micronutrients:

There are many micronutrients that are important and can be obtained from a balanced diet. For BMT survivors, some of the most important micronutrients are *calcium* and *vitamin D*.

Calcium- BMT survivors can be at risk for weakening of the bones. Calcium is stored in the bones and used to perform other functions in the body. It is important for survivors to ingest enough calcium to keep bones strong. Foods rich in calcium include milk, yogurt, cheese, seeds, dark leafy greens, and calcium fortified foods (such as orange juice or oatmeal). The recommended amount of calcium that should be taken in per day is shown by age in the chart below.

Age	Recommended Calcium (mg/day)
1-3 years	700 mg
4-8 years	1000 mg
9-18 years	1300 mg
19-50 years	1000 mg
51+ years	1200 mg

Source: *Calcium and Vitamin D: Important at Every Age,* NIH Osteoporosis and Related Bone Diseases National Resource Center, October 2018.

Vitamin D- Another micronutrient that helps maintain bone health is Vitamin D. This micronutrient helps your body to absorb calcium. Survivors should strive to take in about 600 international units (IU) of Vitamin D per day up to age 70, and 800 IU per day after age 70. Foods rich in Vitamin D include milk, cheese, yogurt, dark leafy greens, fatty fish, and egg yolks