ALLOGENEIC BLOOD & MARROW TRANSPLANT

Patient Education, Book #1
2013 Edition
### TABLE OF CONTENTS

**Chapter 1. Introduction**

- About this Book ................................................................. Page 5
- Important Phone Numbers .................................................. Page 7
- Your Transplant Team ......................................................... Page 8
- Directions, Maps and Parking ............................................. Page 10
- History of Bone Marrow Transplant .................................... Page 13

**Chapter 2. Allogeneic Blood & Marrow Transplant Overview**

- What are Stem Cells .......................................................... Page 17
- Blood Counts and Chemotherapy ........................................ Page 18
- HLA Typing - Finding the Right Donor ............................... Page 20
- Overview – How a Transplant Works .................................. Page 20

**Chapter 3. Pre-transplant Testing and Patient Selection**

- Workup Requirements and Results .................................... Page 25
- Smoking Cessation ............................................................. Page 27
- Donor Testing ................................................................. Page 28
- Informed Consent ............................................................. Page 28
- Clinical Trials ................................................................. Page 29
- Importance of a Caregiver ................................................ Page 29

**Chapter 4. Matched Related Donor Allogeneic BMT** .................................................. Page 33

**Chapter 5. Matched Unrelated Donor Allogeneic BMT** .................................................. Page 43

**Chapter 6. Umbilical Cord Blood Allogeneic BMT** .................................................. Page 51

**Chapter 7. Admission Day**

- What to Pack for the Hospital ............................................ Page 57
If you are reading this book, either you or a loved one is being considered for an *allogeneic blood & marrow transplant*, or “BMT,” here at Cedars-Sinai Medical Center.

“Bone marrow transplant,” “blood & marrow transplant,” “stem cell transplant” and “BMT” all refer to the same procedure. At Cedars-Sinai Medical Center, we have chosen to use the term “blood & marrow transplant” and the acronym “BMT,” so that is how you will see it written throughout this book.

There is a lot of information you need to know and understand about BMT. Your transplant team will teach you all about your transplant. To make it easier, we have created a two book series to reinforce that teaching.

This is Book #1 and it covers everything you need to know up until you are admitted into the hospital for transplant.

Book #2 covers what to expect during and after transplant. It is a guide for you to actively participate in your own recovery.

There are quizzes at the end of each chapter.

**Key Fact:** “Bone Marrow Transplant,” “Blood & Marrow Transplant,” “Stem Cell Transplant” and “BMT” all refer to the same procedure.

These quizzes are to help you remember key points about BMT. Don’t be afraid of them! You can repeat quizzes until you are comfortable with the information. We encourage your main caregiver (spouse, partner etc) to read these books and complete the quizzes with you.

Bring your books with you every time you come to Cedars-Sinai Medical Center. There is a section at the back for important paperwork like lab reports.

Words appearing in bold italics are defined in the glossary at the end of the books.
**Important Phone Numbers**

**Samuel Oschin Cancer Center**

24-hour phone line for clinical problems (fever of 100.4F or greater, vomiting, rash, etc.)

(310) 423-0626

**Transplant Coordinators**

Margarita Guerrero, RN, BSN, OCN ................................................................. (310) 423-3525
Carolina Caso, RN, BSN, CPON ................................................................. (310) 423-2440
Laura Snoussi RN, BSN, OCN ................................................................. (310) 423-6497
Patricia Van Strien, RN, MSN, OCN, CHTC .................................................. (310) 423-5351
Leticia Uy, RN, BSN, OCN ................................................................. (310) 248-8533
Anne Rosenblatt, RN, MSN, Lead BMT Coordinator. ..................................... (310) 248-6691

**BMT Program Assistant**

Mona Homeidan ................................................................. (310) 423-2107

**Samuel Oschin Cancer Center** ................................................................. (310) 423-8030

**Appointments** ................................................................. (310) 423-0650

**Transplant Physicians**

Maria Delioukina, MD ................................................................. (310) 423-1160
Michael Lill, MD ................................................................. (310) 423-1160
Stephen Lim, MD ................................................................. (310) 423-1160
Yuliya Linhares, MD ................................................................. (310) 423-1160
Robert Vescio, MD ................................................................. (310) 423-1825

**Samuel Oschin Outpatient Cancer Center Nurses**

Dr. Lim Patricia Jenkins-Marks, RN, OCN (310) 967-0659
Dr. Delioukina Jillian Otero-Wingate, RN, BSN (310) 423-6588
Dr. Lill Sara Oliva, RN, BSN (310) 423-6299
Dr. Vescio Page Bertolotti RN, BSN, OCN (310) 423-0624
Dr. Linhares Marci Kurtzman RN, OCN (310) 423-0624
Dr. Linhares Melissa Leaverton, RN, BSN, OCN (310) 248-6731

**Financial Coordinator** ................................................................. (310) 423-2684

**Social Work (Outpatient)**

Christina Williams, LCSW ................................................................. (310) 423-1119

**Dietitian Office (Outpatient)** ................................................................. (310) 423-1116

**Rita and Taft Schreiber Blood Donor Facility** ................................................................. (310) 423-5346
Key Contacts

Blood & Marrow Transplant Program Physicians

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Stephan Lim, MD
Associate Director
limsw@cshs.org

Maria Deliukina, MD
Hematologist/Oncologist
maria.delioukina@cshs.org

Yuliya Linhares, MD
Hematologist/Oncologist
yuliya.linhares@cshs.org
Driving Directions

Note: It is illegal to turn left into P6 from Beverly Blvd.

From Beverly Hills
• Follow Wilshire Boulevard east.
• Turn left onto La Cienega Boulevard
• Turn left onto Third Street
• Go one block, turn right onto San Vicente Boulevard
• Go one block, turn left onto Gracie Allen Drive
• Turn right onto George Burns Drive
• Turn right onto Beverly Blvd. and enter P6-Samuel Oschin Cancer Center Parking Lot

From East San Fernando Valley
• Take Laurel Canyon Boulevard south over the Hollywood Hills
• Laurel Canyon Boulevard turns into Crescent Heights Boulevard when you cross Sunset
• Follow Crescent Heights to Beverly Boulevard
• Turn right onto Beverly Boulevard
• Turn left onto San Vicente Boulevard
• Turn right onto Gracie Allen Drive
• Turn right onto George Burns Drive
• Turn right onto Beverly Blvd. and enter P6-Samuel Oschin Cancer Center Parking Lot

From Orange County
• Take the 405 north to the 10 east
• Exit La Cienega Boulevard heading north
• Turn left onto Third Street
• Turn right onto San Vicente Boulevard
• Turn left onto Gracie Allen Drive
• Turn right onto George Burns Drive
• Turn right onto Beverly Blvd. and enter P6-Samuel Oschin Cancer Center Parking Lot

From San Bernardino County
• Take the 10 west
• Exit La Cienega Boulevard heading north
• Turn left onto Third Street
• Turn right onto San Vicente Boulevard
• Turn left onto Gracie Allen Drive
• Turn right onto George Burns Drive
• Turn right onto Beverly Blvd. and enter P6-Samuel Oschin Cancer Center Parking Lot

Front entrance of the Samuel Oschin Cancer Center from P6 parking lot.
Campus Map

Note: It is illegal to turn left into P6 from Beverly Blvd.
History of Blood & Marrow Transplant

Physicians first began investigating bone marrow transplantation (BMT) in the 1950’s. They discovered that bone marrow cells given through an IV could replace a patient’s diseased bone marrow so it would make healthy new blood cells.

BMT is recognized as an effective treatment for certain types of malignant (cancer) and non-malignant (non-cancer) diseases. Stem cells are collected from either the blood or the bone marrow.

At Cedars-Sinai Medical Center, the BMT Program was founded in 1990. Since then, we have completed more than a thousand blood & marrow transplants. This number is growing at a rate of over 140 transplants per year.

During a blood & marrow transplant, high doses of chemotherapy are given to eliminate the disease. Sometimes radiation is also used. As a result of therapy, the bone marrow is destroyed and needs to be replaced with healthy blood-forming stem cells.

Stem cells are collected from either the blood or the bone marrow. The transplant occurs when the collected stem cells are infused through an IV into the patient.

When a person’s bone marrow is replaced with their own stem cells, this is called an autologous blood & marrow transplant. If the bone marrow is replaced by someone else’s stem cells, this is called an allogeneic blood & marrow transplant. This book discuss topics specific to allogeneic BMT. Autologous BMT is a very different procedure with a separate two book series.

Key fact: When a person’s bone marrow is replaced with someone else’s stem cells, this is called an allogeneic blood & marrow transplant.
Quiz: Chapter 1

Question 1

My transplant doctor is:

a) Dr. Michael Lill
b) Dr. Stephen Lim
c) Dr. Robert Vescio
d) Dr. Maria Deliokina
e) Dr. Yuliya Linhares

Question 2

My BMT Coordinator is:

a) Carolina Caso
b) Leticia Uy
c) Margarita Guerrero
d) Anne Rosenblatt
e) Laura Snoussi
f) Patricia Van Strien

Question 3

Bone marrow transplant, blood & marrow transplant, stem cell transplant and BMT all refer to the same procedure.

a) True
b) False

Question 4

In an allogeneic blood & marrow transplant, the stem cells are collected from a sibling, an unrelated person or a baby’s umbilical cord:

a) True
b) False

Question 5

The 24-hour Samuel Oschin Cancer Center nurse line for clinical problems is (310) 423-0626.

a) True
b) False
What Exactly are Blood Stem Cells?

Imagine a family tree. The *stem cell* is the ancestor at the top. All of the descendents come from that ancestor. Like relatives, they look different and perform different functions.

Blood *stem cells* originate inside *bone marrow*, the spongy tissue deep inside of bones. They also float around in circulating blood. We refer to those as *peripheral blood stem cells* or PBSC’s.

**Key Fact:** Stem cells are the grandfather of all blood-forming cells.

A person must have healthy bone marrow and blood cells to live.

Blood *stem cells* can be collected from the bone marrow or the circulating blood. We will discuss this in more detail in Chapter 5.
Complete Blood Count (CBC): The Basics

Blood stem cells reproduce and divide into three main cell types:

- **White blood cells** (WBCs)
- Red blood cells
- **Platelets**

1. **White Blood Cells (WBCs)**

WBCs make up your immune system. They are warriors that fight infections caused by invaders like bacteria, viruses, and fungus. White blood cells are also involved in allergic reactions.

One specific type of white blood cell is the neutrophil. When your neutrophil count is low (below 1), you are neutropenic. When you are neutropenic, you are at risk for infection because your immune system does not have enough warriors to fight back effectively.

You will hear your transplant team talk about your ANC, or absolute neutrophil count. This is the specific number of neutrophils you have that are capable of fighting infections.

Normal Range for WBCs = 4 to 11 (thousand)
Normal Range for ANC = 1.8 – 8 (thousand)

2. **Red Blood Cells (RBCs)**

RBCs contain hemoglobin (HgB). Hemoglobin is a vehicle that drives oxygen around your body. It is what gives you rosy cheeks and pink nail beds.

When hemoglobin levels are low, it is called anemia. Symptoms of anemia include fatigue, shortness of breath and a fast heartbeat. A transfusion of packed red blood cells (PRBCs) can correct anemia.

Typically, we transfuse PRBCs when the hemoglobin is less than 7 G/dl. The normal range for hemoglobin is 13 to 17 G/dL.

3. **Platelets**

Platelets are involved in blood clotting. When you cut yourself, platelets plug the injury and stop the bleeding.

When platelets are low, it is called thrombocytopenia. This condition carries a risk of spontaneous bleeding. The bleeding could occur on the outside (example: a nose bleed) or on the inside (example: in the brain). The risk of major bleeding increases when the platelet count is less than five thousand.

Platelet transfusions can correct low platelets. Typically we transfuse when the count is less than 10 (thousand). The normal range for platelets is 150 to 450 thousand.

White blood cells, red blood cells and platelets make up a complete blood count or CBC. It is very important that you understand what your CBC is and why we check it every time you come to the Samuel Oschin Cancer Center.
Chemotherapy

The National Cancer Institute defines cancer as abnormal cells that divide without control and invade other tissues.

Chemotherapy destroys rapidly dividing cells, making it an effective cancer treatment.

There are hundreds of types of cancer, and just as many different types of chemotherapy. A lot of research has been done to decide which chemotherapy drugs and doses work best for each type of cancer.

The chemotherapy drugs used in a BMT have a common feature: the higher the dose, the greater the number of cancer cells destroyed.

Chemotherapy cannot tell the difference between a rapidly dividing cancer cell and a rapidly dividing healthy cell. The destruction of healthy cells results in side effects from chemotherapy.

Healthy cells that divide rapidly include:

- Hair. This is why many cancer patients lose their hair. Luckily, this is temporary and the hair grows back when treatment is over. In the meantime, we can provide you with head/wig covering resources.

- Gastrointestinal (GI) tract. These cells line your throat, stomach, and intestines. Damage to these cells causes nausea, vomiting, diarrhea and mouth sores. Medications can help alleviate some of these symptoms.

- Bone marrow/blood cells. Destruction of these cells is called myelosuppression. To measure this, we check the complete blood count (CBC). When your CBC numbers are below the normal range, you are myelosuppressed.

Typically, myelosuppression limits the amount of chemotherapy a person can have. The longer myelosuppression lasts, the greater the risk of developing an infection or complications from anemia and/or bleeding.

High doses of certain chemotherapy drugs are very effective at treating cancer but they are also myeloablative. This means that they destroy the bone marrow beyond its ability to ever recover.

To safely recover from high-dose myeloablative chemotherapy, your bone marrow must be “rescued” with healthy stem cells. This is why you need a blood & marrow transplant.

Finding the Right Donor - HLA (Human Leukocyte Antigen) Typing

HLA refers to proteins that live on the surface of white blood cells. The proteins help your immune system recognize which cells belong inside your body (“self”) and which cells do not (“not self”).

Think of HLA typing like a fingerprint on the surface of cells inside your bone marrow. It has nothing to do with your blood type. The HLA system is very diverse with over a quintillion different possible protein combinations! Your unique combination is inherited. Half of your typing comes from your mother and the other half from your father.

