

# NATIONAL MARROW DONOR PROGRAM®

*Creating Connections. Saving Lives.®*



## **STEP ONE: An introduction to marrow and cord blood transplant**

*Office of Patient Advocacy*

1 (888) 999-6743 | 1 (612) 627-8140

# About the National Marrow Donor Program®

---

The National Marrow Donor Program helps people who need a life-saving marrow or cord blood transplant. We connect patients, doctors, donors and researchers to the resources they need to help more people live longer and healthier lives. To achieve our mission, we:

- **Search our Registry – the largest listing of volunteer donors and cord blood units in the world.**
- **Support patients and their doctors throughout the transplant process.**
- **Match patients with the best donor or cord blood unit using innovative science and technology.**

## Table of contents:

---

Understanding your treatment options.....	4
How to take an active role in your treatment.....	5
Questions to ask your doctor about treatment options.....	6
An introduction to marrow and cord blood transplant.....	7
Finding a matched donor or cord blood unit.....	8
Questions to ask your doctor about transplant.....	9
Selecting transplant as a treatment option.....	10
Steps of the search process to find a matched donor or cord blood unit.....	10
Financial issues .....	12
Questions to ask your insurance company .....	13
Questions to ask about a transplant center .....	14
Preparing for transplant.....	15
Overview of risks and side effects of transplant.....	16
Decision-making worksheet.....	18
Resources.....	19
Glossary .....	25
Appendix A: United States Transplant Centers .....	29
Appendix B: International Registries .....	31
Appendix C: Diseases Treatable by BMT .....	32
Appendix D: Questions to ask about treatment options.....	33
Appendix E: Questions to ask your doctor about transplant.....	34
Appendix F: Questions to ask your insurance company.....	35
Appendix G: Questions to ask about a transplant center.....	35

## Considering marrow or cord blood transplant as a treatment option

Dealing with a serious illness changes your life and the lives of people around you. Deciding on the right treatment option can be difficult. It's important to understand and compare treatment options and think about how your decisions will affect you and your family.

One option may be a marrow or cord blood transplant, also called a bone marrow transplant, stem cell transplant or BMT. You can use the information in this booklet to help you discuss treatment options with your doctor and make health care decisions.

### Additional support is available

The National Marrow Donor Program's Office of Patient Advocacy (OPA) supports patients and families every step of the way, from diagnosis through survivorship. We're here to answer your questions about marrow or cord blood transplant and to tell you about resources that might help you make decisions about your treatment options.



**If you need information in another language, the OPA can help.**

**When you call you will need to say – in English – what language you speak. It will take four to eight minutes for an interpreter to join the call. Please stay on the line until you are greeted by the interpreter.**

**Spanish speakers can e-mail OPA at [pacienteinfo@nmdp.org](mailto:pacienteinfo@nmdp.org)**

### Our services are free and confidential.

Our case managers are available Monday through Friday, between the hours of 8 a.m. and 5 p.m. Central Time.

Call us toll-free in the United States at **1 (888) 999-6743**.

Outside of the United States, call **1 (612) 627-8140**.

Reach us by e-mail at: [patientinfo@nmdp.org](mailto:patientinfo@nmdp.org)

More information is available online at:  
[www.marrows.org/patient](http://www.marrows.org/patient)



Bob, transplant recipient,  
with his daughter, Tegan

**You might decide that transplant is your best option, or that another treatment is better.**

**Whatever you decide, it's important to discuss your options with your doctor and ask questions to make sure you understand what to expect from any treatment.**

## Understanding your treatment options

When you face a serious disease, learning about your treatment options can help you be more in control of the situation. The more you know, the better prepared you will be to ask questions and make informed decisions.

A marrow or cord blood transplant is one treatment option for patients with serious blood, immune system or genetic disorders. Your doctor may also talk to you about other options, including:

- **Chemotherapy:** Drugs that are often used to treat leukemia, lymphoma and other diseases. Chemotherapy is also used to prepare patients for transplant.
- **Radiation therapy:** A treatment that uses a form of energy to destroy cancer cells and may also be used to prepare patients for transplant.
- **Blood transfusions:** Red blood cells or platelets given to patients who have too few of these blood cells.
- **Immunotherapy:** A newer treatment option that uses parts of the immune system to fight disease.
- **Clinical trials:** Research studies of new treatments for your disease.
- **Other treatment options**

The treatment your doctor recommends will depend on your disease. It will also depend on your age, overall health and other factors. Different doctors recommend different treatments, so you might want to get a second or third opinion.

## How to take an active role in your treatment

These are suggestions on how to get important information and make informed choices.

- **Learn about your disease.** Ask for written information.
- **Learn about your possible treatment options.** Ask if you have been told about all the available options.
- **Organize your information.** Keep a record of conversations with names and phone numbers. Write down important words and definitions. Ask family and friends to help you collect and organize information.
- **Ask your doctor to explain the treatment options** that he or she feels are the best available to treat your disease. Before you move forward with a treatment, the doctor will explain the treatment in detail so that you understand. You have the right to get the opinions of other doctors. You can refuse any treatment. If you want to change doctors or hospitals, you should check with your insurance company.
- **Ask your doctor how many people he or she has treated with your disease.** Ask about the success rate for recommended treatments. Ask what will happen without the treatment. Repeat back to the doctor what you hear to make sure you understand correctly.
- **Write down questions and answers** or have a friend or family member go with you and take notes. Don't rely on your memory. Ask your doctor if you may record conversations on a tape recorder.
- If you are unsure about the best treatment, **ask for a second and even a third medical opinion.** Contact your insurance company to make sure it covers second opinions.
- **If you have disagreements with your doctor, tell him or her.** Give the doctor a chance to resolve problems with you. Talking openly gives everyone a chance to find the right solution.
- **Know your insurance benefits.** Talk to your insurance provider directly or ask your employer to help you. Your insurance may cover only certain hospitals, doctors or treatments. Check this out as soon as possible to help you understand your options.
- **If you don't find the answer right away, keep asking.** There are hospital social workers and financial workers who can help you find answers about your rights and your insurance.

**Some people want to talk to a person who has had a similar disease and treatment. Remember that each person's experience is unique.**

**Check with your doctor about information you read on the Internet or hear from other patients. It may be very different from your situation.**



Donna, transplant recipient, with her doctor

**For a list of patient resources, see page 19.**



**Keep asking questions until you understand as much as you need to make a decision.**

**Repeat back to your doctor what you think you heard.**

**Find out whether you can call or e-mail your doctor or medical team if you think of more questions later.**

## Clinical trials

You may be offered the opportunity to participate in a clinical trial as a treatment for your disease. These studies try to find better ways to prevent, diagnose, and treat diseases.

Today's most effective standard treatments are based on the results of earlier clinical trials. If a new method or drug works well in a study, it may become a new standard treatment.

Talk to your doctor about clinical trials to learn more about all the options available to you. You can also visit [www.cancer.gov](http://www.cancer.gov) to learn about clinical trials.

## Questions to ask your doctor about treatment options

Before you meet with your doctor, make a list of questions you would like to ask. You can also use the list of questions, Appendix D, on page 33 of this book. Give a copy of your questions to your doctor so you can discuss them together.

If you have a lot to talk about, let your doctor know ahead of time. We encourage you to bring along a family member or friend. This person can take notes and help you remember what was said.

### Sample questions:

- What treatment do you recommend and why?
- What is the goal of this treatment? (A cure? A long-term remission—if so, how long? To control symptoms?)
- How many patients have you treated who have the same disease?
- Are there other treatment options?
- What do you think the chances are the recommended treatment will get rid of the disease—for the short term and the long term?
- What are the possible risks and side effects of the treatment?
- Is it possible to continue work/school during treatment?
- What activities need to be avoided during treatment?
- How long will the treatment last?
- How will we know whether the treatment is working?
- What other choices do we have if the treatment does not work?
- What about clinical trials?

## An introduction to marrow and cord blood transplant

If you are considering a transplant, here are some important facts to know.

There are three sources of blood-forming cells used in transplants:

- Bone marrow from an adult donor
- Peripheral (circulating) blood from an adult donor (also called peripheral blood stem cell or PBSC)
- Umbilical cord blood collected after a baby is born

Marrow is the soft tissue inside your bones that produces blood-forming cells. Blood-forming cells are immature cells that can grow into red blood cells, white blood cells or platelets.

- Red blood cells carry oxygen throughout the body.
- White blood cells help fight infections.
- Platelets help control bleeding.

### Healthy marrow and blood cells are needed to live.

When disease affects marrow so that it cannot function properly, a marrow or cord blood transplant can be a possible life-saving treatment option.

A transplant uses healthy blood-forming cells, either from yourself or a matched donor or cord blood unit, to replace your unhealthy cells with a new blood and immune system.

Note: Many different words are used to describe the transplant process. Your doctor might talk about:

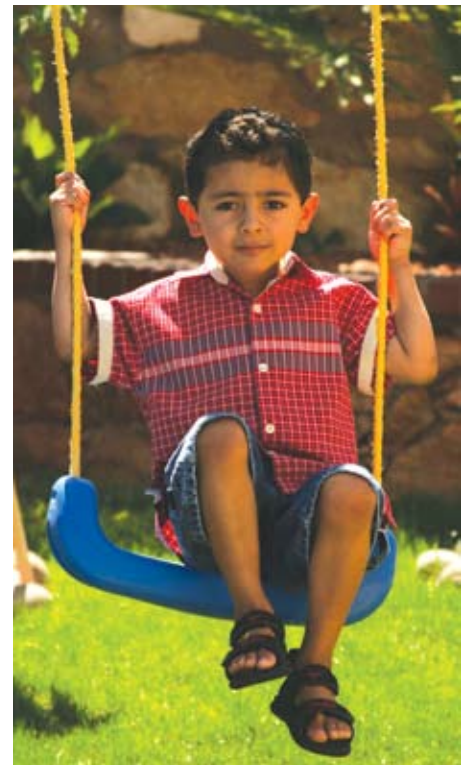
- Marrow or cord blood transplant
- Stem cell transplant
- BMT (blood and marrow transplant)
- HCT (hematopoietic cell transplant)

You might also read about:

- Hematopoietic cells
- Progenitor cells
- Blood-forming cells
- Marrow and blood cells

All these terms refer to the blood-forming cells used in transplantation. A glossary is included in the back of this booklet on page 25.

