



Mapping the Maze

Your personal insurance and financial planning guide to marrow and cord blood transplant





BeTheMatch.org/patient

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Your personal insurance and financial planning guide to marrow and cord blood transplant

We are here to help.

Be The Match® has a team dedicated to supporting patients, caregivers and families before, during and after transplant.

We offer you confidential one-on-one support, financial guidance and free educational resources—DVDs, booklets, online tools and more. Our goal is to get you what you need, when you need it. We can help you learn more about transplant as a treatment option, plan for a transplant, and learn what to expect after transplant.

We offer support in more than 100 languages, including Spanish bilingual staff, and translated materials.

Learn: BeTheMatch.org/patient

Request information: BeTheMatch.org/request

E-mail: patientinfo@nmdp.org

Call: 1 (888) 999-6743

If you need information in another language, we 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.

Be The Match is operated by the National Marrow Donor Program®, which also works with hospitals and physicians to help patients who do not have a matching donor in their family.

On the cover: Mike, transplant recipient, with his wife Sharen

This handbook represents general principles and recommendations. It is not intended to replace, and should not replace, financial, legal, and/or medical advice. Always consult your own professional advisors regarding your specific situation.

The content areas in this material are believed to be current as of this printing, but, over time, legislative and regulatory changes, as well as new developments, may date this material. For the most current information, please visit bethematch.org/patient or call 1 (888) 999-6743 for one-on-one support.

Talking about money-related matters can feel like a very personal topic, but help is available. If you're not sure who to talk to, our one-to-one support is available to help you every step of the way.

Call us at 1 (888) 999-6743 or e-mail patientinfo@nmdp.org.

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Using this booklet can help you:

- Learn what information you need to know
- Answer many of the questions you might have
- Develop a financial plan as you explore treatment options
- Learn about resources available to you

Introduction

Planning for a marrow or cord blood transplant can be complex. We are here to help. We can guide you through the process, explain health care options, help you work with your insurance company, make financial decisions and connect you to recources. Contact us anytime at 1 (888) 999-6743 or email us at patientinfo@nmdp.org.

Understanding the terms

You might decide that a marrow or cord blood 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.

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)

All these terms refer to the blood-forming cells used in transplantation.

There is also a glossary of terms on page 47.

Finding help

In addition to talking with family, friends and financial advisors, you can ask your transplant center staff for advice and help accessing resources. They have a wealth of information to share and experience helping people in your situation.

We coordinate a financial assistance program funded by the Be The Match Foundation®. This program is for patients in need of an unrelated marrow or cord blood transplant, through the Be The Match Registry®. Ask your transplant center coordinator or social worker if you qualify for the Be The Match Patient Assistance Program grants. Your transplant center must apply for this program on your behalf. More information about the Be The Match Foundation is available at BeTheMatchFoundation.org.

Chapter One

Organizing Your Records

To start planning for a transplant, collect and organize your financial and health care information.

Keep a record of the people you talk to, including:

- Their full name
- Title and company
- Phone, fax number and extensions
- E-mail address
- Date and time of the conversation
- Summary of what you discussed

Basic information you will need to get started:

- Insurance policies including health, life, disability and mortgage
- Health insurance member card
- Your Social Security number
- Current bank statements for all checking and savings accounts
- Monthly payment records for mortgage, credit cards and other household bills
 - Records of what charges/payments are automatically made each month
- Statements of stocks, mutual funds, annuities, etc.

Get help organizing your records

If you don't feel well enough to organize your records, it's okay to ask family or friends for help. They might welcome the opportunity to help you so you can focus on healing.

They can help locate and organize information so it's available when you need it.

If you have always maintained your own records, you might just ask for help putting new information into your files or completing the forms in this workbook.

Be aware that due to the The **Health Insurance Portability** and Accountability Act of 1996 (HIPAA) Privacy Rule requirements, clinics, hospitals, health care professionals and others may require a "Release of Information Form" before sharing any confidential information with someone acting on your behalf.