HLA testing is how we find you a donor for allogeneic BMT. The test requires a small blood sample and sometimes a swab of your cheek. Potential donors also give a blood sample, and their results are compared to yours. A suitable donor has the same, or almost the same, HLA “fingerprint” (HLA typing) as you.
Please see the examples below to help you understand HLA matching.

Research has shown that matching these pairs:

- Improves the chance of success for the transplant
- Decreases the risk of transplant related complications

Please see specific chapters to find further information about HLA testing siblings (chapter 4), unrelated donors (chapter 5) and umbilical cord units (chapter 6).

### Key fact:
The HLA markers we look at are called HLA-A, B, C, DRB1 and DQ. These five pairs make a total of ten markers to match. The minimum requirement for an HLA match for adult donors is 8 of 10. For cord blood transplants, we only need to match at HLA-A, B and DRB1, and the minimum match requirement is 4/6.

### Examples of HLA Matching

**A. 6 of 6 Match / 10 of 10 Match**

**PATIENT**
- A
- B
- DRB1
- C
- DQ

**DONOR**
- A
- B
- DRB1
- C
- DQ

- **Example A** shows the patient’s antigens (A, B, DRB1, C and DQ) all match the donor’s antigens. The 6 of 6 match means that there is a perfect match at A, B, DRB1. A 10 of 10 match means there is a perfect match at A, B, DRB1, C and DQ.

**B. 5 of 6 Match / 9 of 10 Match**

**PATIENT**
- A
- B
- DRB1
- C
- DQ

**DONOR**
- A
- B
- DRB1
- C
- DQ

- **Example B** shows that one of the patient’s A antigens does not match one of the donor’s A antigens. Therefore, this is a 5 of 6 match or a 9 of 10 match.

**Processing Time:** Once the HLA lab receives the blood, results take 7-10 business days to process. The search process can take a while, and sometimes it may feel as though nothing is happening. Rest assured, your BMT Coordinator will be checking for results and notifying you immediately when they come back. If you are feeling uneasy, feel free to call your BMT Coordinator for an update at any time.

**Overview: Allogeneic Blood & Marrow Transplant**

**Allogeneic** is defined as “taken from different individuals of the same species”. In the setting of Blood & Marrow Transplant, allogeneic refers to a procedure in which a person receives stem cells from an HLA-matched donor. The donor may be a sibling, an unrelated person, or a baby’s umbilical cord blood.

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Sibling stem cells will be collected at Cedars Sinai Medical Center. This process is explained in more detail in chapter 4.

Unrelated adult donor stem cells will be collected at a hospital close to where they live and brought to Cedars-Sinai Medical Center by courier. Umbilical cord blood units arrive by courier as well. Please see chapters 5 and 6 for further details about these types of BMT.

Conditioning refers to the chemotherapy and radiation given before the transplant. This is also known as the preparative regimen because it prepares the body to receive the donor cells. This therapy is given over a period of four to twelve days depending on the disease being treated and the overall health of the patient.

Once conditioning therapy is complete, the “transplant” will occur.

The donor’s collected stem cells are infused into the patient through a vein. It looks very much like a blood transfusion. An experienced nurse performs the BMT infusion at the bedside.

Following the infusion of stem cells, or “transplant”, is a three to six week hospital stay. During this time, the patient is monitored very closely for side effects. The side effects from conditioning therapy include:

- Low blood counts
- Fever and Infection
- Fatigue
- Bleeding
- Nausea, vomiting and diarrhea
- Mouth sores
- Decreased appetite
- Skin rash

The healthcare team will be managing these side effects with medications, blood transfusions, IV fluids and interventions as appropriate.

Every day, the Complete Blood Count (CBC) will be checked. After conditioning therapy, the CBC values will drop below normal. The neutrophil count will fall close to zero, and can remain low for several weeks. During that time, the patient is at high risk for infections. That is also the time when the patient feels the sickest. When the neutrophils start to recover, so does the patient. This is called engraftment. After four to six weeks, the patient will be discharged home.

Discharge from the hospital is dependent on the following factors:

1. Blood counts have returned to a level the doctor feels is safe
2. No fever or need for IV antibiotics
3. Ability to drink fluids; nausea/vomiting/diarrhea controlled by oral medications.
4. Ability to walk and function safely at home
5. Discharge medications are in hand and medication schedule is understood.

The patient will be required to see their transplant doctor frequently in the first 100 days after transplant.

Chapter 9 will briefly discuss conditioning therapy. Book #2 will go into greater detail about conditioning therapy, transplant, short and long-term side effects, recovery, and post-transplant instructions.
Timeline

The timeline varies depending on the availability of the donor. Once a donor is identified, the hospital admission lasts on average 4-6 weeks, but complications may extend this timeframe. Recovery after discharge may take several months to even a year or more. The following timeline is based on averages. Individual cases vary.

In some cases it may be possible to have some or all of your *allogeneic* BMT done as an outpatient. Your doctor will let you know if this is a safe option for you.

<table>
<thead>
<tr>
<th>Identify a Donor</th>
<th>Conditioning</th>
<th>Transplant</th>
<th>Engraftment</th>
<th>Follow-up with BMT doctor in clinic</th>
</tr>
</thead>
<tbody>
<tr>
<td>3-12 weeks</td>
<td>6-12 days</td>
<td>4-6 week stay in hospital unit 4SW</td>
<td>Required for discharge home</td>
<td>Minimum six months</td>
</tr>
</tbody>
</table>
Quiz: Chapter 2

Question 1
Blood stem cells reproduce and divide to make white blood cells, red blood cells and platelets.

a) True  
b) False

Question 2
When a patient is neutropenic, what are they at risk for?

a) Fatigue  
b) Infections  
c) Nosebleeds

Question 3
When a patient is anemic, they will look pale and feel tired.

a) True  
b) False

Question 4
The complete blood count (CBC) measures white blood cells, red blood cells and:

a) Liver enzymes  
b) Stem cells  
c) Platelets

Question 5
Chemotherapy kills both cancer cells and healthy cells.

a) True  
b) False

Question 6
Myeloablative chemotherapy does what to the patient’s bone marrow?

a) Nothing  
b) Causes an increase in white blood cells  
c) Damages it beyond its ability to recover

Question 7
What is the first step for allogeneic BMT?

a) Engraftment  
b) Pre-testing  
c) Identifying a donor

Question 8
A BMT infusion is a surgical procedure done in the operating room.

a) True  
b) False

Question 9
Approximately how long is the hospital stay for an allogeneic blood & marrow transplant?

a) 5-6 days  
b) 2-4 weeks  
c) 4-6 weeks

Question 10
Patients going through BMT are at an increased risk for infection because:

a) The food in the hospital is so bad  
b) They need blood transfusions  
c) Their ANC and white blood cell count drop to almost zero for several days.
Work-Up Requirements and Results

Before you are admitted to the hospital for transplant, you must complete a “pre-transplant workup”. There are two reasons why this is necessary:

1. The transplant team must be certain that the organs are functioning within a safe range.
2. The insurance company requires these results to authorize payment for the transplant.

Pre-transplant testing may be completed at Cedars-Sinai Medical Center or through a local doctor.

It is highly recommended that you see your dentist prior to having a transplant. Any dental work should be completed BEFORE chemotherapy is given.

All patients must complete:

- **Echocardiogram.** This is an ultrasound of the heart to show how well it pumps blood to the body.

- **EKG.** Measures the electrical activity of the heart.

- **Pulmonary function study.** Measures the lungs’ ability to perform effective breathing and oxygen delivery. This test requires you to follow instructions to breathe in, hold your breath, and exhale forcefully. Caffeine and smoking are not allowed on the day of testing as they will affect the results.

- **Chest X-ray.** Evaluates the heart, lungs and chest wall for abnormalities.

- **Blood and urine tests.** Evaluate kidney and liver function, complete blood count, and in some cases, help to measure disease status

- **Infectious disease panel.** You are screened for a variety of viruses even though you are donating a blood product for yourself. Please be aware that HIV testing is done on all BMT patients.

- **Social work/psychiatric consult.** This must be completed at Cedars-Sinai Medical Center by the BMT social worker. It is requested that your main caregiver be present at this appointment. This is to ensure that you are mentally and emotionally prepared for your transplant.

Once you are admitted to the hospital, specialists in rehabilitation medicine, palliative care, nutrition, and the dentist is available as needed. Some patients will also need:

- **Positron emission tomography (PET scan).** You are injected with a small amount of radioactive sugar that cancer cells quickly consume. This causes them to light up on the scan so that doctors can easily visualize their location in the body. You need to fast prior
to the PET scan to make sure that your own body sugar is not too high.

- **Computed tomography (CT) scan.** A series of X-ray pictures taken of the body from different angles to search for abnormalities. This test is often done at the same time as a PET scan to confirm findings.

- **Magnetic resonance imaging (MRI) scan.** Uses very high powered magnets to form detailed pictures of the body’s soft tissues and identify areas where tumors are present. You may not be able to have an MRI if you have any metal inside your body.

- **Bone scan.** Uses a small amount of radioactive material to create images of bones on a computer screen. This test is useful in finding spread of cancer to bones.

- **Bone marrow biopsy.** A sample of bone marrow is examined to confirm disease status and/or remission.

- **Tissue-specific biopsies.** A small sample of tissue (a lymph node, for example) is removed and examined in the lab. This confirms the presence of disease in a specific location.

Not every patient is a good candidate for an allogeneic blood and marrow transplant. There are many factors that must be considered before moving forward, such as:

- Response to chemotherapy/radiation
- Organ function (heart, lungs, liver, kidneys)
- Overall health and activity level
- Caregiver available to assist with your medical care and transportation

Your transplant doctor will review your medical situation carefully before an approval for the BMT is given. This is for your safety and benefit.

The transplant team may decide that you do not qualify for a transplant because they believe the risks outweigh the benefits. In this case, you will not receive a transplant from Cedars-Sinai Medical Center.

If you do not meet minimum standards for BMT, the following may be suggested:

- Other types of treatments/chemotherapy/radiation
Key Fact: the transplant team may decide that you do not qualify for a transplant because they believe the risks outweigh the benefits.

- A clinical trial at Cedars Sinai Medical Center if one is available, or at another hospital.

- Another opinion from a hospital that may have different standards than Cedars-Sinai Medical Center.

Please feel free to discuss this with your BMT coordinator or transplant doctor.

Smoking Cessation

Cedars Sinai is a completely smoke-free campus. All patients and visitors coming to Cedars-Sinai must be aware that smoking is not permitted anywhere on campus. There is no smoking on sidewalks, in parking structures or inside vehicles (whether parked or driving through campus). This is part of ongoing efforts to ensure a healthy environment for our patients, visitors and employees.

Certain insurance companies will not pay for an allogeneic blood & marrow transplant if you are a smoker. They may require a no-smoking contract be signed and periodically request blood or urine tests to ensure compliance.

Cedars-Sinai recommends the following resources to help patients and visitors quit smoking:


- California Smokers’ Hotline: Free phone-based counseling at 1-800-NO-BUTTS.

- Cedars-Sinai Medical Group Smoking Cessation Clinic


- National Cancer Institute: www.cancer.gov/cancertopics/smoking. Online list of “Free Help to Quit Smoking” resources.

Feel free to discuss options for quitting with the BMT coordinator or your doctor.

Alcohol and Drug Addictions

Like smoking, some insurance companies will not authorize a blood & marrow transplant if you have an alcohol or other drug addiction. They may require a contract be signed and blood tests to periodically screen for these substances.

Being honest with your transplant team about these issues is very important. Our goal is to get you through BMT safely. In order to do that, we need to know if you have any alcohol or drug-related problem or concern. We will then direct you to the right professional and resources for help.
Donor Testing

All *allogeneic* BMT donors must pass a medical examination. A doctor will ask them detailed questions about their health, lifestyle and travel history. Their blood will be tested several times for infectious diseases. These are requirements that ensure safety for both you and the donor. Specific details about donor testing are described in chapter 4 (siblings) chapter 5 (unrelated donors) and chapter 6 (umbilical cords).

Informed Consent

Before admission, the doctor will explain in detail the treatment plan, risks and benefits and expected side effects. This is called *informed consent*.

At the end of this discussion, you must sign consent forms for:

- **Chemotherapy/radiation** and *allogeneic blood & marrow transplant*
- Research participation*
- Transfusion of blood products**

*Not all patients qualify for research. This is discussed in the next section.

**For Jehovah’s Witness patients, this consent form will be omitted because blood products will not be given.

Important tip: The informed consent discussion may be the last time you see the doctor before being admitted to the hospital. This is a good time to ask any remaining questions you have about BMT.

Participating in Research

Thank you for being our partners in health. Please help us help other transplant patients like you.

The Stem Cell Therapeutic and Research Act of 2005 requires us to anonymously collect data about your transplant throughout the first post-transplant year and then annually. This data is analyzed so that outcomes for future transplant patients can be improved worldwide.

Your transplant doctor will eventually discharge you back to your local oncologist. Please let us know which doctor you are seeing so we may contact them for updates on your condition.

Please contact us on each anniversary of your transplant to let us know how you are doing.

Please contact us anytime your address or contact information changes:

Anne Rosenblatt, RN, MSN
Lead BMT Coordinator for Quality Assurance
Phone: (310) 248-6691
e-mail: rosenblatta@cshs.org
Clinical Trials

A *clinical trial* is a research study testing how well new medical treatments work in people. Usually they compare a new method with an already tested one.

There are several clinical trials open in the *Blood & Marrow Transplant* Program at Cedars-Sinai Medical Center. Patients qualifying for clinical trials will be informed and educated about the details of the study.

It is always up to you to decide whether or not you want to participate in the clinical trial you are offered.

If you do not qualify or choose not to participate, you will receive the transplant according to current standards of care. The level of medical care you receive will not change in any way.

Things to consider:

- The study drug may or may not work better than the standard treatment
- The study drug may or may not have fewer side effects
- Your condition may improve, worsen or remain unchanged
- Your personal health information will need to be collected and shared with other clinicians involved in conducting the study

While no benefit is ever guaranteed, we hope the information learned from our research studies will benefit future patients by helping us learn more about the disease and how to treat it.

Importance of a Caregiver

A caregiver is someone who provides emotional support, physical care and practical assistance for you before, during and after BMT. In order to have a transplant at Cedars-Sinai Medical Center, you must identify a caregiver to assist you through the BMT process and recovery.