**A transplant uses healthy blood-forming cells, either from yourself, a matched donor or cord blood unit to replace your unhealthy cells with a new blood and immune system.**



Diego, transplant recipient

**The NMDP specializes in unrelated allogeneic transplants—helping find matched donors or cord blood units for patients who do not have a matched donor in their family.**



Lamar (left), transplant recipient, with Adam (right), his donor

**If you do not have a donor in your family, your doctor can search the National Marrow Donor Program (NMDP) Registry.**

There are two main types of transplant that use blood-forming cells:

- An **autologous** transplant uses a patient's own cells, collected and stored for transplant.
- An **allogeneic** transplant uses matched cells collected from another person, either a family member or an unrelated donor or from cord blood.

If you need a transplant, the type of transplant and cell source that is right for you—marrow or PBSC from a volunteer donor or cord blood—will be determined by your disease and other health factors. The NMDP searches for all three cell sources on the Registry.

The NMDP specializes in unrelated allogeneic transplants—helping find matched donors or cord blood units for patients who do not have a matched donor in their family.

## Finding a matched donor or cord blood unit

An allogeneic transplant requires a close match between the HLA tissue type of the patient and the donor. HLA stands for human leukocyte antigen, a marker that your immune system uses to recognize which cells belong in your body and which do not. HLA tissue type is not the same as blood type. It is much more complex.

HLA tissue types are inherited, with one half coming from your mother, and one half coming from your father. You have a 25 percent chance of matching each brother or sister who has the same parents as you. It is unlikely that any other family member besides a sibling would match you. 70 percent of patients do not have a suitable donor in their family.

If you do not have a donor in your family, your doctor can search the National Marrow Donor Program (NMDP) Registry. The Registry is a computerized listing of tissue types collected from 6 million potential volunteer donors and 46,000 cord blood units. Through relationships with international registries, the NMDP also has access to an additional 4 million donors worldwide. See Appendix B on page 31 to see a listing of International Registries.

There are many different tissue types. Some are common, some are rare. Despite the large number of donors and cord blood units on the Registry, not everyone finds a match. If your doctor cannot find an exact match for you in an appropriate time, he or she may consider using the next closest, suitable match. Good results can still be obtained from a close match.



## Questions to ask your doctor about transplant

You might already be at a transplant center when you receive this booklet. If not, your doctor will refer you for consultation with a doctor who does transplants.

### Sample questions:

- Do you recommend an autologous transplant (which uses the patient’s own cells) or an allogeneic transplant (which uses cells from a family member, unrelated donor or cord blood unit)? Why?
- When do you recommend a transplant? What are the risks of waiting or trying other treatments first?
- If an allogeneic transplant is recommended:
  - Which family members will you test as possible donors?
  - Is a transplant using an unrelated donor or a cord blood unit an option?
  - Is a reduced-intensity transplant an option? (“Reduced-intensity,” and “mini-transplant” are common terms for a non-myeloablative transplant. It refers to a transplant that uses less-intense chemotherapy and less, or no radiation therapy to prepare a patient to receive a transplant.)
- How long will I be in the hospital?
- What do you think the chances are that a transplant will be successful?
- Is there anything about my health or disease that makes my transplant more risky?
- What is a clinical trial? Do you know of any clinical trials that might be appropriate for treatment?
- What are the possible side-effects and complications in the first few months, first year and over the long term?
- What steps will you take to try to prevent these side-effects and complications and how will you treat them if they occur?
- What are the requirements for having a caregiver stay with me before, during and after the transplant?

### Resources for your doctor

You can find more in-depth information to share with your doctor in the Physician Resources section of [www.marlow.org/md](http://www.marlow.org/md):



Lyndsey, transplant recipient, with her doctor

**Keep asking questions until you understand as much as you need to make a decision. Find out whether you can call or e-mail your doctor or nurse if you think of more questions later.**

**This list of questions is available in Appendix E on page 34 of this book and online at: [www.marlow.org/patient](http://www.marlow.org/patient)**



Mark (top left), transplant recipient, with his family

**If you go on to transplant, you will NOT have to find your own donor. That's your transplant center's job. Your transplant team will use all of their experience and resources to find a donor or cord blood unit for you in the shortest amount of time.**

## Selecting transplant as a treatment option

If you and your doctor decide to pursue transplant and move on to a formal search, we will send you another booklet, *Step Two*. Because the search for a donor sometimes moves quickly, you might receive both booklets at the same time.

Friends and family often want to help by being tested to see if they match. It is highly unlikely that anyone you know, other than a sibling would match you.

**In general, we encourage patients and their immediate families to focus their energies on caring for the patient. The NMDP's ongoing recruitment efforts add more than 27,000 new donors to the Registry each month.**

### To join the Registry, people must:

- Be between 18 and 61 years old
- Meet health guidelines
- Be **committed to helping any patient in need**

### Family and friends can contact OPA to learn about other ways to help

- Support the patient and caregiver
- Conduct fundraisers to help cover expenses
- Recruit donors to the Registry

## The search process: finding a matched donor or cord blood unit

It's important to start a search early. Finding a match can take as little as a few weeks to select a cord blood unit, or several months or more to find a donor.

Sometimes no suitable donor or cord blood unit can be found. If that happens, your doctor will look at other treatment options.

### Step 1. Your doctor asks for a preliminary search

You received this booklet because your doctor asked for a preliminary search. This review of the NMDP donor Registry is a free, one-time look at how many possible matches there are for you on the Registry.

### Step 2. Your doctor reviews the preliminary search results

The search report will show the number of potential, closely matched donors and cord blood units for you that are listed on the Registry at that moment. A preliminary search does not involve contacting donors or having other tests done.

### Step 3. Your doctor refers you to an NMDP-affiliated transplant center

Only a hospital with experience performing allogeneic transplant—known as a transplant center—can initiate the next step, the formal search. To help decide which transplant center is best for you, you and your doctor might refer to the NMDP resource, *Choosing a Transplant Center: A Patient’s Guide*, available from OPA.

### Step 4. Your transplant center starts a formal search

In a formal search, the Registry is searched every day to include the most recent additions. Potential matched cord blood units will be ordered, or donors will be contacted for additional testing. There are costs involved in a formal search. These costs may or may not be covered by your insurance. If you have questions about your health care coverage the NMDP’s Office of Patient Advocacy can help.

### Step 5. Arrange for collection of blood-forming cells

Your transplant center doctor will select the source of blood-forming cells for your transplant, either an adult volunteer donor, or a cord blood unit that has been previously donated and stored frozen.

**If an adult donor is chosen**, he or she will be contacted by a donor center and educated about the collection process by a donor center. All communication is coordinated by the NMDP to protect the confidentiality of both the patient and the donor. There will be no direct contact between you and the donor, or your doctor and the donor during your treatment. The donor center will coordinate your doctor’s request for either a marrow donation, or a PBSC donation.

**If a matching cord blood unit is selected**, the NMDP arranges for the cord blood unit to be sent to the transplant center.

**You can also find more information about the transplant process at [www.marrow.org](http://www.marrow.org).**

**Sometimes, a preliminary search moves very quickly to become a formal search.**

**It’s likely that your doctor will simply talk about “your search,” instead of saying “preliminary search” or “formal search.”**

## The Transplant Process

Transplant (“Day Zero”)						
Referred to NMDP Transplant Center	Donor Search	Conditioning (Chemo and/or radiation)	In-Patient Recovery	Out-Patient Recovery	At Home Recovery	The “New Normal”
	<b>Adult donor:</b> About 2 months or longer	Standard transplant: 6-12 days	Standard transplant: 30-100 days	Standard transplant: 100 days or longer	Standard transplant: 100 days or longer	Standard transplant: One year or longer
	<b>Cord blood:</b> About 2 weeks	Mini/reduced intensity transplant: Varies	Mini/reduced intensity transplant: Varies	Mini/reduced Intensity transplant: Varies	Mini/reduced intensity transplant: Varies	Mini/reduced intensity transplant: One year or longer

All time spans are approximate. Your experience may be different. Talk to your doctor about your treatment plan.



Rosemarie and her husband Ed,  
transplant recipient

**More financial information is available in *Mapping the Maze: A Personal Financial Guide to Blood Stem Cell Transplant*, available from OPA.**

## Financial issues

A transplant is expensive. Contact your insurance company and ask to have a transplant case manager assigned to you so you can learn what your plan covers. Some insurance companies pay for transplant and other related costs. Some pay limited transplant costs or none at all.

Most patients have some costs that are not covered by their insurance. It's important to plan for these expenses. Case managers in OPA can help you come up with questions to ask your employer or insurance case manager about what is covered through your insurance.

If you don't have health insurance, case managers in OPA can help you find state or county programs that provide financial aid to those who qualify.

- If you have insurance through your work, ask to speak with the person or department in charge of health benefits. They may be able to answer your questions about insurance coverage.
- Contact your insurance company. Ask to speak to a transplant case manager. If that person cannot help you, ask to speak to the insurance company's patient advocate.
- Ask for a financial worker at your doctor's office, hospital or transplant center. He or she may be able to answer questions. He or she can also tell you about any costs you will have to pay.
- Ask for information in writing.
- When you talk to your insurance company, take clear notes, get the name of the person that you talk to, and record the dates of your conversations.

## Questions to ask your insurance company

Insurance companies or government programs have different ways to pay for treatment and transplant expenses. Some pay for all expenses, some pay for some expenses and some do not pay for any of the expenses. It is very important to find out what expenses are covered.

### Here are some questions to ask your insurance company:

- Does my insurance cover an unrelated marrow or cord blood transplant?
- Does it cover the type of transplant my doctor has recommended?
- What transplant centers will it cover? Can I choose which transplant center I go to? Does my insurance provider ever make exceptions? For example, could I go to a transplant center with the most experience treating a rare disease, even if it was not on the provider list?
- Will it cover a medical evaluation/consultation at a transplant center to see if a transplant is the right treatment?
- Does it cover the cost of testing to identify a matching donor?
- Does it cover the procurement (collection) of marrow from the donor or cord blood units? Are there any limits to what it will pay? If so, what are they?
- What kind of patient costs won't it pay for?
- Does it cover any costs such as travel or lodging for the patient and caregiver?
- Does it cover medications/prescriptions before and after a transplant?
- Would a clinical trial be covered?
- Does the policy have a per-year or a lifetime maximum on how much it will pay?

This information is also available in Appendix F on page 35 to share with your doctor.