This person must be available to drive you to the hospital at anytime of day or night for at least 100 days after your BMT. They do not have to be by your side the whole time. However, they must be a phone call away and able to drop everything to attend to you if needed.

Caregivers are usually friends or family members, but can be anyone you decide. Some things to consider before choosing your caregiver:

- Do you get along well with this person?
- Can this person take you to medical appointments when needed?
- Can they take a leave of absence from work (Family Medical Leave Act – FMLA) and financially support themselves during this extended absence?
• Does this person handle stressful situations well?
• Will this person support your healthcare decisions and be an advocate for you?

Some important roles of the caregiver are:

• Remembering and following medical instructions
• Attending medical appointments and assisting with transportation
• Staying with you in the hospital
• Organizing health information
• Reporting changes in your health condition to the medical team
• Advocating for you
• Communicating with friends and family

_Blood & Marrow Transplant_ is a long, emotionally and physically challenging process for you and your loved ones. Feel free to discuss any concerns you have with your BMT coordinator, nurse, doctor, or social worker.

The National Marrow Donor Program also has many excellent resources for patients and caregivers. Please contact the NMDP’s Be the Match Patient Services at 1-888-999-6743 or marrow.org/patient/caregiving for more information.
Quiz: Chapter 3

Question 1
Pre-transplant testing may take place at Cedars-Sinai or through a local doctor.

a) True
b) False

Question 2
Every patient going through transplant must have their blood checked for infectious diseases like HIV and hepatitis.

a) True
b) False

Question 3
If a patient needs dental work, they should wait until after transplant to get it done.

a) True
b) False

Question 4
It is possible that a patient will not qualify for a transplant and will be offered different treatment instead.

a) True
b) False

Question 5
Patients and visitors that smoke may do so on the Plaza Level as long as they are standing far away from the doors.

a) True
b) False

Question 6
Patients should not ask any questions during the informed consent process, they should just listen to what the doctor says.

a) True
b) False

Question 7
Clinical trials are open for all patients and participation is required.

a) True
b) False

Question 8
If a patient participates in a clinical trial, they are helping future transplant patients.

a) True
b) False
If your sibling is an HLA match to you, they are a "Matched Related Donor" and may donate stem cells for your BMT.

It can be an exciting, heartwarming experience to receive stem cells from your sibling. It can also be very stressful.

Many patients are concerned about what their sibling must go through in order to donate. This chapter discusses the details.

We encourage you to read through this information with your siblings to help prepare them for potential stem cell donation.

**HLA Testing Siblings**

You have a 25% (1 in 4) chance of matching a sibling that has the same mother AND father as you do. This does not mean that if you have four siblings you have 100% chance at finding a match.

Imagine a four sided dice, and one side has your HLA match. If you have four siblings, you get to roll that dice four times. If you have three siblings, you get to roll three times, etc. With each roll you have a 25% (1 in 4) chance of finding a match.

**Key Fact:** You have a 25 percent (1 in 4) chance of matching a sibling that has the same mother AND father as you do.

---

**One example of the inheritance of HLA haplotypes**

<table>
<thead>
<tr>
<th>Mother</th>
<th>Father</th>
</tr>
</thead>
<tbody>
<tr>
<td>M1</td>
<td>F1</td>
</tr>
<tr>
<td>M2</td>
<td>F2</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Child 1</th>
<th>Child 2</th>
<th>Child 3</th>
<th>Child 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>M1</td>
<td>F1</td>
<td>M1</td>
<td>F2</td>
</tr>
<tr>
<td>M2</td>
<td>F1</td>
<td>M2</td>
<td>F1</td>
</tr>
<tr>
<td>M1</td>
<td>F2</td>
<td>M2</td>
<td>F1</td>
</tr>
</tbody>
</table>

**NOTE:** In this illustration Child 2 and Child 4 have matching HLA genes and antigens. Child 2 and Child 1 have one set that matches, and Child 2 and Child 3 do not have any matching HLA haplotypes.

A mother inherits two haplotypes from her parents and a father inherits two haplotypes from his parents. Each passes on one of their two haplotypes to each child, with a total of four combinations of haplotypes possible. Full siblings have approximately a 1 in 4 (25%) chance of being HLA identical. Identical twins will have matching haplotypes. There is sometimes crossover between the HLA genes, thus changing the haplotypes, but this event is rare.

*Graphic courtesy of National Marrow Donor Program.*
We rarely HLA type half siblings or any other family members because there is a very low chance that they will match you. Friends and family that wish to be tested may contact the National Marrow Donor Program at www.bethematch.org or by calling 1-800-MARROW2 (1-800-627-7692).

Insurance authorization is requested prior to HLA testing. If there are co-pays or limits to your policy’s donor search benefits, you will be notified up front. If you or your sibling(s) receive a bill for HLA testing or if you have questions, please contact our financial coordinator at 310-423-2684.

There are two options for HLA typing your siblings:

1. **They may come to Cedars Sinai Medical Center**

   Your BMT Coordinator will give them a doctor's order to have blood drawn at the:

   Plaza Level Laboratory  
   South Tower, Plaza Level  
   Room 2803  
   Phone: 310-423-7445  
   Hours: Monday – Friday 7am – 6pm  
   Saturday 8am – 1pm  
   Closed Sundays and Holidays

   There is no charge for this service.

OR:

2. **They may have their blood drawn at a local lab or doctor's office**

   Your BMT Coordinator will fed-ex empty blood tubes, a doctor's order, and instructions to the address you provide. A pre-paid fed-ex envelope is included to return the blood to Cedars Sinai Medical Center for testing.

   There may be a fee charged by local labs/offices for drawing the blood. We recommend your sibling ask about fees prior to having their blood drawn, as insurance never covers these costs.

   **Key Fact:**
   It is very important that you provide the legal full name as it appears on their identification, date of birth, address and phone number of all of your siblings.

   Samples returned by mail must have the full name, date of birth, and date the blood was drawn labeled on the blood tube.

   Missing or inaccurate information may result in the blood sample being thrown away and will delay identifying your donor!

   Once a sibling match is identified and your pre-transplant testing is complete (See chapter 3) insurance authorization for the transplant will be requested.

   The transplant authorization covers the required testing and procedures for your sibling donor. Your sibling does not have to have their own medical insurance in order to donate for you.
Sibling Donor Pre-Testing

Sibling donor testing will be done at Cedars Sinai Medical Center. It takes about 4 hours to complete and includes:

- **History and physical with a BMT doctor.** The BMT doctor they see will not be the same as the one you see. This is to ensure that they have a doctor acting on their behalf, not one that already has a relationship with you. Questions about their health, travel, and lifestyle will be asked. This is part of screening for infectious diseases.

- **Informed consent.** You are not permitted to attend this appointment. It is a private discussion between your sibling and their BMT doctor. The risks and benefits of donating will be explained to them and they will have an opportunity to ask questions. Donating *stem cells* for you is their choice. The doctor will move forward if your sibling is voluntarily agreeing to the procedure and signs the consent forms.

- **Chest X-ray.** Standard procedure to look for abnormalities in the heart, lungs and chest.

- **EKG.** To measure electrical activity inside the heart.

- **Blood and urine testing.** Testing for a variety of infectious diseases such as HIV, hepatitis and other *viruses* will be done in the blood donor facility. A complete blood count and chemistry panel will also be drawn to evaluate basic organ function.

- **Donor education.** Your BMT Coordinator will ensure your sibling understands the process and schedule for donating stem cells. They may contact the coordinator anytime if they have further questions.

**Key Facts:**

The growth factor medication used for stem cell mobilization is called Neupogen® (GCSF) and it is given as a small injection under the skin.

Stem cells are collected from your sibling’s circulating blood, not their bone marrow.

- **Social work consult.** The social worker will make sure that the donation is voluntary and that the donor understands the psychological/emotional aspects of donating stem cells, as well as the risks and benefits.

Sometimes siblings have a medical condition that would normally exclude them from donating. Your BMT doctor will decide whether medical necessity outweighs the risks involved in using them as your donor. In this case, you will be notified and the risks explained to you.

When all of the results are reviewed and your sibling has signed consent to donate, your admission to the hospital will be scheduled. Usually, *conditioning chemotherapy* begins before your sibling’s stem cell mobilization and collection. Conditioning chemotherapy is discussed in more detail in Chapter 9 and in Book 2.

**Mobilization of Sibling Donor Stem Cells**

Mobilization is the process of using medications called *growth factors* to move stem cells from the *bone marrow* and into the circulating blood.

The medication used for this is called Neupogen® (GCSF) and it is given as a small injection under the skin. This medication is given for five days in a row in the cancer center. On the fifth day, stem cell collection takes place.
The main side effect from Neupogen® is bone pain. Other side effects include:

- Low grade fever
- Left-sided abdominal pain. This is a very rare complication that needs to be reported right away to your nurse or doctor as it could indicate a problem with the spleen.

Your sibling should let the nurse know if they are experiencing side effects so an appropriate medication may be suggested.

**Collection of Sibling Donor Stem Cells**

Stem cells are collected from your sibling’s circulating blood. These are called peripheral blood stem cells or PBSC’s. On collection day, your sibling will come to the cancer center first for Neupogen®. Then, a special IV line must be placed.

There are two possible ways to collect PBSC’s:

1. Two needles (one in each arm) are placed into the vein right below where the arms bend at the elbow. This is the same vein that is used for a whole blood or platelet donation. This method may only be used for donors that have very good veins and can sit for 4 hours without bending their arms.

2. A special IV line called an IJ is placed into the large vein (internal jugular vein) inside the donor’s neck. The line is held in place by a suture and a sterile dressing. This may feel uncomfortable due to its location on the neck.

If you are reading this and feeling uncomfortable about the thought of a catheter in the neck, you are not alone. This topic makes all transplant patients and loved ones nervous.

Things to consider:

- IJ insertion occurs in the Procedure Center, located in South Tower, 5th Floor, room 5725. It is placed by physician proceduralists with the assistance of specially trained nurses.
- The area is numbed prior to insertion. Your sibling will feel pressure but not pain when it goes in.
- Once it is in place, your sibling is able to eat, sleep, read, or do other quiet activities while their stem cells are being collected
- The IJ will be removed as soon as the collection is complete, 1-2 days.

If your sibling is claustrophobic or anxious about the IJ, their transplant doctor may prescribe a medication to help them relax. Once the IJ is placed, an x-ray will be done to make sure it is positioned correctly.

The stem cell collection nurses will assess your sibling’s veins. In many cases, your sibling will get to decide which collection method they would prefer to have.
The process of harvesting stem cells is called **apheresis** and takes place in the Rita and Taft Schreiber Blood Donor Facility. The apheresis room is located on the Street Level of the South Tower, around the corner from the cafeteria.

Each session on the apheresis machine is four to five hours long. During that time your donor is resting in bed and the nurse will be monitoring him or her. He or she may sleep, eat, watch TV or do other quiet activities.

The apheresis machine looks like a cross between a kidney dialysis machine and a washing machine on spin cycle.

**Apheresis works like this:**

1. Blood exits the body through one side of the **IJ** line.
2. It travels through a machine that spins the blood so fast that it separates into different parts.
3. The **stem cells** are removed and collected into a bag hanging above the machine.
4. The rest of the blood is returned to your donor through the other side of the **IJ** line.

All of this happens simultaneously: blood comes out, stem cells removed, blood is returned. Things to consider:

- **Your donor cannot be disconnected from the machine to use the restroom.** A urinal, bedpan and commode are available.

For most donors, the main side effect of apheresis is boredom. However, quiet activities are allowed. The following side effects are also possible:

- **Tingling around the lips and fingers.** This may occur because the anticoagulant being used combines with the calcium in your donor’s body. To prevent these symptoms, a calcium IV drip will be running continuously during the stem cell collection.

- **Discomfort.** Sometimes donors find it uncomfortable to lay in bed for four to five hours. **Growth factors** can cause bone pain, which adds to this discomfort. Tylenol® can help alleviate this.

If your donor experiences any of the side effects listed above, or feels anything different, he or she should make sure to let the apheresis nurse know right away.

At the end of each collection day, the BMT coordinator will receive the stem cell count. Once enough cells are collected, your donor’s **IJ** line will be removed. At that point, stem cell **collection** is complete. Siblings may resume normal work and activities the following day.
Admission and Transplant

In most cases, you will be admitted to the hospital to begin the *conditioning regimen* about a week before your sibling’s stem cell collection. You will be receiving your chemotherapy while they are getting Neupogen® injections for stem cell *mobilization*.

Your sibling’s *stem cells* will be delivered to your 4SW hospital room shortly after they are collected. Your transplant date is the same as the collection date. Book 2 will go into detail about the infusion of donor cells, side effects and recovery.

There are some cases in which the stem cell collection takes place before your admission. In this case, the stem cells would be frozen (cryopreserved) until your transplant date.

**Approximate Timeline/Order of Events: Matched Related Donor**

<table>
<thead>
<tr>
<th>Event</th>
<th>Timeframes</th>
</tr>
</thead>
<tbody>
<tr>
<td>HLA Typing</td>
<td>Patient 10 days once sample is received</td>
</tr>
<tr>
<td></td>
<td>Insurance authorization for HLA testing siblings</td>
</tr>
<tr>
<td></td>
<td>Sibling HLA typing results 7-10 days once sample is received</td>
</tr>
<tr>
<td></td>
<td>Sibling match identified</td>
</tr>
<tr>
<td></td>
<td>Pre-transplant</td>
</tr>
<tr>
<td></td>
<td>Patient testing 1 day (CSMC)</td>
</tr>
<tr>
<td></td>
<td>1-3 weeks (in HMO network)</td>
</tr>
<tr>
<td></td>
<td>Insurance authorization 2-5 business days</td>
</tr>
<tr>
<td></td>
<td>Sibling donor testing 1 day</td>
</tr>
<tr>
<td></td>
<td>Patient informed consent 1 day</td>
</tr>
<tr>
<td></td>
<td>Patient admission</td>
</tr>
<tr>
<td></td>
<td>Patient conditioning regimen 6-12 days</td>
</tr>
<tr>
<td></td>
<td>Sibling stem cell collection Mobilization: 5 days</td>
</tr>
<tr>
<td></td>
<td>Collection: 1-2 days</td>
</tr>
<tr>
<td></td>
<td>Transplant into patient 1-2 days</td>
</tr>
<tr>
<td></td>
<td>Patient recovery in hospital 3-4 weeks</td>
</tr>
<tr>
<td></td>
<td>Patient recovery at home, with close follow-up in clinic Minimum 100 days, usually 6 months or longer</td>
</tr>
</tbody>
</table>

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**Reaching the new normal: 9-12 months**
Is my sibling too old to donate?
Age is not a major factor in determining whether your sibling may donate. Donor testing results and overall health will determine if your sibling is eligible.

What if my sibling has a pre-existing medical condition?
These will be considered on a case by case basis. The BMT doctor will determine whether or not they are healthy enough to safely donate stem cells for you. Some medical conditions do not increase the risk of donating at all (examples: diabetes, high blood pressure), while others would make them not eligible to donate (examples: HIV, cancer).

Will donating stem cells hurt my sibling?
The procedures are generally well tolerated and painless. There are minimal risks to your sibling donating peripheral blood stem cells. Bone pain is the most common complaint; their BMT doctor will recommend medications to relieve this. Mild discomfort may be experienced from the special IV lines used during stem cell collection. Most sibling donors resume normal activities the day after donation.

Can my sibling do anything to make their stem cells stronger and improve my transplant?
No. Sibling donors cannot do anything to improve the outcome of your transplant. There is no way to be certain that your transplant will cure you. There are many factors that contribute to the success of a transplant such as your diagnosis, stage of your disease, age and overall health. Unfortunately, complications from transplant are always a possibility.

What if my sibling does not have medical insurance?
Once we receive authorization for your transplant, your insurance covers your sibling’s medical costs related to your transplant. This includes their HLA typing, donor testing, stem cell mobilization, and stem cell collection.

What if my sibling lives in another state/country?
Your BMT coordinator will help facilitate visa applications for siblings from other countries to travel to the USA for donation. We will also work together with you and your sibling to schedule appointments and stem cell collection. Application fees and travel costs (including flights) for the sibling are not usually covered by your insurance.

Are there other costs that insurance does not pay for?
Costs that are not covered include, but are not limited to: loss of salary due to missed work, hotel and transportation costs, personal expenses, fees charged by outside labs for drawing the sample for initial HLA testing.

What if my sibling is unavailable during the time I need the transplant?
If your sibling cannot be in Los Angeles for the preferred date for your transplant, we may collect their stem cells early and freeze (cryopreserve) them.

What if my sibling is pregnant?
We cannot mobilize stem cells during pregnancy. If your transplant cannot wait until after the baby is born, we will look for an unrelated donor or umbilical cord units for you.
What if my sibling and I do not get along?
It is up to you to let your transplant team know if you do not wish to HLA type certain siblings. Because stem cell donation is voluntary, your sibling must decide if they are willing to participate. If they are willing to donate and you do not want to accept their stem cells, you may opt out of having them as your donor. There are many emotions involved in stem cell donation between siblings. It can bring people closer together but it also has potential to pull people further apart. It is up to you and your sibling to decide what to do. The BMT psychosocial department is available to assist with issues related to patient/donor relationships at 310-423-0638. Please speak with your BMT coordinator and/or doctor about any concerns you have about your potential sibling donors.

Will I become more like my sibling after transplant?
Yes and no! Your personality will not become more like your sibling after BMT. However, you will have their DNA inside your bone marrow and will likely convert to their blood type.

What if my sibling is in prison?
We are not able to HLA test incarcerated siblings, so they cannot be donors.
Quiz: Chapter 4

Question 1
Each full sibling has a ________ chance of being an HLA match:

a) 50%
b) 25%
c) 75%
d) 100%

Question 2
Siblings may have blood drawn for testing at Cedars Sinai or in a local lab. What information does the BMT coordinator need?

a) Legal name spelled correctly
b) Birthdate
c) Address
d) Phone number
e) All of the above

Question 3
The medication used to mobilize sibling donor cells is called:

a) Heparin
b) Neupogen
c) Dilaudid
d) Hydrocortisone

Question 4
Sibling stem cells are collected from their:

a) Circulating blood
b) Bone marrow
c) Siblings may decide which method of collection they prefer

Question 5
Siblings may resume normal work and activities the day after they donate stem cells

a) True
b) False
About 70 percent of patients do not have an HLA-matched family member. For this big group of patients, an unrelated donor search is needed.

**National Marrow Donor Program**

The National Marrow Donor Program®, or NMDP, is a non profit organization that operates the world’s largest bone marrow donor registry called Be the Match®. Through relationships with international donor and umbilical cord blood registries, a single search provides access to over 12 million volunteer donors and 400,000 cord blood units worldwide. Your BMT Coordinator will work closely with the NMDP to find you a suitable donor or cord blood units for transplant.

**Insurance**

Insurance authorization for unrelated donor search will be requested. Depending on your policy, this process may or may not be covered. You will be notified if we cannot get authorization to perform an unrelated search. The NMDP has some funding available to help patients whose search is not covered by their policy. Your BMT Coordinator will connect you with these resources if necessary.

**Unrelated Donor HLA Testing**

Potential donors will be asked to have their blood drawn and sent to Cedars Sinai Medical Center for HLA testing. This process may take 4 to 8 weeks to complete. Donors may work or have other commitments, so we must wait until they can schedule their blood draw. Sometimes donors listed have moved, or are otherwise unavailable for testing.

Your BMT Coordinator will monitor the status of each of the requested donors, and let you know when results are available. There is no way to get personal information like the name or address of any potential donor.

**Minimum HLA Match Requirement**

Unrelated donors must be at least an 8/10 HLA match to you in order to proceed with transplant.

Please refer back to page 20 to review the HLA matching diagram.

**Before Your Admission**

Once the best donor(s) are identified you will be scheduled for pre-transplant testing (refer back to chapter 3 for more information). The pre-testing results will be used to get insurance authorization for the transplant.

Once insurance authorization is received, your BMT coordinator will officially request your donor. A backup donor will be requested to remain on hold. If the donor agrees, they will move forward with donor testing.

**Unrelated Donor Testing**

Unrelated donors will be tested in the city/country where they live. This will happen after you have completed your pre-transplant testing and insurance authorization for the transplant has been received.

**Key Facts:**
The NMDP facilitates unrelated donor BMT. Unrelated donors must be at least 8/10 HLA match in order to proceed with transplant.
Your BMT Coordinator will know the date testing will take place and receive notice of donor “clearance” if everything goes well. You will not be admitted to the hospital until after donor clearance has been received.

You will be told your donor’s gender, age, and what HLA match they are to you (9/10, 10/10, etc.)

Sometimes donors have a medical condition or live in a country that would normally exclude them from donating. Your BMT doctor will decide whether a donor is suitable for you. If there are any potential risks involved with using a particular donor, you will be notified and the risks explained.

Donors are educated about the entire process and asked to sign a consent form. Once they have signed consent and their stem cell collection has been confirmed, your BMT Coordinator will schedule your admission to the hospital.

Although unlikely at this late stage, donors are volunteers that may back out at any time. If that happens, a backup donor would be asked to donate stem cells for your transplant.

**Unrelated Donor Stem Cell Collection**

Stem cells for BMT can be collected directly from either the unrelated donor’s bone marrow or their circulating blood (peripheral blood stem cells or PBSC’s). There is minimal risk to the donor regardless of the collection method. The pain is usually mild and full recovery takes less than a week.

**Key Facts:**
Stem cells for BMT can be collected directly from either the unrelated donor’s bone marrow or their circulating blood (peripheral blood stem cells or PBSC’s).

There are advantages and disadvantages to receiving a marrow product or a PBSC product. Your BMT doctor will decide which type of stem cell is preferred for your transplant. The donor, with the advice of their doctor, will decide if they are willing to give what is asked. In most cases, we will accept either product.

1. **Bone marrow collection:**
   - Takes place in an operating room. The donor is put under anesthesia during the procedure.
   - Bone marrow is pulled out by a needle and syringe placed into the back of the pelvic bone, near the hip.
   - To get enough stem cells, multiple aspirations must be taken, until 1-2 quarts have been collected. It sounds like a lot, but actually it is only 2-5% of a person’s bone marrow. The donor will regenerate those cells within one month.

**Key Facts:**
When an unrelated donor is identified, you will be told their gender, age, and what HLA match they are to you (9/10, 10/10, etc.) Blood & Marrow Transplant patients and unrelated donors are always anonymous to one another for a minimum of one year after transplant.
• When the donor wakes up, they may have some discomfort in their lower back. The pain is generally mild, and can usually be relieved with Tylenol®.

• There will be several puncture wounds from where the needle was inserted, but no stitches or surgical incisions. Donors may resume normal activity within a couple of days.

2. PBSC Collection:

• Is not a surgical procedure, donors are awake and no anesthesia is required

• Donors have a special IV placed and are hooked up to an “apheresis” machine

• Blood exits the body through one side of the IV line

• The blood spins through the machine very fast so that it separates into different cellular parts. Only a small amount of blood is inside the machine at any given time, about the volume of a cup of coffee.

• The stem cells collect into a bag overhead, while the rest of the blood is returned to the donor at the same time.

• All of this happens simultaneously: blood comes out, stem cells removed, blood is returned to the donor

• Donor can resume normal activity immediately after the IV line is removed.

Admission and Transplant

In most cases, you will be admitted to the hospital to begin the conditioning regimen about a week before your donor’s stem cell collection. You will be receiving your chemotherapy while they are preparing for donation. See chapter 9 for more information about conditioning regimens.

Your donor’s stem cells will be hand carried from the collection center to Cedars Sinai Medical Center. Because of our geographical location on the west coast, most unrelated BMT’s occur in the evening. Your transplant time will depend on when the stem cell product arrives, and whether it needs further processing (such as removing the red blood cells).

Book 2 will go into detail about the infusion of donor cells, side effects and recovery.

Patient/Donor Confidentiality

Blood & Marrow Transplant patients and donors are ALWAYS anonymous to one another for a minimum of one year after transplant. In some cases, you are allowed to send anonymous correspondence before one year. Rules about contact vary by country. Please speak with your BMT Coordinator for more information about donor contact.
Joining the NMDP Registry

Be The Match® adds approximately 37,000 new donors to their registry each month. International donor registries are also expanding, and access to them continually improves.

Often, friends and family members wish to be tested to see if they are a match for you. They may even want to organize a donor drive. The best way for them to help is by joining the unrelated donor registry. Even if they are not a match for you, they may help another patient in need of a donor. Contact Be The Match at BeTheMatch.org or by calling 1-800-MARROW2 (1-800-627-7692).

If no suitable adult donor can be found, umbilical cord units may be considered for your BMT (see chapter 6 for more details).

Matched Unrelated Donor Allogeneic BMT Frequently Asked Questions

1. Why does it take so long to coordinate an unrelated donor BMT?
In order to maintain strict patient/donor confidentiality, the transplant center and the donor center do not have direct contact with one another. The NMDP serves as a liaison, and they do their best to quickly move requests back and forth between the two. Many attempts are made to contact the top donors on your search, who must then go to have blood drawn. Usually we request 5-10 donors be tested, and hope that samples start coming soon. Once samples are received, they take up to ten days to process. Once a donor is identified, pre-testing and authorization take a couple of weeks to complete. Then the donor needs to complete testing, and you must complete your conditioning regimen. If you are feeling like “nothing is happening” during your BMT search process, contact your coordinator for an update. We do everything we can to move things forward for you as quickly as possible.

2. What if my donor has a pre-existing medical condition?
These will be considered on a case by case basis. The BMT doctor will determine whether or not they are healthy enough to safely donate stem cells for you. Some medical conditions do not increase the risk of donating at all (examples: diabetes, high blood pressure), while others would make them not eligible to donate (examples: HIV, cancer).

3. When can I find out who my donor is?
Can I send my donor a thank you gift?
In most cases, after a year if both you and the donor sign a consent form authorizing personal contact. Sometimes anonymous contact such as a thank you card or small gift that does not contain your name or any personally identifying information is allowed before one year. Please see page 45 for detailed information about donor contact or speak with your BMT Coordinator.
4. What is the difference between marrow and PBSC (peripheral blood stem cell) product?
The difference is the location they are collected from. Marrow product is collected from the back of the pelvic bone near the hip. PBSC’s are collected from the circulating blood via a special IV line. In some diseases, marrow product is preferred over PBSCs. In most cases, we will accept either product and are most concerned about the degree of HLA matching (9/10, 10/10 etc.)

5. How do the cells get here?
The cells are hand carried by a courier, assigned by the donor center. You will not meet the individual carrying the cells. They will be given directly to the stem cell laboratory at Cedars Sinai Medical Center for processing. Your transplant date is based on the arrival time of the cells to Cedars-Sinai.

6. Will I become more like my donor after transplant?
Yes and no! Your personality will not become more like your donor. Some people claim that their tastes change or that they are interested in new hobbies after their transplant. This can not be scientifically verified. However, you will have their DNA inside your bone marrow and will likely convert to their blood type.

7. Will donating hurt my donor?
The procedures are generally well tolerated with minimal risk to the donor. Mild discomfort for a short period of time may be experienced. Most donors may resume normal activities the day after a PBSC donation, and within a couple of days after a marrow donation.

8. Is there financial assistance available through the NMDP?
Yes. The NMDP has two financial assistance programs available:

1. Search Assistance Funds to help if your insurance plan does not cover the costs of finding an unrelated donor.
2. Transplant Support Assistance Funds help pay for some costs during the first six months after transplant that are not covered by insurance (such as food, transportation, temporary housing near the hospital)

For more information about these programs and other important resources, talk to your BMT coordinator or visit BeTheMatch.org and click on “Patients and Families” or call 1-800-MARROW2 (1-800-627-7692).