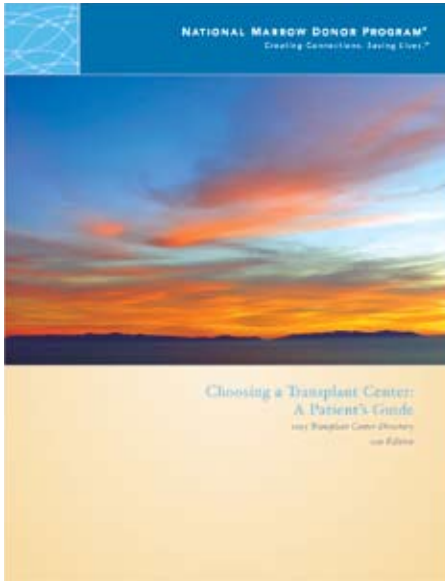


Sharen, wife and caregiver to transplant recipient

**Our case managers can help you with your insurance questions and issues about coverage.**

**To talk to a case manager, contact the Office of Patient Advocacy (OPA) at 1-888-999-6743.**

**Our services are free and confidential.**



**What are your thoughts after talking with or visiting the transplant center?**

**Did they answer your questions in a way that helped you understand the process?**

**Did they seem willing to help you solve any problems you might have?**

**Did they return your phone calls within a reasonable time?**

**Did you get the feeling they would take good care of you?**

## Next steps: Learning about transplant centers

Hospitals that have experience performing marrow or cord blood transplants have special departments called transplant centers. Not all hospitals perform transplants. You may have to travel to receive a transplant.

Some centers specialize in certain kinds of patients or diseases. Your doctor might recommend a specific transplant center. Your insurance company might also have rules about which transplant centers are covered in your insurance plan.

A list of NMDP transplant centers in the United States is in Appendix A on page 29 of this book. Information about each NMDP transplant center is also available in *Choosing A Transplant Center: A Patient's Guide*. The guide contains detailed information about each NMDP U.S. transplant center including:

- Statistics to help you compare centers
- Transplant costs
- Charts showing numbers of transplants by disease
- HLA match requirements

We encourage you to discuss this information with your doctor.

## Questions to ask about a transplant center:

- How long has this transplant center performed unrelated transplants?
- Does this transplant center do transplants for my disease?
- How many unrelated donor transplants has this center done for my disease?
- Does this transplant center have experience with patients who are my age?
- Does this center have experience with cord blood transplants?
- What is the patient and unrelated donor match level required at this center?
- What steps must my doctor take to find out if I would qualify as a patient at this transplant center? Do I need a formal consultation or visit to a transplant center first?
- What is the survival rate at this transplant center for patients like me? For example: same disease, disease stage, age, and similar health factors.

## Other considerations

- How important is geographic location to you and your family? Is it important for you to be close to family and friends? Or, would you rather go to the transplant center with the most experience, even if it is far from home?
- If the transplant center is far from home, will the transplant center help make arrangements for your family or caregiver? Do they have housing near the transplant center?
- How will the transplant center inform you about the progress of the search for an unrelated donor? Will they call you or ask that you call them? How often can you expect to get progress reports?

## Preparing for transplant

To get your body ready for a transplant, you will receive chemotherapy—with or without radiation. This will destroy or suppress your immune system so it cannot attack the new cells you receive from your donor. This treatment is called a preparative regimen, or conditioning. It is also used to destroy diseased cells before the transplant.

Some patients get preparative regimens that use smaller doses of chemotherapy and less radiation. This treatment is called a reduced-intensity, non-myeloablative, or mini-transplant. This option makes transplant possible for patients who might not be able to tolerate the standard, high-dose regimen.

After the treatment your body will be less able to fight infection, so you will have to stay in the hospital until your immune system recovers. This usually takes a month or more.

Some patients are able to undergo the preparative regimen on an outpatient basis. Each transplant center decides which method is best to treat its patients.

## Receiving your new cells

You will usually receive your new cells one or two days after you complete the preparative regimen. The donated cells arrive in plastic bags. Marrow and PBSC donations look just like the ones used to collect blood from blood donors. Cord blood donations are much smaller. The cells in the bags are infused (put into your body) through an intravenous (IV) line, much like a blood transfusion. You will be awake to receive the donated cells.

The donated cells “know” where they belong in the body. They move through your bloodstream to settle in your bone marrow. This is where the donated cells will begin to grow and produce new red blood cells, white blood cells and platelets.



Kay and her husband Woody,  
transplant recipient

**Information about each  
transplant center can  
also be found at  
[www.marlow.org/access](http://www.marlow.org/access)**



Everett, transplant recipient, with his doctor

**Most survivors have some long-term effects or complications from their transplant. Some of these go away over time. Others can be long lasting.**

**Some are fairly easy to manage, but other long-term effects are serious or painful.**

**You cannot control or predict whether you will have these long-term effects, but you and your doctor can take steps to deal with them if they develop.**

## Life after transplant

In the first months after transplant your focus will be on recovery: eating well, avoiding infections, getting care from your doctor and following other guidelines to stay healthy. Many survivors say recovery takes at least a full year. However, you may feel better more quickly or more slowly. In time, you will probably be ready to return to work or school and other activities.

## Overview of risks and side effects of transplant

Every person's transplant experience is unique. Treatment and recovery depend on diagnosis, age, donor and other health factors.

### Graft-versus-host disease (GVHD)

GVHD is a common side effect of an allogeneic transplant in which the immune cells from the donor (the graft) attack the body of the transplant patient (the host). GVHD can affect the skin, eyes, stomach and intestines as well as other parts of the body. It can range from mild to life-threatening.

### Fatigue

Fatigue (feeling tired) is the most common long-term effect of transplant. In the first months after your transplant, you can expect to feel tired much of the time. Some transplant survivors say they never have as much energy as they did before their transplant, but most learn to manage their fatigue.

### Memory and concentration problems

Many people who have received chemotherapy say they have problems with short-term memory or concentration. For most people, this effect is not serious enough to keep them from returning to their job or school.

### Thyroid problems

Some transplant survivors who had total body irradiation (TBI) can get hypothyroidism or other thyroid problems. The symptoms of hypothyroidism include fatigue, weight gain and depression.

### Risk of secondary cancers

Chemotherapy and radiation therapy both increase a person's risk of getting another kind of cancer later. People who had total body irradiation (TBI) or get chronic GVHD have an even higher risk.



## Cataracts

Some survivors develop cataracts (a clouding of the lens in your eye) about three to four years after transplant.

## Numbness and tingling in the hands and feet

Numbness and tingling in the hands and feet can be a side effect of some kinds of chemotherapy. It may get better over time, but it may never go away completely. It may also get worse over time.

## Infertility

Most people who have a bone marrow or cord blood transplant are unable to have children as a result of their treatment.

## Sexual problems

Many people have some sexual problems, such as loss of interest, pain or other dysfunction.

## Feelings of depression, anger or guilt

Recovery is a slow process and can be frustrating, contributing to changing emotions.

## Living with restrictions

Because you will have a weakened immune system after transplant, you will have additional restrictions that may affect your lifestyle.

**Additional information about risks, side effects and treatment is available at [www.marlow.org/patient](http://www.marlow.org/patient).**

## Late effects in children

Transplant can also affect growth and development in children, including: learning difficulties, skeletal growth, growth hormone deficiency, late onset puberty, infertility and other problems.

*“When I returned home, I thought that the worst was over. However, I developed painful shingles. I also had nausea and diarrhea. Corticosteroids affected my appetite and I put on weight. It was a year and a half before I really began to feel well.”*

—Ivo, transplant recipient



Ivo, transplant recipient

**We hope this booklet has been helpful to you in considering transplant as a treatment option.**

**If you decide to pursue transplant as a treatment option, or would like additional information, contact the Office of Patient Advocacy at 1 (888) 999-6743.**

**You can also refer to the additional resources on the following pages.**

**If you need to write down your thoughts about your treatment options, this decision guide can help.**

## A guide to making decisions

If you need to write down your thoughts about your treatment options, this decision guide can help. It will help you identify your personal needs and goals, plan the next steps and communicate your view to others involved in the decision.

**Clarify the decision.** What are your treatment options?

### 1. How far along are you with your decision? (check the box that applies to you)

- I have not yet thought about all my treatment options
- I am considering my treatment options
- I am close to choosing a treatment option
- I have already made my choice

### 2. What is your decision-making role?

- I prefer to decide on my own or after considering the opinions of others
- I prefer to make the decision with my spouse/partner or family
- I prefer my doctor makes the decision for me

### 3. Weigh your treatment options

Use the balance scale below to help you compare your treatment options. You can also share this scale with others involved in your decision.

	PROS		CONS	
	Reasons to choose treatment option	Personal importance	Reasons to avoid treatment option	Personal importance
Option #1 is:				
Option #2 is:				
Option #3 is:				

### 4. What are your next steps?

- Talk to my family about my treatment options
- Ask my doctor more questions about my treatment options
- Get more information from other sources (Internet, another doctor, support groups, patient organizations) about my treatment options
- Make a treatment decision

## Resources

Many organizations are available to help you and your family.

This list should not be considered as an endorsement of these organizations by the NMDP. The choice to work with these groups is solely that of the patient and his or her representative. For the most current listing of resources, please visit our patient organization database at [www.marlow.org/resources](http://www.marlow.org/resources).

### General Cancer Resources

#### (S) American Cancer Society

1599 Clifton Road N.E.  
Atlanta, GA 30329-4251  
(800) 227-2345  
Web site: [www.cancer.org](http://www.cancer.org)

ACS is a health organization dedicated to eliminating cancer as a major health problem by preventing cancer, saving lives, and diminishing suffering from cancer, through research, education, advocacy, and service.

#### (S) CancerCare

275 7th Avenue  
New York, NY 10001  
(800) 813-4673 (HOPE)  
(212) 712-8080  
Fax: (212) 712-8495  
Web site: [www.cancercare.org](http://www.cancercare.org)  
E-mail: [info@cancercare.org](mailto:info@cancercare.org)

CancerCare is dedicated to helping people face the many challenges of a cancer diagnosis. Provides free professional help to people with all cancers through counseling, education, information and referral and direct financial assistance.

#### Cancer Hope Network

Two North Road  
Chester, NJ 07930  
(877) 467-3638 (HOPENET)  
Fax: (908) 879-6518  
Web site: [www.cancerhopenetwork.org](http://www.cancerhopenetwork.org)  
E-mail: [info@cancerhopenetwork.org](mailto:info@cancerhopenetwork.org)

Provides individual support to cancer patients and their families by matching them with trained volunteers who have undergone and recovered from a similar cancer experience.