9. Can my friends/family organize a donor drive for me?
Yes! This is also done through the Be The Match®. Please contact them directly for information about organizing a donor drive. BeTheMatch.org or 1-800-MARROW2 (1-800-627-7692).
### Approximate Timeline/Order of Events: Matched Unrelated Donor

#### Donor search
- Patient HLA typing: 10 days once sample is received
- Insurance authorization for search: 2-5 business days
- Search and request HLA typing of unrelated donors: 8-12 weeks

#### Donor identified

#### Pre-transplant
- Patient testing: 1 day (CSMC)
- Insurance authorization: 2-5 business days
- Donor pre-donation testing: 2-3 weeks from request date
- Patient informed consent: 1 day

#### Patient admission

- Patient conditioning regimen: 6-12 days
- Donor stem cell collection (concurrent with patient conditioning):
  - Mobilization: 5 days
  - Collection: 1-2 days
- Transplant into patient: 1 day
- Patient recovery in hospital: 3-6 weeks
- Patient recovery at home, with close follow-up in clinic: Minimum 100 days, usually 6 months or longer

### Reaching the new normal: 9-12 months
Quiz: Chapter 5

Question 1

The organization that helps coordinate unrelated blood & marrow transplants is called:

a) The American Cancer Society  
b) National Institute of Health  
c) BMT Infonet  
d) National Marrow Donor Program

Question 2

The minimum HLA match requirement for unrelated donor BMT is:

a) 10/10  
b) 9/10  
c) 8/10  
d) 7/10

Question 3

The search for an unrelated donor can take 4 to 8 weeks to complete.

a) True  
b) False

Question 4

Unrelated donors must remain anonymous for a minimum of one year. Prior to transplant, you may be told your donor's age, gender, and HLA match.

a) True  
b) False

Question 5

Friends and family members between 18-44 years of age may sign up to be potential donors through this organization:

a) Cedars-Sinai Medical Center  
b) American Red Cross  
c) a and b only  
d) Be the Match

Question 6

Stem cells can be collected from an unrelated donor's bone marrow or circulating blood.

a) True  
b) False
The umbilical cord of a newborn infant is a rich source of blood stem cells. Families choose to donate their baby’s umbilical cord hoping that someone else will benefit from using it. If there are no suitable unrelated donors available, or if you need to be transplanted very quickly, umbilical cord blood may be used for your transplant.

Blood from the umbilical cord and placenta is collected immediately after a baby is born. Once collected, it is referred to as a cord blood unit. It is frozen in liquid nitrogen (cryopreserved) and then safely stored at a cord blood bank.

The NMDP® has access to hundreds of thousands of cord blood units stored all around the world. The search for umbilical cord units will begin at the same time as the search for unrelated adult donors.

**UCB Testing**

UCB also requires HLA testing. However, the process is much faster (one to three weeks). Insurance authorization for HLA testing cords is included in the request for testing unrelated adult donors. Depending on your policy, this may or may not be covered. You will be notified if we cannot get authorization to perform an unrelated search. The NMDP has some funding available to help patients whose search is not covered by their policy. Your BMT Coordinator will connect you with these resources if necessary.

UCB is tested for infectious diseases before it is frozen. The mother (and whenever possible the father) is also screened for infectious diseases prior to their cord blood donation. It is tested again for infectious diseases before it is used for transplant.

Sometimes cords have been tested in a laboratory that does not have the same standards as the United States. If there are any potential risks involved with using a particular cord unit, you will be notified and the risks explained.

**Benefits and Risks**

There are benefits and risks to using UCB for your transplant.

**Benefits:**

- **Lower HLA match requirement.** Minimum HLA match requirement for a cord unit is 4/6 (refer to page 20 to review HLA matching diagram). There is lower risk associated with cord blood mismatches than adult donors because a baby’s immune system is not well developed at birth.

- **Quicker access.** The cells are readily available for HLA testing and transplant because they are stored at a cord blood bank. Unlike adult donors who may have other commitments, a cord can be tested and shipped within a couple of weeks.

- **Less graft versus host disease (GVHD).** GVHD is a common complication following allogeneic BMT. This complication ranges from mild to life threatening. GVHD will be explained in detail in Book 2. Studies show that patients receiving cord blood transplants...
get GVHD less than patients who received adult stem cells. Also, when GVHD does occur following cord blood transplant, it tends to be less severe.

Risks:

- **Lower number of cells/time to engraft.** Cord blood units contain much fewer stem cells than an adult donor collection. We always use two cord blood units for your transplant. However, it takes about 5–6 weeks for them to grow and repopulate your bone marrow (engraft) as opposed to 3–4 weeks with an adult donor. During this increased period of waiting, you are at risk for complications related to low blood counts, such as infection, anemia and bleeding.

- **Graft failure.** The risk of the cells failing to grow is higher with umbilical cord blood transplants because they are so small. This is also why we transplant two units at a time. We keep two backup cord blood units on hold to use in case this happens.

- **No backup cells available from the same source.** If your disease relapses after transplant, there is no way to obtain more cells from the transplanted cord units.

- **Newer option.** The first umbilical cord blood transplant was done in 1988. There is not as much information about the long term effects compared to adult donor marrow or PBSC transplant. Doctors are still learning about the differences between the three sources of cells for BMT.

Confidentiality

The identity of cord blood donors is confidential. The units are listed by number and cord blood bank. There is never any personally identifying information available. You will be told the gender of the baby, their blood type and their birthdate only.

Before your admission:

Once the best four cord blood units are found (two for transplant, two for backup), you will be scheduled for pre-transplant testing (refer back to chapter 3 for more information). The pretesting results will be used to get insurance authorization for the transplant.

Admission and Transplant

Once insurance authorization is received and you have signed consent forms for transplant, your BMT coordinator will order the best two cord blood units for you. You will not be admitted to the hospital to begin your conditioning regimen (see chapter 9) until the UCB units have arrived and been inspected at Cedars Sinai Medical Center.

UCB is sent from the country of origin by world courier. They are transported in a locked container in liquid nitrogen. The cord blood units can be safely stored at Cedars Sinai Medical Center until you are ready to receive the transplant. They do not expire.

Book 2 will go into detail about the infusion of UCB stem cells, side effects and recovery.
Frequently Asked Questions

1. Can I use my child's stored umbilical cord blood unit?
   In most cases the answer is no. Your baby receives exactly half of their genetic makeup from you and the other half from their dad (refer to diagram on page 20). This means that your baby's cord would be a 3/6 HLA match to you, and therefore falls below the minimum match requirement for transplant.

2. Is the recovery for a cord blood transplant different than an adult donor stem cell transplant?
   Yes, because the number of cells present in a cord blood unit is so much smaller than an adult donation. Your hospital stay will be 2-3 weeks longer. Your risk for infection is increased because of this longer period of neutropenia (low white blood cell counts). You may also be dependent on blood and platelet transfusions for longer than someone who received adult donor stem cells.

3. Will I become more like my cord blood donors after transplant?
   Two cord blood units are transplanted, but only one will survive and grow inside your bone marrow. Your personality will not become more like your donor. However, you will have their DNA inside your bone marrow and will likely convert to their blood type.

4. How do the cords get here?
   They are shipped from the country of origin in a special container in liquid nitrogen. They go directly to the stem cell laboratory at Cedars Sinai Medical Center for processing.

5. What if the cord blood unit gets lost or damaged?
   If a cord unit gets lost or damaged, a backup unit will be requested. We will not admit you to the hospital to begin your conditioning regimen until the cord blood units for transplant have been received, inspected, and approved by our stem cell lab.

6. How small are they?
   The actual volume is about an ounce (30ml) per cord unit. This amount of liquid would fill a standard medicine cup. The lab will add components called albumin and dextran to ease the infusion, so the volume may appear slightly larger.

7. Are umbilical cord blood cells the same as embryonic stem cells?
   No. Umbilical cord blood cells divide to produce white blood cells, red blood cells, and platelets. They are collected from the placenta and umbilical cord after a baby is born. If not donated or stored for the baby's future use, these tissues are discarded.

   Embryonic stem cells divide to produce any cell (muscle, bone, nerve, tissue, blood). They are usually collected from an embryo produced by in-vitro fertilization and then cultured in a Petri-dish in a lab. Treatments using these cells are controversial and primarily still in the research phase.
### Approximate Timeline/Order of Events: Umbilical Cord Blood BMT

<table>
<thead>
<tr>
<th>Donor search</th>
<th>Patient HLA testing</th>
<th>10 days once sample is received</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Insurance authorization for search</td>
<td>2-5 business days</td>
</tr>
<tr>
<td></td>
<td>No suitable adult donors available</td>
<td>8-12 weeks</td>
</tr>
<tr>
<td></td>
<td>Cord search and HLA typing</td>
<td>Concurrent with adult donor search</td>
</tr>
</tbody>
</table>

**Cords identified**

| Pre-transplant         | Patient testing                           | 1 day (CSMC)                    |
|                       |                                            | 1-3 weeks (in HMO network)      |
|                       | Insurance authorization                    | 2-5 business days               |
|                       | Cords purchased                            | 1 day                           |
|                       | Patient informed consent                   | 1 day                           |
|                       | Cords arrive at Cedars-Sinai               | 1-2 weeks after purchase        |

**Patient admission**

<table>
<thead>
<tr>
<th>Patient conditioning regimen</th>
<th>6-12 days</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cords transplanted</td>
<td>1 day</td>
</tr>
<tr>
<td>Patient recovery in hospital</td>
<td>6-8 weeks</td>
</tr>
<tr>
<td>Patient recovery at home, with close follow-up in clinic</td>
<td>Minimum 100 days, usually 6 months or longer</td>
</tr>
</tbody>
</table>

**Reaching the new normal: 9-12 months**
**Quiz: Chapter 6**

**Question 1**

The minimum match requirement for UCB transplant is:

a) 9/10  
b) 4/6  
c) 5/6  
d) 7/8

**Question 2**

Recovery after UCB transplant is faster than other types of BMT.

a) True  
b) False

**Question 3**

The benefits of using umbilical cords for transplant are:

a) Quicker access  
b) Less graft versus host disease (GVHV)  
c) Lower match requirement  
d) All of the above

**Question 4**

How many umbilical cord units are used for transplant?

a) 1  
b) 2  
c) 3  
d) 4

**Question 5**

The identity of the child whose cord is used for transplant will always remain anonymous. No type of donor correspondence is ever allowed.

a) True  
b) False
CHAPTER 7: ADMISSION

What to Pack for the Hospital

• Book #2 along with all of your completed quizzes
• A copy of your *Advance Directive for Health Care*. A blank Advanced Directive Form is included in the Appendix of this book.
• Comfortable, clean pajamas, loose “sweat” outfits, T-shirts, socks, underwear, slippers, bathrobe, athletic shoes. Note: There is no laundry service for patient belongings. Hospital gowns are always available.
• Soft head cover, such as a scarf, hat or baseball cap
• Favorite pillow or blanket, freshly washed. Brightly colored is best to distinguish it from hospital supply.
• A brand new soft toothbrush and dental floss
• Personal assistive devices, such as eyeglasses, hearing aides, walker, cane
• Stuff to do! Books, crossword puzzles, laptop computer with CDs/DVDs*, etc.
• Pictures, calendar, posters to decorate your room.
• A special project – scrapbook, knitting, etc.
• Newly purchased magazines
• Camera*
• Cell phone* and charger

What NOT to Pack:

• Crafts that require the use of sharp needles (no needlepoint)
• Razorblades, cuticle scissors, nail clippers (consider clipping nails short and manicuring them prior to admission)
• Jewelry
• Make-up (brand new makeup may be brought and lightly applied)
• Perfumed lotions, creams (unscented, new lotions may be brought, although the hospital will supply you with skin lotion)
• Food (as well as vitamins, minerals, herbs and probiotics)
• Fresh flowers, dried flowers, plants

*Bringing expensive items to the Medical Center is done at your own risk.
Here's what to expect on admission day:

1. **Lab draw.** Most of the time, patients first report to the Samuel Oschin Cancer Center for labs. The BMT coordinator will let you know what time to arrive.

   Medications. Some patients may receive part of their treatment in the Samuel Oschin Cancer Center before admission. Examples: Rituxan®, Ofatumumab®, Kepivance®. Your BMT Coordinator will let you know if this applies to you.

2. **IV placement.** Most of the time, you will need to have a three lumen *peripherally inserted central catheter* (3L PICC) line placed. This is a long-term IV line placed into the upper arm that is used for the transplant admission. Your BMT coordinator will communicate the time for this appointment.

   - If you already have a functioning three lumen PICC line, it will be used for transplant.
   - A single or two lumen PICC line usually will be replaced with a three lumen PICC.
   - PAS PORT and Portacath lines will not be used for transplant. Patients with these lines will have a three lumen PICC placed.

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**Key Fact:** Phone number of the 4SW Nursing Station is (310) 423-4415

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*4SW patient room*
3. **Registration and admission to 4th Floor Southwest (4SW).** Once you have been assigned a bed and it is available, you will be phoned and given instructions. Sometimes the bed is not available until the evening. If *chemotherapy* is scheduled to begin on admission day it will be given, even if it is late at night.

- Patients who do have a **PICC** line placed on admission day may report directly to 4SW when the bed becomes available.

- Patients who do not need a PICC line placed on admission day will need to register for admission in the South Tower–Street Level Admissions Department, room 1720, prior to arrival on 4SW. Call (310) 423-3761 to find out when your bed will be ready.
Quiz: Chapter 7

Question 1
The following item should be packed to bring to the hospital:

a) Soft toothbrush and dental floss
b) Needlepoint craft
c) Favorite foods

Question 2
Laptops and electronic devices are allowed but patients bring them to the hospital at their own risk.

a) True
b) False

Question 3
Most allogeneic BMT patients will need a 3L PICC line. Where is this line placed?

a) Into the large vein in the neck
b) Into the chest on the left side
c) Into the upper arm
Conditioning Regimens (also known as “Preparative Regimens”)

Recall that conditioning refers to chemotherapy and radiation given prior to transplant day.

**Conditioning regimens** are an important part of the BMT process, and are carefully chosen based on their intensity. Your doctor will consider factors such as your age, overall health, organ function, and disease status to determine what type of conditioning regimen you will receive.

Goals for conditioning:

1. Make room inside your bone marrow for the new donor cells to grow.
2. Minimize the risk of complications during and after transplant
3. Maximize disease response and transplant success

Maintaining your safety is always our top priority.

*Myeloablative, reduced intensity,* and *non-myeloablative* are words used to describe different methods of preparing your body for *allogeneic* BMT. Their names come from the effect they have on your bone marrow.

Recall that myeloablative chemotherapy destroys the bone marrow beyond its ability to ever recover function. Reduced intensity involves using less toxic doses of chemotherapy. Non-myeloablative regimens utilize the transplanted donor immune system to achieve disease response.
### Three Methods of Conditioning Used in BMT

<table>
<thead>
<tr>
<th></th>
<th>Myeloablative</th>
<th>Reduced Intensity</th>
<th>Non-myeloablative</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Intensity</strong></td>
<td>Strong</td>
<td>Medium</td>
<td>Mild</td>
</tr>
<tr>
<td><strong>Recommended age of patient</strong></td>
<td>50 or younger</td>
<td>51 - 64</td>
<td>65 or older</td>
</tr>
<tr>
<td><strong>Main benefit</strong></td>
<td>Highest possible dose of chemo/radiation therapy to destroy the disease</td>
<td>Less potential for toxicity to other organs, faster recovery post transplant</td>
<td>Very survivable, low risk for infection, can be done outpatient</td>
</tr>
<tr>
<td><strong>Main risk</strong></td>
<td>Infection, organ toxicity</td>
<td>Relapse from disease, infection post-transplant</td>
<td>Relapse from disease post-transplant</td>
</tr>
<tr>
<td><strong>Chemotherapy included?</strong></td>
<td>Yes</td>
<td>Yes</td>
<td>Sometimes</td>
</tr>
<tr>
<td><strong>Radiation included?</strong></td>
<td>Sometimes</td>
<td>Sometimes</td>
<td>Yes</td>
</tr>
</tbody>
</table>
| **Mechanism of action in achieving disease remission** | • High dose chemo +/- radiation  
• Donor immune response | • Medium dose chemo +/- radiation  
• Donor immune response | • Donor immune response only |
| **Examples of common regimens** | • Busulfan + Cytoxan  
• TBI + Cytoxan + VP16  
• Fludarabine + Cytoxan + TBI | • Fludarabine + Melphalan | • TLI+ATG  
• Fludarabine + low dose TBI |

Once the method of conditioning is determined, the actual regimen will be selected. Regimens usually have strange names like FluMel or TBI+Cy+VP16. These names come from the combination of drugs and radiation that are included in the regimens.

Side effects from chemotherapy vary greatly. Most patients do not experience all of the side effects listed. Many side effects can be prevented or relieved with medications.

**Key Fact:** All of these regimens require transplant of donor stem cells in order to recover normal bone marrow function.
The following represents frequently used *conditioning regimens* and their main side effects. There are potential side effects not listed here. Feel free to discuss these drugs in more detail with your nurse or doctor.

There may be chemotherapy drugs the transplant doctor decides to use that are not listed here. Your BMT Coordinator can provide you with information about those drugs.

### Drug Information Table - Chemotherapy

<table>
<thead>
<tr>
<th>Generic Drug Name</th>
<th>Brand name</th>
<th>Regimen Name</th>
<th>Potential Side Effects</th>
<th>Long-Term Potential Side Effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>Busulfan</td>
<td>Busulfex®</td>
<td>Busulfan Bu+Cy+VP16</td>
<td>• Nausea/vomiting • Mouth sores • Seizures</td>
<td>• Lung or liver toxicities • Infertility</td>
</tr>
<tr>
<td>Cyclophosphamide</td>
<td>Cytoxan®</td>
<td>TBI+Cy+VP16 Bu+Cy+VP16</td>
<td>• Nausea/vomiting • Bladder toxicity • Hair loss • Mouth sores</td>
<td>• Heart toxicity • Infertility • Secondary leukemia</td>
</tr>
<tr>
<td>Etoposide</td>
<td>VP16®</td>
<td>BEAM or TBI+Cy+VP16 Bu+Cy+VP16</td>
<td>• Nausea/vomiting • Low blood pressure • <strong>Allergic reaction</strong></td>
<td>• Secondary leukemia • Infertility</td>
</tr>
<tr>
<td>Melphalan</td>
<td>Alkeran®</td>
<td>BEAM or high-dose Melphalan</td>
<td>• Nausea/vomiting/diarrhea • Mouth sores</td>
<td>• Secondary leukemia</td>
</tr>
<tr>
<td>Rituximab</td>
<td>Rituxan®</td>
<td>R+ BEAM R+TBI+CY+VP16</td>
<td>• <strong>Fever/chills</strong> • Allergic reaction • Body aches</td>
<td>• Infection</td>
</tr>
<tr>
<td>Fludarabine</td>
<td>Fludara®</td>
<td>Flu+Mel Flu+Cy+TBI Flu+Bu</td>
<td>• Fever, infections • Nausea/vomiting • Diarrhea • Fatigue, dizziness • Cough • Skin rash</td>
<td>• Secondary leukemia</td>
</tr>
</tbody>
</table>

Some drugs used for conditioning are not chemotherapy. They are used to prevent your immune system from attacking the new donor cells. They are also used to suppress the new donor immune system from attacking your body (we call this *graft-versus-host disease*, and it is further explained in book 2). This class of drugs is called “immunosuppressants”. All allogeneic BMT patients will receive immunosuppression beginning a few days before transplant. Immunosuppresion is critical to the success of the transplant and will continue for a minimum of six months after transplant.
### Drug Information Table – Immunosuppressants

<table>
<thead>
<tr>
<th>Generic Drug Name</th>
<th>Brand Name</th>
<th>Route of Administration</th>
<th>Potential Side Effects</th>
<th>Long-Term Potential Side Effects</th>
</tr>
</thead>
</table>
| ATG (Anti-Thymocyte Globulin) | Thymoglobulin® | IV infusion | • Allergic reaction  
• Flu-like symptoms  
• Swelling/flushing  
• Nausea/vomiting/diarrhea | • Infection  
• Secondary cancer |
| Alemtuzumab | Campath® | IV infusion | • Allergic reaction  
• Flu-like symptoms  
• Infection  
• Low blood pressure | • Infection |
| Methotrexate | | IV infusion | • Mouth sores  
• Nausea/vomiting | • Kidney, lung and liver toxicity |
| Cyclosporine | Sandimmune® | IV infusion, oral capsules or liquid | • Nausea/vomiting  
• High blood pressure  
• Tremor/shaking/flushing  
• Swelling of the gums  
• Abnormal body hair growth | • Kidney and liver toxicity  
• Infection |
| Mycophenolate | Cellcept® | IV infusion  
Oral - capsules or liquid | • Infection  
• Diarrhea, vomiting  
• Leg swelling  
• High blood pressure/headache  
• Low blood counts and infections  
• Birth defects (talk to MD about appropriate contraception while taking Cellcept) | • Secondary cancers  
• Infection |
| Tacrolimus FK506 | Prograf® | IV infusion  
Oral - capsules or liquid | • Headache/dizziness  
• Shaking/seizures  
• Tingling/numbness  
• Nausea/vomiting/diarrhea | • Secondary cancers  
• Infection |
| Sirolimus | Rapamune® | Oral -tablet or liquid | • Infection  
• Nausea, vomiting, diarrhea  
• Stomach or joint pain  
• Allergic reaction | • Secondary cancer  
• Infection |
The following medications are called *chemoprotectants* because they help to protect healthy *cells* from the damaging effects of high dose *chemotherapy* and *radiation* therapy.

**Drug Information Table – Chemoprotectants**

<table>
<thead>
<tr>
<th>Drug Name</th>
<th>Also known as</th>
<th>Purpose</th>
<th>How it is given</th>
</tr>
</thead>
<tbody>
<tr>
<td>Palifermin</td>
<td>Kepivance®</td>
<td>Reduces the severity and duration of mouth sores after high dose radiation and <em>chemotherapy</em></td>
<td>Given through an IV for 3 days before chemo/radiation and again for 3 days after chemo/radiation ends</td>
</tr>
<tr>
<td>Amifostine</td>
<td>Ethyol®</td>
<td>Reduces the severity and duration of unwanted GI side effects after high dose Melphalan. Currently this drug is being used experimentally for this purpose.</td>
<td>Given through an IV over 5 minutes for 2 doses. The first dose is given the day before transplant admission. The second dose is given before the melphalan dose.</td>
</tr>
<tr>
<td>Calcium phosphate rinse</td>
<td>Caphosol®</td>
<td>Reduces the incidence and severity of mouth sores; moistens and cleans the mouth</td>
<td>Oral mouth rinse 4x per day and as needed.</td>
</tr>
</tbody>
</table>

**Key Fact:** Immunosuppresion is critical to the success of the transplant and will continue for a minimum of six months after transplant.
Radiation

Not all patients will need radiation. If radiation is part of your treatment plan, the transplant doctor will refer you to a radiation oncologist for consultation one to two weeks before admission to the hospital.

After the consult, you will have measurements taken. A CT scan may be used to determine exactly where the radiation will be directed.

1. Cranial Boosts

*Cranial boosts* describe radiation that is focused on the head, specifically the brain and the fluid surrounding the brain. This fluid is called cerebrospinal fluid or “CSF”, and leukemia/lymphoma cells can hide there. Cranial boosts occur over six days prior to admission for transplant.

2. Total Body Irradiation (TBI)

TBI means radiation delivered across the entire body. The purpose of TBI in *autologous BMT* is to kill residual cancer cells that are not visible on imaging scans. TBI is done for patients with resistant lymphomas or leukemia. TBI will occur once you are admitted for transplant, and is part of the *conditioning regimen*.

3. Total Lymphoid Irradiation (TLI)

TLI exposes all of the lymph nodes, the thymus, and the spleen to radiation. These organs are all part of your immune system. TLI results in strong suppression of your immune system. This prepares your body to accept the new donor stem cells during your BMT.

4. Post Transplant Consolidation (also called Involved Field Radiation)

This type of radiation is used for patients with resistant or residual disease in a specific area like the neck or chest. About three weeks after discharge, you will be referred to a radiation oncologist for a consultation. Then daily radiation directed towards the location of the resistant tumor will begin. This treatment may take four to six weeks to complete.

You will not be radioactive after radiation therapy. Radiation has side effects similar to those of chemotherapy. The radiation therapists will provide specific education about what to expect following different treatments.

---

**Key Facts:** The phone number for Radiation Oncology Scheduling is (310) 423-4204.

Radiation has side effects similar to those of chemotherapy.
Quiz: Chapter 8

Question 1
The following factors will be considered when choosing the best conditioning regimen:

a) Age  
b) Disease status  
c) Overall health  
d) Organ function  
e) All of the above

Question 2
The three types of conditioning regimens are called:

a) Strong, medium, nonmyeloablative  
b) Myeloablative, reduced intensity, nonmyeloablative  
c) intensive, reduced toxicity, mildly ablative

Question 3
Without immunosuppressant medications, transplant would not be possible.

a) True  
b) False

Question 4
All patients will receive immunosuppression before and for a minimum of six months after transplant:

a) True  
b) False

Question 5
All patients will receive radiation therapy as part of their conditioning regimen prior to transplant.

a) True  
b) False

Question 6
Radiation has similar side effects to chemotherapy.

a) True  
b) False
Going through an **allogeneic blood & marrow transplant** is an intense experience for all patients and their caregivers.

This chapter could very easily become a book of its own, discussing the psychosocial issues associated with BMT preparation, admission and recovery.

Cedars-Sinai Medical Center is very committed to providing patients and their families with the support they need to cope with this life changing experience.

Patients and caregivers will be encouraged to take one day at a time, and focus on the long-term benefits of transplant. They will be given every opportunity to discuss feelings, concerns, questions, and issues with their BMT team at every step along the way. A medical social worker is available both outpatient and inpatient for counseling, emotional support and help with resources.

There are also extensive online and written resources available for patients and caregivers addressing a wide spectrum of topics related to emotional support and coping.

**Important Tip:** A medical social worker is available both outpatient and inpatient for counseling, emotional support and help with resources.

We recommend the following:

1. **Be The Match - Patients and Families Support and Resources**
   - Free one-on-one support and access to educational resources, DVDs, booklets, online tools and guidance
   - BeTheMatch.org/patient/support_and_resources
   - 1-888-999-6743
   - Email: patientinfo@nmdp.org

2. **BMT Infonet: Blood and Marrow Transplant Information Network**
   - Easy to understand information, publications and products for BMT patients and families reviewed by medical experts for accuracy.
   - www.bmtinfonet.org
   - 1-888-597-7674
   - Email: help@bmtinfonet.org

Please do not hesitate to bring up any questions or concerns you have. We are here to help you.
Recommended Resources for Patients and Caregivers

American Cancer Society Guestroom Policy
Phone: (800) 227-2345

This program provides discounted hotel accommodations based upon availability. ACS has contracts with the Westin Hotel and the Radisson Hotel, both located near LAX. The program does not cover any other expenses incurred during the stay such as parking or meals.

The program is for anyone with a diagnosis of cancer who is coming into the LA area for treatment. CSOCC staff or patients may call to check on availability.