#### (S)= Spanish language support

#### Caring Bridge

3440 Federal Drive, Suite 100  
Eagan, MN 55122  
(651) 452-7940  
Fax: (651) 681-7115  
Web site: [www.caringbridge.org/marrow](http://www.caringbridge.org/marrow)  
E-mail: [info@caringbridge.org](mailto:info@caringbridge.org)

This free, easy-to-use Internet service helps family and friends stay informed and in touch with loved ones.

#### (S) Gilda's Club Worldwide

322 Eighth Avenue, Suite 1402  
New York, N.Y. 10001  
(888) 445-3248 (GILDA-4-U)  
(917) 305-1200  
Fax: (917) 305-0549  
Web site: [www.gildasclub.org](http://www.gildasclub.org)  
E-mail: [info@gildasclub.org](mailto:info@gildasclub.org)

Cancer support community where men, women and children with cancer and their families and friends join with others to build social and emotional support as a supplement to medical care in free, nonresidential, home-like setting.

#### National Cancer Institute (NCI)

Cancer Information Service Room  
3036A 6116 Executive Blvd., MSC8322  
Bethesda, MD 20892-2580  
(800) 422-6237 (1-800-4-CANCER)  
(310) 435-3848  
Web site: [www.cancer.gov](http://www.cancer.gov)

Information on cancer, current cancer treatment options and clinical trials.

#### The Wellness Community

919 18th Street N.W., Suite 54  
Washington, D.C. 20006  
(888) 793-9355  
(202) 659-9709  
Fax: (202) 659-9301  
Web site:

[www.thewellnesscommunity.org](http://www.thewellnesscommunity.org)  
E-mail: [help@thewellnesscommunity.org](mailto:help@thewellnesscommunity.org)

A national nonprofit organization that provides free support, education and hope for people with cancer.

### Transplant Resources

#### (S) Blood & Marrow Transplant Information Network (BMT InfoNet)

2310 Skokie Valley Road, Suite 104  
Highland Park, IL 60035  
(888) 597-7674  
(847) 433-3313  
Fax: (847) 433-4599  
Web site: [www.bmtinfonet.org](http://www.bmtinfonet.org)  
E-mail: [help@bmtinfonet.org](mailto:help@bmtinfonet.org)

Strives to provide high quality medical information in easy-to-understand language, so that bone marrow and blood cell transplant patients can be active, knowledgeable participants in their health care planning and treatment.

BMT InfoNet's "Patient-to-Survivor Program" links patients to survivors who can share information and provide emotional support.

## Resources (continued)

### **BMT Support Online**

P.O. Box 10303  
Dothan, AL 36304  
(586) 575-9910  
Fax: (810) 277-5118  
Web site: [www.bmtsupport.org](http://www.bmtsupport.org)  
E-mail: [bmt-support@bmtsupport.org](mailto:bmt-support@bmtsupport.org)

Provides interactive chat area, and two online support groups – one for patients and survivors, the other for caregivers. Both groups meet weekly at scheduled times (see Web site for more information).

### **BMT-TALK (Internet Mailing List)**

Online peer support for patients, survivors and caregivers.  
To subscribe, visit [www.acor.org](http://www.acor.org) and click on “mailing lists.”  
Under “Browse Alphabetically,” click on “B” then click on BMT-TALK.

### **(S) Bone Marrow Foundation**

377 East 88th Street, Suite 1B  
New York, NY 10128  
(800) 365-1336  
(212) 838-3029  
Web site: [www.bonemarrow.org](http://www.bonemarrow.org)  
E-mail: [theBMF@BoneMarrow.org](mailto:theBMF@BoneMarrow.org)

The mission of The Bone Marrow Foundation is to improve the quality of life for marrow and stem cell transplant patients and their families by providing financial aid, education and support programs.

### **The Marrow Foundation**

400 Seventh Street N.W., Suite 206  
Washington, D.C. 20004  
(202) 638-6601  
Fax: (202) 638-0641  
Web site:  
[www.themarrowfoundation.org](http://www.themarrowfoundation.org)  
E-mail: [tmf@nmdp.org](mailto:tmf@nmdp.org)

Secures funding from private sources to sponsor research to improve the understanding and outcome of unrelated donor marrow and blood cell transplantation, works to increase the size and diversity of the National Marrow Donor Program Registry of volunteer donors and cord blood units, and assists transplant patients with uninsured financial needs through its Patient Assistance Funds, accessed through the National Marrow Donor Program’s Office of Patient Advocacy.

### **(S) National Bone Marrow Transplant Link (NBMT LINK)**

20411 W. 12 Mile Road  
108 Southfield, MI 48076  
(800) 546-5268  
(248) 358-1886  
Web site: [www.nbmtlink.org](http://www.nbmtlink.org)  
E-mail: [info@nbmtlink.org](mailto:info@nbmtlink.org)

The nbmtLink helps patients, as well as their caregivers, families and the health care community meet the many challenges of marrow and blood cell transplant by providing vital information and support services.

“Peer Support on Call” program offers emotional support through one-on-one conversations with volunteers who are transplant survivors, caregivers and donors.

### **(S) National Marrow Donor Program (NMDP)**

Office of Patient Advocacy  
3001 Broadway Street N.E., Suite 500  
Minneapolis, MN 55413  
(888) 999-6743  
(612) 627-8140  
Fax: (612) 627-8195  
Web site: [www.marrow.org](http://www.marrow.org)

The NMDP’s Office of Patient Advocacy (OPA) supports patients, families and physicians from diagnosis through survivorship. OPA offers programs, resources and services that meet each patient’s needs whether through one-on-one counseling, educational materials or information in other languages.

## Aplastic Anemia

### **(S) Aplastic Anemia and MDS International Foundation, Inc.**

P.O. Box 613  
Annapolis, MD 21404-0613  
(800) 747-2820  
(410) 867-0242  
Fax: (410) 867-0240  
Web site: [www.aamds.org](http://www.aamds.org)  
E-mail: [help@aamds.org](mailto:help@aamds.org)

AAMDS serves as a resource for patient assistance, advocacy and support. Provides educational materials and medical information, supports research to find treatments and a cure for aplastic anemia, myelodysplastic syndromes and related disorders.

**(S)= Spanish language support**

## Resources (continued)

### Fanconi Anemia

#### (S) Fanconi Anemia Research Fund, Inc.

1801 Willamette Street #200  
Eugene, OR 97401  
(800) 828-4891  
(541) 687-4658  
Fax: (541) 687-0548

Web site: [www.fanconi.org](http://www.fanconi.org)  
E-mail: [info@fanconi.org](mailto:info@fanconi.org)

Provides newsletter and support network for patients and families affected by Fanconi anemia.

### Leukemia

#### Granny Barb and Art's Leukemia Links

Web site: [www.acor.org/leukemia](http://www.acor.org/leukemia)  
E-mail: [flataua@acm.org](mailto:flataua@acm.org)

Provides links to sites on the Internet that provide information about leukemia and blood and marrow cell transplantation.

#### Leukemia Research Foundation

820 Davis Street, Suite 420  
Evanston, IL 60201  
(847) 424-0600  
Fax: (847) 424-0606  
Web site: [www.leukemia-research.org](http://www.leukemia-research.org)  
E-mail: [info@lrfmail.org](mailto:info@lrfmail.org)

Publishes a newsletter and provides counseling and support for leukemia patients. Also offers financial aid for patients with leukemia, lymphoma or myelodysplasia.

#### (S) Leukemia and Lymphoma Society

1311 Mamaroneck Avenue  
White Plains, NY 10605  
(800) 955-4572  
(914) 949-5213  
Fax: (914) 949-6691  
Web site: [www.lls.org](http://www.lls.org)  
E-mail: [infocenter@lls.org](mailto:infocenter@lls.org)

Dedicated to finding cures for leukemia, lymphoma, Hodgkin's lymphoma and myeloma and improving the quality of life of patients and their families. Supports medical research and provides health education materials.

Local chapters in each state offer information on local resources and support groups. Provides a Patient-Aid Program to give limited supplementary financial assistance to patients.

The Society's "First Connection" program connects patients or family members with volunteer survivors who have been successfully treated for the same diagnosis.

### Lymphoma

#### (S) Lymphoma Research Foundation of America

Los Angeles Office:  
8800 Venice Boulevard, Suite 207  
Los Angeles, CA 90034  
(800) 500-9976  
(310) 204-7040  
Fax: (310) 204-7043

New York Office:  
111 Broadway, 19th Floor  
New York, NY 10006  
(800) 235-6848  
(212) 349-2910  
Fax: (212) 349-2886  
Web site: [www.Lymphoma.org](http://www.Lymphoma.org)  
E-mail: [lrf@lymphoma.org](mailto:lrf@lymphoma.org)

Supports lymphoma research and legislative advocacy for lymphoma research. Provides education and emotional support programs for patients and their families.

### Myeloma

#### (S) International Myeloma Foundation

12650 Riverside Drive, Suite 206  
North Hollywood, CA 91607  
(800) 452-2873  
(818) 487-7455  
Fax: (818) 487-7454  
Web site: [www.myeloma.org](http://www.myeloma.org)  
E-mail: [theIMF@myeloma.org](mailto:theIMF@myeloma.org)

Publishes a newsletter and provides patient information on myeloma. Supports myeloma education and research.

(S)= Spanish language support

## Resources (continued)

### Multiple Myeloma Research Foundation

51 Locust Ave, Suite 201  
New Canaan, CT 06840  
(203) 972-1250  
Web site: [www.multiplemyeloma.org](http://www.multiplemyeloma.org)  
E-mail: [info@themmrf.org](mailto:info@themmrf.org)

Provides information and newsletter for patients and families affected by multiple myeloma.

### Sickle Cell Disease

#### (S) Sickle Cell Disease Association of America Inc. (SCDAA)

231 East Baltimore Street, Suite 800  
Baltimore, MD 21202  
(800) 421-8453  
(410) 528-1555  
Fax: (410) 421-8453  
Web site: [www.sicklecelldisease.org](http://www.sicklecelldisease.org)  
E-mail: [scdaa@sicklecelldisease.org](mailto:scdaa@sicklecelldisease.org)

Assists member organizations and the public through education, advocacy and other initiatives which promote awareness and support for sickle cell programs and patients.

### Organizations serving children

#### (S) Candlelighters Childhood Cancer Foundation

P.O. Box 498  
Kensington, MD 20895-0498  
(800) 366-2223 (CCCCF)  
(301) 962-3520  
Fax: (301) 962-3521  
Web site: [www.candlelighters.org](http://www.candlelighters.org)  
E-mail: [staff@candlelighters.org](mailto:staff@candlelighters.org)

Provides support, information and advocacy for families of children with cancer, survivors of childhood cancer and the professionals who work with them.

**(S)= Spanish language support**

#### Chai Lifeline

(877) 242-4543 (CHAI LIFE)  
Fax: (292) 465-0949  
Web site: [www.chailifeline.org](http://www.chailifeline.org)  
E-mail: [info@chailifeline.org](mailto:info@chailifeline.org)

Provides advocacy, information and resources for children.

#### Kids Cancer Network

P.O. Box 4545  
Santa Barbara, CA 93140  
(805) 693-1017  
Web site: [www.kidscancernetwork.org](http://www.kidscancernetwork.org)  
E-mail: [info@kidscancernetwork.org](mailto:info@kidscancernetwork.org)

A national support outreach to children and families facing childhood cancer. Medical professionals with pediatric oncology patients will find excellent and encouraging resources.

Services include: affection connection certificates and Your Story section, prayers section, pen-pals, "FUNLETTERS" online.

#### Kids Connected

27071 Cabot Road, Suite 102  
Laguna Hills, CA 92653  
(800) 899-2866  
Web site: [www.kidsconnected.org](http://www.kidsconnected.org)  
E-mail: [info@kidsconnected.org](mailto:info@kidsconnected.org)

Offers understanding, education and support for children whose parents are affected by cancer, through a variety of programs and communication opportunities.

#### National Children's Cancer Society

Society 1015 Locust, Suite 600  
St. Louis, MO 63101  
(800) 532-6459  
(314) 241-1600  
Web site: [www.nationalchildrenscancer.org](http://www.nationalchildrenscancer.org)  
E-mail: [krudd@children-cancer.com](mailto:krudd@children-cancer.com)

Provides financial assistance, emotional support, advocacy, and educational information to children with cancer and their families.

#### Neuroblastoma Children's Cancer Society

P.O. Box 957672  
Hoffman Estates, IL 60195  
(800) 532-5162  
(847) 605-1245  
Fax: (847) 605-0705  
Web site: [www.neuroblastomacancer.org](http://www.neuroblastomacancer.org)  
E-mail: [info@neuroblastomacancer.org](mailto:info@neuroblastomacancer.org)

Provides publications and support services for neuroblastoma patients and their families.

#### Ulman Cancer Fund for Young Adults

4725 Dorsey Hall Drive, Suite A  
Ellicott City, MD 21042  
(888) 393-3863 (FUND)  
(410) 964-0202  
Web site: [www.ulmanfund.org](http://www.ulmanfund.org)  
E-mail: [info@ulmanfund.org](mailto:info@ulmanfund.org)

Provides support programs, education and resources free of charge to benefit young adults, their families and friends, who are affected by cancer and to promote awareness and prevention of cancer.

### Legal

#### (S) Cancer Legal Resource Center

Loyola Law School  
919 Albany Street  
Los Angeles, CA 90015-1211  
(866) 843-2572  
(213) 736-1455  
Web site: [www.wlcdr.org](http://www.wlcdr.org)

The Cancer Legal Resource Center provides information and education on cancer related legal issues to cancer patients, survivors, family members, health care professionals and others impacted by the disease.

## Resources (continued)

### (S) Equal Employment Opportunity Commission

1801 L Street, N.W.  
Washington, D.C. 20507  
(202) 663-4900  
(800) 669-4000  
Web site: [www.eeoc.gov](http://www.eeoc.gov)  
E-mail: [info@ask.eeoc.gov](mailto:info@ask.eeoc.gov)  
Provides information on job discrimination.

## Financial

### (S) Children's Organ Transplant Association (COTA)

2501 Cota Drive  
Bloomington, IN 47403  
(800) 366-2682  
Web site: [www.cota.org](http://www.cota.org)  
E-mail: [jennifer@cota.org](mailto:jennifer@cota.org)

Provides fundraising assistance to children and young adults needing a life-saving transplant and promotes organ, marrow and tissue donation. COTA also provides matching funds of up to \$10,000 to patients through its fundraising programs.

### National Association of Hospital Hospitality Houses (NAHHH)

P.O. Box 18087  
Asheville, NC 28814  
(800) 542-9730  
Fax: (828) 253-8082  
Web site: [www.nahhh.org](http://www.nahhh.org)  
E-mail: [helpinghomes@nahhh.org](mailto:helpinghomes@nahhh.org)

Offers referrals to free or low-cost lodging near medical facilities.

### (S)= Spanish language support

### National Foundation for Transplants

1102 Brookfield Road, Suite 200  
Memphis, TN 38119  
(800) 489-3863  
Fax: (901) 684-1128  
Web site: [www.transplants.org](http://www.transplants.org)  
E-mail: [info@transplants.org](mailto:info@transplants.org)  
Assists those who need to raise funds for marrow transplants. Maintains accounts to which tax-deductible contributions can be made.

### National Transplant Assistance Fund

150 N. Randor Chester Rd., Suite F  
120 Randor, PA 19087  
(800) 642-8399  
(610) 535-6105  
Fax: (610) 535-6106  
Web site: [www.transplantfund.org](http://www.transplantfund.org)  
E-mail: [ntaf@transplantfund.org](mailto:ntaf@transplantfund.org)  
Assists with fundraising for all types of organ and marrow or blood cell transplants.

### Pharmaceutical Patient Assistance Programs

P.O. Box 63716  
Philadelphia, PA 19147  
(215) 625-9609  
Fax: (419) 858-7221  
Web site: [www.needymeds.com](http://www.needymeds.com)  
Many pharmaceutical manufacturers have special programs to help people purchase the drugs they need but cannot afford. Locate program information under "drug list" on the Web site.

### Pharmaceutical Research & Manufacturers Association

1100 15th Street N.W.  
Washington, D.C. 20005  
(800) 762-4636 (202) 835-3400  
Fax: (202) 835-3414  
Web site: [www.phrma.org](http://www.phrma.org)  
Provides a directory on drug companies that provide medications for patients who could not otherwise afford them. The directory contains information on what medications are covered based on eligibility criteria.

## Clinical Trials

### Clinicaltrials.gov

Web site: [www.clinicaltrials.gov](http://www.clinicaltrials.gov)  
Provides regularly updated information about federally and privately supported clinical research in human volunteers. ClinicalTrials.gov gives information about a trial's purpose, who may participate, locations, and phone numbers for more details.

## Transportation

### Angel Flight America, Inc.

National Office  
8864 Airport Blvd., Suite 200  
Leesburg, FL 34788  
(877) 858-7788  
(901) 332-4034  
Web site: [www.angelflightamerica.org](http://www.angelflightamerica.org)

A national nonprofit organization that provides free air transportation for patients in financial need, who are seeking medical treatment away from home.

### Angel Flight for Veterans

4620 Haygood Road, Suite 1  
Virginia Beach, VA 23455  
(757) 271-2289  
Web site: [www.angelflightveterans.org](http://www.angelflightveterans.org)  
Provides no-cost or greatly reduced rate, long-distance medical transportation for veterans and active duty military personnel and their families, who need to travel to distant, specialized medical care.

## Resources (continued)

### Miracle Flights for Kids

2756 N. Green Valley Parkway  
Suite 115  
Green Valley, NV 89014-2120  
(702) 261-0494  
Fax: (702) 261-0497  
Web site: [www.miracleflights.org](http://www.miracleflights.org)  
E-mail: [flightcoordinator@miracleflights.org](mailto:flightcoordinator@miracleflights.org)

Provides free air transportation to sick kids and adults who are unable to receive the medical care they need in their own community.

### National Patient Travel Helpline

4620 Haygood Road, Suite 1  
Virginia Beach, VA 23455  
(800) 296-1217  
(757) 318-9174  
Fax: (757) 318-9107  
Web site: [www.PatientTravel.org](http://www.PatientTravel.org)  
E-mail: [mercymedical@erols.com](mailto:mercymedical@erols.com)

Makes referrals to charitable, charitably assisted and special discounted patient air transport services for medical purposes based on an evaluation of the patient's needs.

## Survivorship

### (S) National Coalition for Cancer Survivorship (NCCS)

1010 Wayne Avenue, Suite 770  
Silver Spring, MD 20910  
(877) 622-7937  
Fax: (301) 565-9670  
Web site: [www.canceradvocacy.org](http://www.canceradvocacy.org)  
E-mail: [info@canceradvocacy.org](mailto:info@canceradvocacy.org)

National advocate for rights of cancer patients and survivors. Provides publications and referrals.

**(S)** = Spanish language support

## Other

### Immune Deficiency Foundation

40 W. Chesapeake Avenue, Suite 308  
Towson, MD 21204  
(800) 296-4433  
Fax: (410) 321-9165  
Web site: [www.primaryimmune.org](http://www.primaryimmune.org)  
E-mail: [idf@primaryimmune.org](mailto:idf@primaryimmune.org)

Publishes a newsletter and provides patient and family support services and education.

### National Lymphedema Network

Latham Square  
1611 Telegraph Avenue, Suite 1111  
Oakland, CA 94612-2138  
(800) 541-3259  
(510) 208-3200  
Fax: (510) 208-3110  
Web site: [www.lymphnet.org](http://www.lymphnet.org)  
E-mail: [nlm@lymphnet.org](mailto:nlm@lymphnet.org)

Offers publications, hot line, support groups and pen pal program for lymphedema patients.

### National Organization for Rare Disorders

55 Kenosia Avenue  
P.O. Box 1968  
Danbury, CT 06813-1968  
(800) 999-6673 (voice mail only)  
(203) 744-0100  
Fax: (203) 798-2291  
Web site: [www.rarediseases.org](http://www.rarediseases.org)  
E-mail: [orphan@rarediseases.org](mailto:orphan@rarediseases.org)

Serves as a clearinghouse for information about rare disorders. Maintains a database of articles on rare diseases.

## Insurance

### Medicare

7500 Security Blvd.  
Baltimore, MD 21244-1850  
(800) MEDICARE  
Web site: [www.medicare.gov](http://www.medicare.gov)

Provides information about eligibility for Medicare Insurance.