Referral Process:

- Call (800) 227-2345 anytime, 24 hours a day, and ask to speak with a Cancer Information Specialist

- Provide patient’s name, address, general information regarding diagnosis and dates needed

- ACS will investigate availability at the hotels and notify patient once a room has been located

Information courtesy of the American Cancer Society
## Advocacy Resources

<table>
<thead>
<tr>
<th>Name</th>
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<th>How you can learn more</th>
</tr>
</thead>
<tbody>
<tr>
<td>BMT InfoNet</td>
<td>Transplant patients</td>
<td>Provides information on all aspects of transplant, including financial assistance and insurance. Refers patients whose insurance denies transplant costs to non-profit organizations and attorneys.</td>
<td>Phone: 1 (888) 597-7674&lt;br&gt;Online: bmtinfonet.org</td>
</tr>
<tr>
<td>National Association of State Comprehensive Health Insurance Plans</td>
<td>Uninsured patients</td>
<td>Provides information about high-risk insurance pools, as well as a central listing of states with high-risk insurance pools.</td>
<td>Online: naschip.org</td>
</tr>
<tr>
<td>National Bone Marrow Transplant Link (NBMTLink)</td>
<td>Transplant patients</td>
<td>Helps patients, as well as their caregivers, families and the health care community meet the many challenges of marrow and cord blood transplant by providing information and support services. The “Peer Support on Call” program offers emotional support through one-on-one conversations with volunteers.</td>
<td>Phone: 1 (800) 546-5268&lt;br&gt;Online: nbmtlink.org</td>
</tr>
<tr>
<td>Patient Advocate Foundation</td>
<td>All patients</td>
<td>Helps patients resolve insurance, employment, and/or debt crisis disputes related to their diagnosis.</td>
<td>Phone: 1 (800) 532-5274&lt;br&gt;Online: patientadvocate.org</td>
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## Financial Aid

<table>
<thead>
<tr>
<th>Name</th>
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</tr>
</thead>
<tbody>
<tr>
<td>American Cancer Society</td>
<td>Cancer patients</td>
<td>Some individual chapters provide limited grants.</td>
<td>Phone: 1 (800) ACS-2345&lt;br&gt;Online: cancer.org</td>
</tr>
<tr>
<td>CancerCare</td>
<td>Cancer patients</td>
<td>Small grants; information and resources about financial assistance.</td>
<td>Phone: 1 (800) 813-HOPE&lt;br&gt;1 (800) 813-4673&lt;br&gt;Online: cancercare.org</td>
</tr>
<tr>
<td>Cancer Financial Assistance Coalition (CFAC)</td>
<td>Cancer Patients</td>
<td>Provides a central listing of financial assistance organizations.</td>
<td>Online: cancerfac.org</td>
</tr>
</tbody>
</table>

*Mapping the Maze — Patient Resources: Accessing Additional Information*

*Information courtesy of the National Marrow Donor Program*
## Financial Aid (continued)

<table>
<thead>
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</tr>
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<tr>
<td>First Hand Foundation</td>
<td>Pediatric patients (under 18)</td>
<td>Income based grants for clinical expenses, durable medical goods, relocation expenses, and some vehicle modification expenses</td>
<td>Phone: 1 (816) 201-1569 Online: cerner.com/firsthand</td>
</tr>
<tr>
<td>HealthWell Foundation</td>
<td>Patients with some diagnoses (includes MDS and multiple myeloma)</td>
<td>Provides financial assistance with prescription drug coinsurance, copayments, and deductibles, health insurance premiums; income-based eligibility</td>
<td>Phone: 1 (800) 675-8416 Online: <a href="http://www.healthwellfoundation.org">www.healthwellfoundation.org</a></td>
</tr>
<tr>
<td>Leukemia &amp; Lymphoma Society</td>
<td>Patients with leukemia, lymphoma, multiple myeloma or MDS</td>
<td>Patient Financial Aid: Small grants for some uncovered expenses, including prescriptions, medical tests, and transportation costs Co-Pay Assistance: Helps pay private health insurance premiums, private insurance co-pays, and Medicare co-pays (must have drug coverage, based on income level)</td>
<td>Phone: 1 (800) 955-4572 Online: leukemia-lymphoma.org</td>
</tr>
<tr>
<td>Lymphoma Research Foundation</td>
<td>Lymphoma patients</td>
<td>Small financial grants for some uncovered expenses, such as child care, travel, medical aids/devices, camps, wigs, and hygiene products</td>
<td>Phone: 1 (800) 500-9976 Online: lymphoma.org</td>
</tr>
<tr>
<td>National Children’s Cancer Society</td>
<td>Children with cancer</td>
<td>Provides direct financial assistance for medical and non-medical expenses related to treatment for children with cancer</td>
<td>Phone: 1 (800) 5-FAMILY 1 (800) 532-6459 Online: nationalchildrenscancersociety.org</td>
</tr>
<tr>
<td>Patient Access Network Foundation</td>
<td>Patients with specific conditions, including non-Hodgkins lymphoma, MDS, multiple myeloma</td>
<td>Provides financial assistance for deductibles, co-payments and coinsurance</td>
<td>Phone: 1 (866) 316-7263 Online: patientaccessnetwork.org</td>
</tr>
<tr>
<td>Patient Services Incorporated</td>
<td>Patients with chronic diagnoses (includes CML)</td>
<td>Provides financial assistance for insurance premiums, and co-pays; determines eligibility for financial hardship waiver programs</td>
<td>Phone: 1 (800) 366-7741 Online: uneedpsi.org</td>
</tr>
</tbody>
</table>

Information courtesy of the National Marrow Donor Program
## Financial Planning

<table>
<thead>
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<tbody>
<tr>
<td>Certified Financial Planner Board of Standards, Inc.</td>
<td>Anyone wanting to verify a financial planner’s CFP certification</td>
<td>This independent professional regulatory organization owns the CFP, CERTIFIED FINANCIAL PLANNER™, certification marks. Call to find out if a financial planner has a current CFP certification.</td>
<td>Phone: 1 (800) 487-1497 Online: cfp.net</td>
</tr>
<tr>
<td>Financial Planning Association</td>
<td>Anyone who needs to find a financial planner</td>
<td>Connects you with certified financial planners (CFPs)</td>
<td>Phone: 1 (800) 322-4237 Online: fpnet.org</td>
</tr>
<tr>
<td>National Endowment for Financial Education (NEFE)</td>
<td>People with questions about money</td>
<td>Provides articles, tools and resources to help people learn how to manage their money</td>
<td>Phone: 1 (303) 741-6333 Online: nefe.org smartaboutmoney.org</td>
</tr>
<tr>
<td>National Foundation for Credit Counseling</td>
<td>People with questions about financial planning and debt</td>
<td>Provides consumer counseling and education on budgeting and debt reduction</td>
<td>Phone: 1 (800) 388-2227 Online: nfcc.org</td>
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## Fundraising

<table>
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<tbody>
<tr>
<td>Children’s Organ Transplant Association (COTA)</td>
<td>Children and young adults in need of transplant</td>
<td>Provides fundraising assistance, including organizing and training, planning events/activities, working with the media, and finding multiple funding sources</td>
<td>Phone: 1 (800) 366-2682 Online: cota.org</td>
</tr>
<tr>
<td>National Foundation for Transplants</td>
<td>Transplant candidates</td>
<td>Sets up fundraising campaigns in a patient’s community, to help pay for transplant-related costs not covered by insurance</td>
<td>Phone: 1 (800) 489-3863 Online: transplants.org</td>
</tr>
<tr>
<td>National Transplant Assistance Fund &amp; Catastrophic Injury Program</td>
<td>Transplant and catastrophic injury patients</td>
<td>Provides fundraising assistance to begin and sustain successful fundraising campaigns</td>
<td>Phone: 1 (800) 642-8399 Online: transplantfund.org</td>
</tr>
</tbody>
</table>

Information courtesy of the National Marrow Donor Program
### Housing Information

<table>
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<tr>
<td>National Association of Hospital Hospitality Houses</td>
<td>Patients who need temporary housing</td>
<td>Provides information on all known patient housing</td>
<td>Phone: 1 (800) 542-9730 Online: nahhh.org</td>
</tr>
</tbody>
</table>

### Legal Resources

<table>
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<tbody>
<tr>
<td>American Association for Justice</td>
<td>All patients</td>
<td>Provides referrals to a lawyer who appeals denials from health care companies</td>
<td>Phone: 1 (800) 424-2725 Online: justice.org</td>
</tr>
<tr>
<td>Cancer Legal Resource Center</td>
<td>Cancer patients</td>
<td>Provides information about patients’ rights, and resources to help with insurance coverage, employment issues, medical care questions, and estate planning</td>
<td>Phone: 1 (866) 843-2572 Online: disabilityrightslegalcenter.org</td>
</tr>
</tbody>
</table>

### Prescription Assistance Programs

Post-transplant medications can be very costly if you do not have prescription coverage. Many drug companies have programs to provide free medicines (including chemotherapy drugs). Eligibility requirements vary, but most are available to people not covered by private or public insurance programs.

<table>
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<tr>
<td>NeedyMeds</td>
<td>Patients without prescription coverage, based on income level</td>
<td>Provides information about patient assistance programs that provide free or discounted prescription medications</td>
<td>Online: needymeds.com</td>
</tr>
<tr>
<td>Partnership for Prescription Assistance</td>
<td>Patients without prescription coverage, based on income level</td>
<td>Provides information about how qualified patients can get free or nearly free medications</td>
<td>Phone: 1 (888) 4PPA-NOW 1 (888) 477-2669 Online: ppark.org</td>
</tr>
</tbody>
</table>
**Travel Assistance**

<table>
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</thead>
<tbody>
<tr>
<td>Air Care Alliance</td>
<td>All patients</td>
<td>Provides a central listing of free air transportation services</td>
<td>Phone: 1 (888) 260-9707 Online: aircareall.org</td>
</tr>
<tr>
<td>Aplastic Anemia &amp; MDS International Foundation</td>
<td>AA or MDS patients who are in a clinical trial</td>
<td>Provides families up to $500 for travel expenses to participate in a clinical trial</td>
<td>Phone: 1 (800) 747-2820 Web: aamds.org</td>
</tr>
<tr>
<td>National Patient Air Transport HELPLINE</td>
<td>All patients</td>
<td>Provides information and referrals to patients in financial need who require air transport to distant locations. This organization also provides information on discounts from all known commercial airline services.</td>
<td>Phone: 1 (800) 296-1217 Online: patienttravel.org</td>
</tr>
</tbody>
</table>
Cancer and Fertility

Cancer and its treatments can affect a person’s fertility. Fertility refers to your ability to have children in the future. After cancer treatment, some women go through early menopause. Other women continue to have their menstrual cycles but have trouble getting pregnant. This can affect your quality of life.

There are ways to protect your fertility, such as egg freezing or embryo freezing. Egg freezing and embryo freezing are well-known methods of fertility preservation. The best time to do this is before starting cancer treatment. Both treatments require about two weeks of hormone injections to stimulate the ovaries.

You can request to see a fertility specialist for more information. Discuss your options carefully with your doctor.

Be sure that you understand the risks and benefits of your options. Even though you may choose not to go through with treatments to protect your fertility, it is still important to talk about this issue. Studies have show that women who address their fertility before treatment have less feelings of regret.

The Center for Fertility and Reproductive Medicine at Cedars-Sinai provides the following services:

- Protective fertility
- Egg freezing
- Embryo freezing
- In vitro fertilization
- Ovarian reserve testing
- Preconception counseling
- Genetic screening
- Hormone replacement therapy
- Birth control methods
- Surrogacy, egg or sperm donation

The Center for Fertility and Reproductive Medicine works collaboratively with your oncology team to provide the best individualized care. For more information or to schedule a consultation, please call (310) 423-9964.
Blood is an important, life-saving resource. Almost all patients going through Blood & Marrow Transplant will need blood and/or platelet transfusions.

Often family and friends will ask if they can help in any way. A wonderful opportunity exists for them to give not only to the patient but to the whole cancer community.

One blood donation can save up to four lives. It takes 45 minutes to donate red cells and 90 minutes to donate platelets.

For appointments or blood donation questions, please call the Rita and Taft Schreiber Blood Donor Facility at:

1-877-71-BLOOD
(1-877-712-5663)

Family and friends may donate blood and platelets at Cedars Sinai Medical Center, or at a local blood bank. Usually these donations go towards replenishing the community blood supply.
**Quiz: Chapters 9 & 10**

**Question 1**

The patient and/or caregiver should always speak with their BMT team about any questions, issues or concerns at any point in the process.

a) True  

b) False

**Question 2**

A patient’s caregiver would like to organize a blood drive. What should they do?

a) Look online  
b) Make sure friends and family are eligible to donate first  
c) Contact the Blood Donor Facility at 1-877-71-BLOOD for information about the mobile blood donation clinic

**Question 3**

The cancer community is always in need of blood. Giving blood is giving the gift of life, and can save four lives per donation.

a) True  

b) False
**Absolute neutrophil count ("ANC"):** the number of one type (neutrophils) of white blood cells in the blood which fight infection.

**Advance Directive for Health Care:** a document that specifies who you want to make medical decisions for you if you cannot speak for yourself, and what medical interventions you do/ do not want.

**Allergic reaction:** the immune system has a hypersensitive response to a substance (ex. drug, latex, tape). Can result in rash, itching, swollen tongue, difficulty breathing.

**Allogeneic:** taken from another person’s tissues, cells or DNA.

**Allogeneic blood & marrow transplant:** a procedure in which a person receives stem cells from another person, either a sibling or an unrelated person. The cells are genetically similar to the patient.

**Anemia:** a condition in which the red blood cell count is below normal.

**Apheresis:** a procedure in which blood is collected, stem cells are taken out and the rest of the blood is returned to the donor.

**Apheresis catheter:** also known as an internal jugular (IJ) or Mahurkar, this is a 2 lumen IV line that is placed into the internal jugular vein for the purpose of apheresis.

**Autologous:** taken from an individual’s own tissues, cells, or DNA.

**Autologous blood & marrow transplant:** a procedure in which a person receives stem cells that they donated for themselves.

**Bacteria:** a group of single-celled organisms that can cause disease.

**Blood & marrow transplant:** a procedure to replace bone marrow that has been destroyed by treatment with high doses of chemotherapy or radiation. Transplant may be autologous or allogeneic.

**Bone marrow:** the spongy tissue deep inside of bones where stem cells divide to make white blood cells, red blood cells, and platelets.

**Bone marrow harvest:** a procedure in which a donor’s stem cells are collected in the operating room by aspirating bone marrow with a needle from the back side of the pelvic bone.

**Bone marrow transplant:** a procedure to replace bone marrow that has been destroyed by treatment with high doses of chemotherapy and/or radiation. Transplant may be autologous or allogeneic.

**Cancer:** A term for diseases in which abnormal cells divide without control and can invade nearby tissues. Cancer cells can also spread to other parts of the body through the blood and lymph systems.

**Cell:** the individual unit that makes up the tissues of the body. All living things are made up of one or more cells.

**Chemotherapy:** a treatment using drugs that kill cancer cells.

**Chemoprotectant:** a non-chemo drug that protects healthy cells from the toxic effects of anticancer drugs.

**Clinical trial:** a research study testing how well new medical approaches work in people. Usually they compare a new method with an already tested one.
Conditioning regimen: a term used for the chemotherapy, with or without radiation therapy, given to prepare the patient’s body for transplant. The regimen generally lasts 2 to 10 days prior to the transplant.

Cranial boosts: radiation that is specifically focused on the head to kill cancer cells hiding in the cerebrospinal fluid (CSF).

Cryopreservation: method used to prepare stem cell products for freezing and long-term storage and prevent cell destruction. Ten percent DMSO (dimethyl sulfoxide) is added to the product as a preservative. It is frozen in liquid nitrogen.

Directed donation: when friends/family donate blood products specifically for their loved one.