### (S) Patient Advocate Foundation

700 Thimble Shoals Blvd., Suite 200  
Newport News, VA 23606  
(800) 532-5274  
Fax: (757) 873-8999  
Web site: [www.patientadvocate.org](http://www.patientadvocate.org)  
E-mail: [help@patientadvocate.org](mailto:help@patientadvocate.org)

Provides information on state insurance options for individuals who have difficulty finding affordable coverage. Provides legal intervention services and counseling to resolve job discrimination and/or insurance issues. Educates patients about managed care. Online blood cancer resource page.

### Social Security

(800) 772-1213  
Web site: [www.ssa.gov](http://www.ssa.gov)

Offers income insurance programs such as Social Security Disability (SSD) and Supplemental Security Income (SSI).

### State Children's Health Insurance Program

7500 Security Boulevard  
Baltimore, MD 21244-1850  
(410) 786-3000  
Web site: <http://new.cms.hhs.gov/home/schip.asp>

Partnership between the federal government and the states designed to provide health insurance coverage for low income children under age 19 who are not eligible for Medicaid. Contact your local Department of Health and Human Services for more information.



## Glossary of terms

### Absolute Neutrophil Count (ANC)

Neutrophils are a type of white blood cell that helps protect the body from infection. Numbers of neutrophils in the circulating blood are used as an indicator of engraftment after transplant, or recovery after chemotherapy. See Neutrophil.

### Acute Lymphoblastic Leukemia (ALL)

A rapid-onset cancer of the lymphoblasts, a type of white blood cell. Also called acute lymphocytic leukemia.

### Acute Myelogenous Leukemia (AML)

A rapid-onset cancer of the myeloblasts, a type of white blood cell. AML occurs in all ages and is the more common acute leukemia in adults. Also known as acute non-lymphocytic leukemia (ANLL).

### Acute Non-lymphocytic Leukemia (ANLL)

An older term for acute myelogenous leukemia (AML).

### Allele

One of the different forms of gene that can occur at a single spot on a chromosome. A part of DNA representing a gene inherited from each parent to make a pair. Alleles are part of the HLA tissue type used to match patients and donors. See HLA.

### Allogeneic Bone Marrow or Blood Stem Cell Transplant

Any bone marrow or blood stem cell transplant that uses cells from a person other than the patient. The donated cells can come from a related or unrelated donor.

### Anemia

The condition of having less than the normal number of red blood cells or less than the normal amount of hemoglobin in the red blood cells. This condition decreases the blood's ability to carry oxygen.

### Antigens

Proteins found on most cells of the body and capable of stimulating the immune system.

### Apheresis

A procedure where blood is taken from a person's arm and circulated through a machine. The machine separates and collects certain cells such as blood-forming cells, white blood cells or platelets. The rest of the blood is returned through the other arm. See Central Line, Peripheral Blood Stem Cell (PBSC) Donation.

### Aplastic Anemia

A condition where the bone marrow does not make enough white blood cells, red blood cells and platelets.

### Autologous Marrow or Blood Stem Cell Transplant

A transplant using the patient's own marrow or blood cells.

### Blast Cells

Blood cells that will never completely develop. Another term for leukemic cells.

### Blast Phase

The advanced stage of chronic myelogenous leukemia or chronic lymphocytic leukemia when the number of abnormal white blood cells in the bone marrow and blood is very high. Also called blast crisis.

### Blood-forming Cells

Early stage cells that can grow into red blood cells, white blood cells and platelets. Also called hematopoietic cells.

### Bone Marrow

The soft, blood-forming tissue inside of bones. Marrow makes blood-forming cells, white blood cells, red blood cells and platelets.

### Bone Marrow Transplant (BMT)

The process of giving healthy marrow to patients whose marrow is damaged or diseased.

### Central Line

A thin, flexible, spaghetti-sized tube that is inserted into a large vein in the body, usually in the chest or groin. It is used to take blood samples and to give drugs and blood products. Also known as a venous catheter.

### Chemotherapy

A drug treatment that kills cancer cells. Used to prepare patients for a marrow or blood cell transplant. See Conditioning.

### Chronic Lymphocytic Leukemia (CLL)

A cancer of the mature lymphocytes, a type of white blood cell. CLL often involves the lymph nodes. It is the most common form of leukemia in older adults, and usually occurs in persons over the age of 60.

### Chronic Myelogenous Leukemia (CML)

A cancer characterized by a life-threatening increase in myeloid cells - a type of white blood cell - made in the bone marrow. Also known as chronic myelocytic leukemia and chronic granulocytic leukemia. It occurs most often in persons over age 45 and is associated with the presence of the Philadelphia chromosome.

### Conditioning

The process used to prepare a patient to receive a marrow or blood cell transplant by first killing the diseased cells and the patient's own immune cells. Chemotherapy with or without radiation therapy is often used. Also known as preparative regimen.

## Glossary of terms (continued)

### Confirmatory HLA Testing (CT)

Repeating a donor's HLA tests, usually at higher resolution, to make sure the tissue type matches the recipient.

### Confirmatory Typing

To make sure that a potential donor is the best match for a patient, he or she is asked to give another blood sample for additional testing. Confirmatory typing refers to both confirmatory HLA testing, and testing for infectious diseases. The potential donor also completes a health history to help determine if donating would pose any special risks for either the patient or the donor. If confirmed as a match, the donor is requested for a workup to prepare for the donation.

### Congenital Disorder

Any disorder existing before or at birth. The condition may or may not be hereditary.

### Cooley's Anemia

Another name for a severe form of thalassemia known as thalassemia major. Thalassemia is not just one disease. It is a grouping of genetic (inherited) defects in which the body does not make enough hemoglobin. This causes severe anemia.

### Cord Blood

The blood collected from the umbilical cord and placenta after a baby is born. Cord blood contains a high concentration of blood-forming cells that can be used in transplantation. See Blood-forming Cells.

### Cytomegalovirus (CMV)

A virus that can cause pneumonia, gastroenteritis or urinary tract infection in people with weakened immune systems. Many healthy people infected with the virus have no symptoms. People with weakened immune systems may experience serious symptoms.

### DNA (Deoxyribonucleic Acid)

The molecule that contains a person's genetic information.

### Donor Workup

The process that a closely matched potential donor goes through to make sure he or she is healthy and ready to donate marrow or blood cells.

### Engraftment

The stage when the transplanted blood-forming cells start to grow and make healthy new blood cells.

### Fanconi Anemia (FA)

A rare, inherited type of aplastic anemia. Found most often in young children and characterized by a high rate of cancer and leukemia. See Aplastic Anemia.

### Graft-Versus-Host Disease (GVHD)

A condition where the transplanted marrow or blood cells react against the patient's tissues. It is caused by the donor's T cells. See T cell.

### Hematopoietic Cells

Early stage cells found in the blood that can grow into red blood cells, white blood cells or platelets. Also called blood-forming cells or progenitor cells.

### Hemoglobin

The part of a red blood cell that carries oxygen.

### Histiocytosis

A rare but possibly life-threatening disorder similar to cancer, in which histiocytes start to multiply and attack the person's own tissues or organs.

### Histocompatibility

Refers to the degree of tissue matching between two persons. See HLA, HLA Typing.

### HLA (Human Leukocyte Antigen\*)

Refers to proteins found on almost all cells of the body and making up the main part of each person's tissue type. HLA testing is used to match patients and donors for stem cell and organ transplants. \*These proteins were originally described on white blood cells and called human leukocyte antigens, the term from which HLA was derived.

### HLA Typing

The test by which HLA antigens and alleles are identified. See Allele, Antigens.

### Hodgkin's Disease

A lymphoma that can usually be cured. However, when standard chemotherapy fails, Hodgkin's disease may be treated by an autologous marrow or blood stem cell transplant. It is less often treated by an allogeneic marrow or cord blood transplant. It occurs most often in young adults. See Allogeneic, Autologous.

### Leukemia

A group of cancers of the white blood cells. Leukemias can be acute (rapid onset) or chronic (slow onset). A person with leukemia has a very high number of abnormal white cells.

### Lymphocyte

A type of white blood cell, and an important part of the body's immune system. There are two recognized types of lymphocytes, T cells and B cells. T cells are a kind of lymphocyte that cause graft-versus-host disease. See Graft-Versus-Host Disease.

### Lymphoma

A cancer of the lymph tissue. Hodgkin's disease is one type of lymphoma. All other lymphomas are grouped together and are called non-Hodgkin's lymphoma.

### Malignant

Cancerous.

## Glossary of terms (continued)

### **Marrow**

The soft, blood-forming tissue that fills the cavities of bones. Marrow is responsible for making blood-forming cells, white blood cells, red blood cells and platelets. See Blood-forming Cells.

### **Match**

In a marrow or blood cell transplant, the match refers to how much alike the donor's and patient's tissue types are.

### **Molecular HLA Typing**

At the level of a molecule. Molecular HLA typing is the same as DNA-based typing.

### **Multiple Myeloma**

A cancer of the plasma cells in the blood. Often associated with bone pain and infections. More common in men than women.

### **Myelodysplastic Syndrome or Disorder (MDS)**

Also called pre-leukemia or “smoldering” leukemia. It is a disease of the bone marrow in which too few platelets, red blood cells and white blood cells are made.

### **Myelofibrosis**

A disease that causes scar tissue to form in the bone marrow. As a result of the scar tissue, normal blood cell production is blocked.

### **Myeloproliferative Disorder (MPD)**

A group of disorders caused by increased production of blood cells by the marrow.

### **Neuroblastoma**

A cancerous tumor of early stage cells that occurs in children. It is sometimes treated by a marrow or blood cell transplant.

### **Neutrophil**

Neutrophils are a type of white blood cell that helps protect the body from infection. Numbers of neutrophils in the circulating blood are used as an indicator of engraftment after transplant, or recovery after chemotherapy.

### **Non-Hodgkin's Lymphoma (NHL)**

A cancer of the lymph tissue. See Lymphoma.

### **Non-Myeloablative Transplant**

Also known as a “mini transplant” or “low intensity” or “reduced intensity” regimen. A type of transplant that uses lower doses of chemotherapy and/or radiation to prepare a patient for transplant. See Conditioning.

### **Peripheral Blood Stem Cell (PBSC) Donation**

Peripheral blood stem cells are collected through the process known as apheresis. The donor's blood is withdrawn through a sterile needle in one arm and passed through a machine that separates the blood-forming cells. The rest of the blood is returned to the donor.

### **Platelet**

A blood cell that helps control bleeding.

### **Protocol**

A specific plan for treatment of a disease or for a research study.

### **Relapse**

The return of a disease following a remission. See Remission.

### **Remission**

When signs and symptoms of disease are gone after treatment.

### **Sarcoma**

A cancer of the bone, cartilage, fat, muscle, blood vessels, or other connective or supportive tissue.

### **Serologic Testing**

A typing method used to determine an individual's HLA antigens.

### **Severe Aplastic Anemia**

See Aplastic Anemia.

### **Severe Combined Immunodeficiency Disease (SCID)**

A genetic disease in which the immune system cannot produce antibodies or T cells to protect a person's body. It is often treated with a marrow or blood cell transplant.

### **Sickle Cell Anemia**

A genetic condition caused by a change in the hemoglobin gene. Inheriting two sickle genes causes sickle cell anemia. Symptoms include moderately severe anemia and recurrent episodes of painful sickle crisis. Sickle cell anemia is sometimes treated with a marrow or blood cell transplant.

### **Sickle Cell Trait**

A person who has one gene for sickle cell anemia has sickle cell trait. Sickle cell trait cannot change to become sickle cell disease. A person will develop sickle cell anemia only if both parents pass on the trait (gene) to him or her.

### **Stem Cell Transplant**

Refers to the use of blood stem cells as a treatment for cancer or other diseases. See Allogeneic, Autologous.

### **Stem Cells**

Any of the cells in the body that can grow into other kinds of cells. Blood stem cells grow into white blood cells, red blood cells and platelets. In blood stem cell transplants, blood stem cells are given to patients after they are treated for the disease of the blood.

## Glossary of terms (continued)

---

### **T cell**

A type of white blood cell that plays an important part in the immune system.

### **Thalassemia**

Thalassemia is not just one disease. It is a group of genetic (inherited) disorders all of which involve underproduction of hemoglobin, resulting in profound anemia. See Anemia.

### **Tumor**

Any abnormal over-growth of cells. Tumors can be caused by cancer cells or non-cancer cells.

### **Umbilical Cord Blood**

The blood collected from the umbilical cord and placenta after a baby is born. Cord blood contains a large number of blood-forming cells.

### **Unrelated Bone Marrow Transplant or Blood Cell Transplant**

A marrow or blood cell transplant in which the donor is not related to the patient.

### **Wiskott-Aldrich Syndrome**

An inherited disease of the immune system where the white blood cells cannot fight infection. It occurs only in boys.

## APPENDIX A: United States Transplant Centers

Call OPA at 1(888) 999-6743 for contact information

Center Name.....	City, State
University of Alabama at Birmingham.....	Birmingham, AL
University of Arkansas for Medical Sciences.....	Little Rock, AR
City of Hope Samaritan .....	Phoenix, AZ
Phoenix Children’s Hospital.....	Phoenix, AZ
University Medical Center .....	Tucson, AZ
City of Hope National Medical Center .....	Duarte, CA
Scripps Green Hospital .....	La Jolla, CA
UCSD Medical Center.....	La Jolla, CA
Loma Linda University Medical Center .....	Loma Linda, CA
Cedars-Sinai Medical Center .....	Los Angeles, CA
Children’s Hospital of Los Angeles .....	Los Angeles, CA
University of California (UCLA).....	Los Angeles, CA
Children’s Hospital & Research Center Oakland.....	Oakland, CA
Children’s Hospital of Orange County (CHOC) .....	Orange, CA
University of California-Davis .....	Sacramento, CA
Children’s Hospital and Health Center .....	San Diego, CA
UCSF Medical Center.....	San Francisco, CA
Stanford Hospital and Clinics .....	Stanford, CA
University of Colorado - Children’s Hospital.....	Denver, CO
Presbyterian/St. Lukes Medical Center .....	Denver, CO
Yale University/Yale New Haven Hospital .....	New Haven, CT
Children’s National Medical Center .....	Washington, DC
Georgetown University Hospital.....	Washington, DC
Christiana Care Health Services .....	Newark, DE
Shands Hospital - University of Florida.....	Gainesville, FL
Mayo Clinic Jacksonville/Nemours (Ped.).....	Jacksonville, FL
Mayo Clinic Jacksonville/St. Luke’s Hospital .....	Jacksonville, FL
Miami Children’s Hospital .....	Miami, FL
University of Miami .....	Miami, FL
All Children’s Hospital.....	St. Petersburg, FL
H. Lee Moffitt Cancer Center & Research Inst. ....	Tampa, FL
Children’s Healthcare of Atlanta at Egleston .....	Atlanta, GA
Emory University Hospital .....	Atlanta, GA
Northside Hospital .....	Atlanta, GA
Hawaii Bone Marrow Transplant Program.....	Honolulu, HI
University of Iowa Hospitals and Clinics .....	Iowa City, IA
The Children’s Memorial Medical Center.....	Chicago, IL
Northwestern Memorial Hospital.....	Chicago, IL
Rush-Presbyterian-St. Luke’s Medical Center.....	Chicago, IL
Univ of Chicago Stem Cell Transplant Program .....	Chicago, IL
Univ. of Illinois at Chicago (UIC) Med. Ctr.....	Chicago, IL
Loyola University Medical Center.....	Maywood, IL
St. Francis Hospital and Health Centers.....	Beech Grove, IN
Indiana University Bone Marrow/ Stem Cell Transplant Program.....	Indianapolis, IN
University of Kansas Medical Center.....	Kansas City, KS
University of Kentucky Medical Center .....	Lexington, KY
University Medical Center, Inc., University of Louisville Hospital. ....	Louisville, KY
Children’s Hospital/LSUHSC.....	New Orleans, LA
Tulane University Hospital and Clinic .....	New Orleans, LA
LSU Health Sciences Center .....	Shreveport, LA
Beth Israel Deaconess Medical Center.....	Boston, MA
Dana Farber/Partners Cancer Care.....	Boston, MA
Tufts-New England Medical Center .....	Boston, MA
UMASS Memorial Health Care .....	Worcester, MA
Greenbaum Cancer Center; U. of Maryland.....	Baltimore, MD
Johns Hopkins University.....	Baltimore, MD
National Institutes of Health.....	Bethesda, MD
University of Michigan Medical Center .....	Ann Arbor, MI
Oakwood Hospital and Medical Center .....	Dearborn, MI
Henry Ford Health System .....	Detroit, MI
Karmanos Can Inst/Wayne St Univ & Harper Hos.....	Detroit, MI

For transplant center updates visit [www.marlow.org/access](http://www.marlow.org/access) or call 1(888) 999-6743.



# APPENDIX A: United States Transplant Centers

DeVos Children’s Hosp/Spectrum Health.....Grand Rapids, MI	Children’s Hospital of Philadelphia ..... Philadelphia, PA
University of Minnesota BMT Program/ Fairview UMC .....Minneapolis, MN	Hahnemann University Hospitals ..... Philadelphia, PA
Mayo Clinic Rochester .....Rochester, MN	Temple University..... Philadelphia, PA
Barnes-Jewish Hosp/Washington U Sch of Med .....St. Louis, MO	Thomas Jefferson University Hospital, Inc. .... Philadelphia, PA
Cardinal Glennon Children’s Hospital .....St. Louis, MO	University of Pennsylvania Medical Center ..... Philadelphia, PA
Kansas City Blood/Marrow Transpl. Program ...Kansas City, MO	University of Pittsburgh Cancer Center ..... Pittsburgh, PA
St. Louis University Medical Center .....St. Louis, MO	West Pennsylvania Cancer Institute; The West Pennsylvania Hospital ..... Pittsburgh, PA
University of Mississippi Medical Center ..... Jackson, MS	Medical University of South Carolina ..... Charleston, SC
Duke University Medical Center.....Durham, NC	Roper Hospital..... Charleston, SC
UNC Hospitals.....Chapel Hill, NC	Avera Cancer Institute .....Sioux Falls, SD
Wake Forest University	Vanderbilt University Medical Center ..... Nashville, TN
Baptist Medical Center.....Winston-Salem, NC	St. Jude Children’s Research Hospital..... Memphis, TN
The Nebraska Medical Center ..... Omaha, NE	UT Blood and Marrow Transplant Center ..... Memphis, TN
Hackensack University Medical Center ..... Hackensack, NJ	Baylor University Medical Center ..... Dallas, TX
The Cancer Institute of New Jersey.....New Brunswick, NJ	Children’s Medical Center of Dallas ..... Dallas, TX
Roswell Park Cancer Institute ..... Buffalo, NY	Medical City Dallas Hospital..... Dallas, TX
North Shore University Hospital.....Manhasset, NY	The Univ of Texas SW Medical Center at Dallas ..... Dallas, TX
Schneider Children’s Hospital ..... New Hyde Park, NY	Cook Children’s Medical Center .....Fort Worth, TX
The Children’s Hospital of New York .....New York, NY	M.D. Anderson Cancer Center..... Houston, TX
Memorial Sloan-Kettering Cancer Center .....New York, NY	Texas Children’s Hospital ..... Houston, TX
Mount Sinai Hospital.....New York, NY	Texas Tech University Health Sciences Center..... Lubbock, TX
New York Presbyterian Hospital at Cornell .....New York, NY	Texas Transplant Institute .....San Antonio, TX
Strong Memorial Hospital ..... Rochester, NY	LDS Hospital..... Salt Lake City, UT
Zalmen A. Arlin Cancer Institute ..... Valhalla, NY	University of Utah ..... Salt Lake City, UT
Cincinnati Children’s Hospital Medical Center ...Cincinnati, OH	INOVA Fairfax Hospital ..... Fairfax, VA
The Jewish Hospital.....Cincinnati, OH	Medical College of Virginia..... Richmond, VA
Cleveland Clinic Foundation..... Cleveland, OH	Seattle Cancer Care Alliance .....Seattle, WA
University Hospitals of Cleveland..... Cleveland, OH	VA Puget Sound Health Care System.....Seattle, WA
Arthur G James Cancer Hospital/ Richard J Solove Res Ins..... Columbus, OH	University of Wisconsin Hospital and Clinics .....Madison, WI
Columbus Children’s Hospital ..... Columbus, OH	Childrens’ Hospital of Wisconsin/ Midwest Childrens’ Cancer Center .....Milwaukee, WI
HCA Health Services of Oklahoma, Inc.....Oklahoma City, OK	Froedtert Memorial Lutheran Hosp. Can. Ctr. .... Milwaukee, WI
Oregon Health & Science University .....Portland, OR	West Virginia University Hospitals, Inc. .... Morgantown, WV
Penn State Milton S. Hershey Medical Center .....Hershey, PA	