Engraftment: the point after transplant when the blood cell counts have recovered. Specifically, the white blood cell count is greater than 1000, the Absolute Neutrophil Count is greater than 500, and the platelet count is greater than 20,000.

Fever: body temperature of 100.4F (38C) or greater, indicates potential infection.

Fungus: a type of plant that may be a source of infection for people with weakened immune systems. Mushrooms, yeasts and molds are examples.

Graft versus host disease (GVHD): A complication from allogeneic BMT that occurs when the transplanted cells begin attacking the normal cells of the patient. Main organs affected are the skin, the liver and the gastrointestinal tract.

Growth factors: medications that stimulate the bone marrow to produce stem cells.

Graft failure: occurs when the transplanted stem cells fail to adequately repopulate the patient’s bone marrow.

Hemoglobin: the substance inside red blood cells that carries oxygen to the tissues.

HLA (Human leukocyte antigen): protein markers on cells that the immune system uses to recognize “self” from “not self”.

IJ (internal jugular) line: also known as an apheresis catheter or Mahurkar, this is a 2 lumen IV line that is placed into the internal jugular vein for the purpose of apheresis.

Informed consent: a process in which a doctor gives the patient information about the possible risks, benefits and limits of a procedure, treatment, trial or genetic testing. The patient then decides if they wish to participate.

Leukemia: a cancer that starts in the bone marrow, and causes large numbers of abnormal white blood cells to be produced and enter the blood. These cells crowd out healthy functioning blood cells.

Lymphoma: a cancer that begins in the cells of the immune system, can be classified as Hodgkins or non-Hodgkins lymphoma.

Mobilization: the process of moving stem cells from the bone marrow to the circulating (peripheral) blood. This is done using growth factors with or without chemotherapy.

Mucositis: a complication of some cancer therapies in which the lining of the digestive system becomes inflamed. This often presents as mouth sores.

Multiple myeloma: a type of cancer that begins in plasma cells (white blood cells that produce antibodies).

Myeloablative: a severe form of myelosuppression.

Myelosuppression: decreased bone marrow activity after chemotherapy resulting in reduced production of white blood cells, red blood cells and platelets.
**Neutropenia:** a condition in which there is a lower-than-normal number of neutrophils (a type of white blood cell).

**Neutrophil:** a type of white blood cell that is usually the “front line of defense” in preventing and treating infection in our bodies. They are normally the highest in number of all of the white blood cells.

**Peripheral blood stem cells:** stem cells that have moved from the bone marrow into the circulating blood.

**PICC (peripherally inserted central catheter):** a semi-permanent IV catheter inserted into a large vein in the arm. The tip of the catheter is close to the upper right chamber of the heart. Medications, blood products and IV fluids can be given through this catheter.

**Platelets:** blood cells that prevent and stop bleeding.

**Preparative regimen:** a term used for the chemotherapy, with or without radiation therapy, given to prepare the patient’s body for transplant. The regimen generally lasts 2 to 10 days prior to the transplant.

**Radiation:** energy released in the form of particle or electromagnetic waves and used to treat cancer.

**Red blood cells:** disc-shaped cells that contain hemoglobin to carry oxygen through the blood stream to the body’s tissues.

**Stem cells:** cells that can self-renew or divide to produce different types of cells. For example, bone marrow stem cells produce white blood cells, red blood cells and platelets.

**Thrombocytopenia:** a condition in which there is a lower-than-normal number of platelets in the blood. It may result in easy bruising and/or bleeding.

**Total body irradiation:** radiation given to the whole body to kill cancer cells prior to blood & marrow transplant.

**Umbilical cord blood unit:** stem cells collected from the umbilical cord and placenta after birth cryopreserved for future medical use.

**Virus:** a very small non-living infectious agent that replicates by injecting its DNA into a human cell. When that cell divides, it reproduces the viral DNA which may cause infection.

**White blood cell:** type of immune cell that helps the body fight infection and disease.
ADVANCE HEALTH CARE DIRECTIVE

INSTRUCTIONS

Part 1 of this form lets you name another individual as agent to make health care decisions for you if you become incapable of making your own decisions, or if you want someone else to make those decisions for you now even though you are still capable. You may also name an alternate agent to act for you if your first choice is not willing, able, or reasonably available to make decisions for you.

Your agent may not be an operator or employee of a community care facility or a residential care facility where you are receiving care, or your supervising health care provider or an employee of the health care institution where you are receiving care, unless your agent is related to you or is a coworker.

Unless you state otherwise in this form, your agent will have the right to:

1. Consent or refuse consent to any care, treatment, service, or procedure to maintain, diagnose, or otherwise affect a physical or mental condition.
2. Select or discharge health care providers and institutions.
3. Approve or disapprove diagnostic tests, surgical procedures, and programs of medication.
4. Direct the provision, withholding, or withdrawal of artificial nutrition and hydration and all other forms of health care, including cardiopulmonary resuscitation.
5. Donate organs or tissues, authorize an autopsy, and direct disposition of remains.

However, your agent will not be able to commit you to a mental health facility, or consent to convulsive treatment, psychosurgery, sterilization or abortion for you.

Part 2 of this form lets you give specific instructions about any aspect of your health care, whether or not you appoint an agent. Choices are provided for you to express your wishes regarding the provision, withholding, or withdrawal of treatment to keep you alive, as well as the provision of pain relief. You also can add to the choices you have made or write down any additional wishes. If you are satisfied to allow your agent to determine what is best for you in making end of life decisions, you need not fill out Part 2 of this form.

Give a copy of the signed and completed form to your physician, to any other health care providers you may have, to any health care institution at which you are receiving care, and to any health care agents you have named. You should talk to the person you have named as agent to make sure that he or she understands your wishes and is willing to take the responsibility.

You have the right to revoke this advance health care directive or replace this form at any time.
**PART 1 – POWER OF ATTORNEY FOR HEALTH CARE**

**DESIGNATION OF AGENT:**
I designate the following individual as my agent to make health care decisions for me:

Name of individual you choose as agent: ____________________________________________

Address: _______________________________________________________________________
_______________________________________________________________________________

Telephone: ________________________________________________________________
(home phone) (work phone) (cell/pager)

OPTIONAL: If I revoke my agent’s authority or if my agent is not willing, able, or reasonably available to make a health care decision for me, I designate as my first alternate agent:

Name of individual you choose as first alternate agent: ________________________________

Address: _______________________________________________________________________
_______________________________________________________________________________

Telephone: ________________________________________________________________
(home phone) (work phone) (cell/pager)

OPTIONAL: If I revoke the authority of my agent and first alternate agent or if neither is willing, able, or reasonably available to make a health care decision for me, I designate as my second alternate agent:

Name of individual you choose as second alternate agent: _____________________________

Address: _______________________________________________________________________
_______________________________________________________________________________

Telephone: ________________________________________________________________
(home phone) (work phone) (cell/pager)

**AGENT’S AUTHORITY:**
My agent is authorized to make all health care decisions for me, including decisions to provide, withhold, or withdraw artificial nutrition and hydration and all other forms of health care to keep me alive, except as I state here:

______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________

(Add additional sheets if needed.)
WHEN AGENT’S AUTHORITY BECOMES EFFECTIVE:
My agent’s authority becomes effective when my primary physician determines that I am unable to make my own health care decisions.

(Initial here)

OR

My agent’s authority to make health care decisions for me takes effect immediately.

(Initial here)

AGENT’S OBLIGATION:
My agent shall make health care decisions for me in accordance with this power of attorney for health care, any instructions I give in Part 2 of this form, and my other wishes to the extent known to my agent. To the extent my wishes are unknown, my agent shall make health care decisions for me in accordance with what my agent determines to be in my best interest. In determining my best interest, my agent shall consider my personal values to the extent known to my agent.

AGENT’S POSTDEATH AUTHORITY:
My agent is authorized to make anatomical gifts, authorize an autopsy and direct disposition of my remains, except as I state here or in Part 3 of this form:

(Add additional sheets if needed.)

NOMINATION OF CONSERVATOR:
If a conservator of my person needs to be appointed for me by a court, I nominate the agent designated in this form. If that agent is not willing, able or reasonably available to act as conservator, I nominate the alternate agents whom I have named, in the order designated.
PART 2 – INSTRUCTIONS FOR HEALTH CARE

If you fill out this part of the form, you may strike any wording you do not want.

END OF LIFE DECISIONS:
I direct that my health care providers and others involved in my care provide, withhold, or withdraw treatment in accordance with the choice I have marked below:

Choice Not To Prolong Life:

_(Initial here)_

I do not want my life to be prolonged if (1) I have an incurable and irreversible condition that will result in my death within a relatively short time, (2) I become unconscious and, to a reasonable degree of medical certainty, I will not regain consciousness, or (3) the likely risks and burdens of treatment would outweigh the expected benefits,

OR

Choice To Prolong Life:

_(Initial here)_

I want my life to be prolonged as long as possible within the limits of generally accepted health care standards.

RELIEF FROM PAIN:
Except as I state in the following space, I direct that treatment for alleviation of pain or discomfort be provided at all times, even if it hastens my death:

________________________________________

__(Add additional sheets if needed.)__

OTHER WISHES:
(If you do not agree with any of the optional choices above and wish to write your own, or if you wish to add to the instructions you have given above, you may do so here.) I direct that:

________________________________________

________________________________________

________________________________________

__(Add additional sheets if needed.)__
PART 3 – DONATION OF ORGANS AT DEATH (OPTIONAL)

I. Upon my death:
I give any needed organs, tissues, or parts __________________________

(Initial here)

OR
I give the following organs, tissues, or parts only: __________________________

________________________________________________________

________________________________________________________

(Initial here)

II. If you wish to donate organs, tissues, or parts, you must complete II. and III.

My gift is for the following purposes:

Transplant ________ Research ________

(Initial here) (Initial here)

Therapy ________ Education ________

(Initial here) (Initial here)

III. I understand that tissue banks work with both nonprofit and for-profit tissue processors and distributors. It is possible that donated skin may be used for cosmetic or reconstructive surgery purposes. It is possible that donated tissue may be used for transplants outside of the United States.

1. My donated skin may be used for cosmetic surgery purposes.

Yes ________ No ________

(Initial here) (Initial here)

2. My donated tissue may be used for applications outside of the United States.

Yes ________ No ________

(Initial here) (Initial here)

3. My donated tissue may be used by for-profit tissue processors and distributors.

Yes ________ No ________

(Initial here) (Initial here)

(Health and Safety Code Section 7158.3)
PART 4 – PRIMARY PHYSICIAN (OPTIONAL)

I designate the following physician as my primary physician:

Name of Physician: ______________________________________________________
Telephone: _______________________________________________________________
Address: __________________________________________________________________

OPTIONAL: If the physician I have designated above is not willing, able, or reasonably available to act as my primary physician, I designate the following physician as my primary physician:

Name of Physician: ______________________________________________________
Telephone: _______________________________________________________________
Address: __________________________________________________________________

PART 5 – SIGNATURE

The form must be signed by you and by two qualified witnesses, or acknowledged before a notary public.

SIGNATURE:

Sign and date the form here

Date: ____________________________ Time: ____________________________ AM / PM

Signature: ____________________________________________________________
(patient)

Print name: ____________________________________________________________
(patient)

Address: __________________________________________________________________

STATEMENT OF WITNESSES:

I declare under penalty of perjury under the laws of California (1) that the individual who signed or acknowledged this advance health care directive is personally known to me, or that the individual’s identity was proven to me by convincing evidence, (2) that the individual signed or acknowledged this advance directive in my presence, (3) that the individual appears to be of sound mind and under no duress, fraud, or undue influence, (4) that I am not a person appointed as agent by this advance directive, and (5) that I am not the individual’s health care provider, an employee of the individual's health care provider, the operator of a community care facility, an employee of an operator of a community care facility, the operator of a residential care facility for the elderly, nor an employee of an operator of a residential care facility for the elderly.
**FIRST WITNESS**

Name: ________________________________ Telephone: ________________

Address: __________________________________________________________

_______________________________________________________________

Date: ________________________________ Time: ________________________ AM / PM

Signature: ________________________________________________________

(witness)

Print name: ______________________________________________________

(witness)

**SECOND WITNESS**

Name: ________________________________ Telephone: ________________

Address: __________________________________________________________

_______________________________________________________________

Date: ________________________________ Time: ________________________ AM / PM

Signature: ________________________________________________________

(witness)

Print name: ______________________________________________________

(witness)

**ADDITIONAL STATEMENT OF WITNESSES:**

At least one of the above witnesses must also sign the following declaration:

I further declare under penalty of perjury under the laws of California that I am not related to the individual executing this advance health care directive by blood, marriage, or adoption, and to the best of my knowledge, I am not entitled to any part of the individual's estate upon his or her death under a will now existing or by operation of law.

Date: ________________________________ Time: ________________________ AM / PM

Signature: ________________________________________________________

(witness)

Print name: ______________________________________________________

(witness)
YOU MAY USE THIS CERTIFICATE OF ACKNOWLEDGMENT BEFORE A NOTARY PUBLIC INSTEAD OF THE STATEMENT OF WITNESSES.

State of California

County of ____________________________

On ____________________________ before me, (name and title of the officer) ____________________________________________ personally appeared (name(s) of signer(s)) ____________________________________________ , who proved to me on the basis of satisfactory evidence to be the person(s) whose name(s) is/are subscribed to the within instrument and acknowledged to me that he/she/they executed the same in his/her/their authorized capacity(ies), and that by his/her/their signature(s) on the instrument the person(s), or the entity upon behalf of which the person(s) acted, executed the instrument.

I certify under PENALTY OF PERJURY under the laws of the State of California that the foregoing paragraph is true and correct.

WITNESS my hand and official seal. [Civil Code Section 1189]

PART 6—SPECIAL WITNESS REQUIREMENT

If you are a patient in a skilled nursing facility, the patient advocate or ombudsman must sign the following statement:

STATEMENT OF PATIENT ADVOCATE OR OMBUDSMAN

I declare under penalty of perjury under the laws of California that I am a patient advocate or ombudsman as designated by the State Department of Aging and that I am serving as a witness as required by Section 4675 of the Probate Code.

Date: ____________________________ Time: ____________________________ AM / PM

Signature: ____________________________________________ (patient advocate or ombudsman)

Print name: ____________________________________________ (patient advocate or ombudsman)

Address: ____________________________________________