## APPENDIX B: International Registries

### International Registries with Cooperative Search Agreements with the NMDP

The NMDP also maintains independent and cooperative relationships, mostly through formal agreements, with many registries outside the United States. The registries listed below can be searched at the request of an NMDP transplant center. The registries in other countries include:

- Australian Bone Marrow Donor Registry
- Austrian Bone Marrow Donors
- Marrow Donor Program Belgium
- Buddhist Tzu-Chi Stem Cells Center
- Canadian Blood Services
- Czech Bone Marrow Donor Registry (Prague)
- Central Bone Marrow Donor Registry (Pilsen)
- The Cyprus Bone Marrow Donor Registry
- France-Grefte de Moelle
- ZKRD German National Registry
- Hungarian Bone Marrow Donor Registry
- Irish Unrelated Bone Marrow Registry
- Italian Bone Marrow Donor Registry
- Japan Marrow Donor Program
- Korea Marrow Donor Program (KMDP)
- DONORMO Mexican Marrow Donor Registry
- New Zealand Bone Marrow Donor Registry
- Portuguese Bone Marrow Donors Registry (CEDACE)
- Bone Marrow Donor Program Singapore
- Slovenija Donor (Slovenia)
- Spanish Bone Marrow Donor Registry (REDMO)
- Swiss Blood Stem Cells
- Welsh Bone Marrow Donor Registry

Through reciprocal arrangements, these registries are also able to search the NMDP Registry. The NMDP is involved in ongoing discussions with additional international registries to further expand this cooperative international Network. Additional fees may result from searches initiated with international registries.

Any registry that does not have a cooperative agreement with the NMDP can be searched directly by your transplant center.

### Bone Marrow Donors Worldwide

When your transplant center searches the NMDP Registry, they also search a worldwide database called the Bone Marrow Donors Worldwide (BMDW). The BMDW ([www.bmdw.org](http://www.bmdw.org)) lists donors from 58 donor registries and 48 countries and 37 cord blood banks in 21 countries. This includes the following United States donor and cord blood registries:

- American Bone Marrow Donor Registry
- Caitlin Raymond International Registry
- Cellgene Cord Blood Bank
- Elie Katz Umbilical Cord Blood Program
- Gift of Life Bone Marrow Foundation
- Michigan Community Blood Centers Cord Blood Bank
- National Cord Blood Program, New York Blood Center
- National Marrow Donor Program
- StemCyte, Inc.
- University of Colorado Cord Blood Bank

## APPENDIX C: Diseases treatable by matched, unrelated BMT

---

### Leukemias and lymphomas, including:

- Acute myelogenous leukemia
- Acute lymphoblastic leukemia
- Chronic myelogenous leukemia
- Chronic lymphocytic leukemia
- Juvenile myelomonocytic leukemia
- Hodgkin's lymphoma
- Non-Hodgkin's lymphoma

### Multiple myeloma and other plasma cell disorders

Severe aplastic anemia and other marrow failure states, including:

- Severe aplastic anemia
- Fanconi anemia
- Paroxysmal nocturnal hemoglobinuria (PNH)
- Pure red cell aplasia
- Amegakaryocytosis / congenital thrombocytopenia

### SCID and other inherited immune system disorders, including:

- Severe combined immunodeficiency (SCID, all sub-types)
- Wiskott-Aldrich syndrome

### Hemoglobinopathies, including:

- Beta thalassemia major
- Sickle cell disease

### Hurler's syndrome and other inherited metabolic disorders, including:

- Hurler's syndrome (MPS-IH)
- Adrenoleukodystrophy
- Metachromatic leukodystrophy

### Myelodysplastic and myeloproliferative disorders, including:

- Refractory anemia (all types)
- Chronic myelomonocytic leukemia
- Agnogenic myeloid metaplasia (myelofibrosis)

### Familial erythrophagocytic lymphohistiocytosis and other histiocytic disorders

### Other malignancies



## APPENDIX D: Questions to ask about treatment options

Before you meet with your doctor, make a list of questions you would like to ask. You can use a copy of this worksheet. Give a copy of your questions to your doctor so you can discuss them together.

If you have a lot to talk about, let your doctor know ahead of time. We encourage you to bring along a family member or friend. This person can take notes and help you remember what was said.

### Sample questions:

- What treatment do you recommend and why?
- What is the goal of this treatment? (A cure? A long-term remission—if so, how long? To control symptoms?)
- How many patients have you treated who have the same disease?
- Are there other treatments options?
- What do you think the chances are the recommended treatment will get rid of the disease—for the short term and the long term?
- What are the possible risks and side effects of the treatment?
- Is it possible to continue work/school during treatment?
- What activities need to be avoided during treatment?
- How long will the treatment last?
- How will you know whether the treatment is working?
- What other choices are there if the treatment does not work?
- What about clinical trials?

**This list is also available at: [www.marrows.org/PATIENT/discussing\\_options\\_with\\_doctor.html#options](http://www.marrows.org/PATIENT/discussing_options_with_doctor.html#options)**

Keep asking questions until you understand as much as you need to make a decision. Repeat back to your doctor what you think you heard. Find out whether you can call or e-mail your doctor or medical team if you think of more questions later.

## APPENDIX E: Questions to ask your doctor about transplant

If transplant is an option, your doctor will refer you to a transplant doctor for a consultation.

### Sample questions:

- Do you recommend an autologous transplant (which uses the patient's own cells) or an allogeneic transplant (which uses cells from a family member, unrelated donor or cord blood unit)? Why?
- When do you recommend a transplant? What are the risks of waiting or trying other treatments first?
- If an allogeneic transplant is recommended:
  - Which family members will you test as possible donors?
  - Is a transplant using an unrelated donor or a cord blood transplant an option?
  - Is a reduced-intensity transplant an option?
- How long will I need to be in the hospital, or stay near the hospital?
- What do you think the chances are that a transplant will be successful?
- Is there anything about my health or disease that makes my transplant more risky?
- What is a clinical trial? Will I be involved in a clinical trial? Do you know of any clinical trials that might be appropriate for me?
- What are the possible complications in the first few months, first year and over the long term?
- What steps will you take to try to prevent these complications and how will you treat them if they occur?
- What are the requirements for having a caregiver stay with me before, during and after the transplant?

Keep asking questions until you understand as much as you need to make a decision. Find out whether you can call or e-mail your doctor if you think of more questions later.

## Resources for your doctor

You can find more in-depth information to share with your doctor in the **Physician Resources** section of [www.marrow.org](http://www.marrow.org):

- Recommended Timing for Transplant Consultation
- Referring a Patient for Transplant
- Advances in Auto & Allo Transplants
- Transplant Outcomes by Disease & Disease Stage

This list is also available at:

[www.marrow.org/PATIENT/discussing\\_options\\_with\\_doctor.html#options](http://www.marrow.org/PATIENT/discussing_options_with_doctor.html#options)

## Appendix F: Questions to ask your insurance company

Insurance companies or government programs have different ways to pay for treatment and transplant expenses. Some pay for all expenses, some pay for part of the expenses and some do not pay for any expenses. It is very important to find out what expenses are covered.

### Here are some questions to ask your insurance company:

- Will my insurance cover a medical evaluation/consultation at a transplant center to see if a transplant is the right treatment?
- Does my insurance cover an unrelated donor marrow or blood cell transplant?
- Does it cover the type of transplant my doctor has recommended?
- What transplant centers will it cover?
- Can I choose which transplant center I go to?
- Does my insurance provider ever make exceptions? For example, could I go to a transplant center with the most experience treating a rare disease, even if it was not on the provider list?
- Does it cover the testing to identify a matching donor?
- Does it cover the procurement (collection) of the marrow or blood cells from the donor? Are there any limits to what it will pay? If so, what are they?
- Does it cover any costs such as travel or lodging for the patient and caregiver?
- Does it cover medications/prescriptions before and after a transplant?
- Would a clinical trial be covered?
- Does the policy have a per-year or a lifetime maximum on how much it will pay?

## Appendix G: Questions to ask about a transplant center

- How long has this transplant center been performing unrelated transplants?
- Does this transplant center do transplants for my disease?
- How many unrelated donor transplants has this center done for my disease?
- Does this transplant center have experience with patients who are my age?
- What match levels are required for an unrelated donor or cord blood transplant at this center?
- What steps must my doctor take to find out if I would qualify as a patient at this transplant center?
- Do I need a formal consultation or evaluation at the transplant center first?
- What is the survival rate at this transplant center for patients like me? For example: same disease, disease stage, age, and other health factors.

### Other considerations

- How important is geographic location to you and your family? Is it important for you to be close to family and friends? Or, would you rather go to the transplant center with the most experience, even if it is far from home?
- If the transplant center is far from home, will the transplant center help make arrangements for your family or caregiver?
- Do they have housing near the transplant center?
- How will the transplant center inform you about the progress of the search for an unrelated donor? Will they call you or ask that you call them?

*English*

If you would like help translating this information, please call 1-888-999-6743.

*Español*

Si desea ayuda para traducir esta información, puede llamar al 1-888-999-6743.

*Português*

Se você necessitar de ajuda para a tradução destas informações, favor ligar para 1-888-999-6743.

*Tagalog*

Kung kailangan mo ng tulong sa pagsalin ng impormasyong ito, tawagan lamang ang 1-888-999-6743.

中文

如您需要幫助翻譯這些資料，請致電 1-888-999-6743。

한국어

이 정보의 한국말 번역이 필요하시면, 1-888-999-6743으로 전화하십시오.

*Tiếng Việt*

Nếu muốn được giúp đỡ để thông dịch thông tin này, xin gọi số 1-888-999-6743.



**National Marrow Donor Program®**

Office of Patient Advocacy  
3001 Broadway St. N.E.  
Suite 500  
Minneapolis, MN 55413

[www.marrow.org/patient](http://www.marrow.org/patient)

The National Marrow Donor Program® helps people who need a life-saving marrow or cord blood transplant. We connect patients, doctors, donors and researchers to the resources they need to help more people live longer and healthier lives.

Entrusted to operate the C.W. Bill Young Cell Transplantation Program