Important things to know about your health insurance:

- The type of health insurance you have
- What procedures are covered
- Reimbursement rates
- In-network and out-ofnetwork benefits
- If the labs and services that your hospital or doctor uses are covered
- Other transplant related benefits

Chapter Two

Evaluating Your Health Insurance Coverage

Before you can begin your transplant process, you need to find out what kind of health insurance policy you have, and what transplant-related costs are covered.

Learn about your health insurance coverage

Your health care insurance will probably be your largest source of funding for the transplant. Ask your health care insurance company for a case manager or patient advocate who can help you get the maximum benefit from your policy.

Many different types of health insurance are available. For example:

- If you are employed, you may be covered under a company group plan.
- If you are self-employed or not currently employed, you may have an individual policy.
- Veterans may be covered under TRICARE or the Veterans' Health Care Policy.
- Other government insurance programs exist for people who are disabled, or who fall within certain age and/or income guidelines.

Each policy varies in what treatments or procedures it covers and in how much you might need to pay out-of-pocket. You are subject to the terms of the policy as it is written. Read your policy carefully to understand the way the policy works in order to maximize benefits and receive the best coverage allowed.

Common types of health insurance:

Individual (or individual and family) health insurance

Individual and family health insurance is a type of health insurance coverage made available directly to individuals and/or families. Instead of going through an employer group or organization, you would buy an individual and family health policy directly from an insurance company. The contract is between the individual (policy-holder) and the insurance company.

Group health insurance

Group health insurance is health insurance through a group plan—usually through an employer. Employers can buy group policies and offer them to eligible employees and their families as a benefit of working for that company. Employers can cover a portion or all of the cost of the plan. These plans generally offer more benefits for less money than an individual and/or family health policy. Most policies require you to pay a deductible or a co-payment.

Self-funded policy

Rather than purchasing a health care policy from an insurance company, some employers create their own self-funded policies to offer their employees. The premiums collected from the employer and employees fund the policy. Many people are not aware that their employer's group plan is actually a self-funded policy. An important difference with this type of policy is that the employer or group, instead of the insurance company, decides what is covered and the amount of coverage provided. The policy can be administered either by the employer or by a third party administrator (TPA), such as an insurance company. A TPA can pay claims based on guidelines provided by the group or employer, but the employer can override a decision made by the TPA and authorize a service previously denied.

Managed care (HMO, PPO, POS)

Managed-care plans, such as an HMO or PPO, control what services are provided and who can provide them. They may require pre-authorization, co-payments and restrict you to using physicians and hospitals that are part of the managed-care plan network.

Be sure to ask about the policy for pre-authorization and about your provider network.

If you have this type of health care coverage, your transplant center will have to get approval for the transplant procedure from the managed-care plan before you can begin treatment. The transplant center will also need approval for the testing needed to find a matched donor or cord blood unit.

Health Maintenance Organization (HMO)

HMOs offer an approved network that includes a limited choice of doctors and hospitals. You must choose a primary care physician (PCP) from the list of approved doctors in the network. Your PCP must provide a referral for services before they will be covered by the plan. If you go to doctors, hospitals or transplant centers outside the HMO plan network without plan approval, then you usually will have to pay those costs. The plan most likely will not pay them.



Ask your health care insurance company for a case manager or patient advocate who can help you get the maximum benefit from your policy.



Preferred Provider Organization (PPO)

Like an HMO, this plan offers an approved network of physicians, hospitals, and transplant centers, but it is less restrictive about what providers you see within that network. Unlike an HMO, a PPO does not require you to choose a primary care physician (PCP) or to get a referral to be seen within the network. However, you would still have to follow the health plan's pre-authorization rules and some doctors may not see you unless another doctor referred you. Most PPOs, unlike HMOs, allow you to see a doctor outside the plan network, but your costs will be higher than if you stayed with an in-network provider. You would be responsible to pay a yearly deductible and coinsurance if you choose to go outside the PPO network of doctors and services.

Point of Service (POS)

A point-of-service plan combines features of an HMO, a PPO and an indemnity plan (a plan that asks you to pay a certain amount before the insurance plan begins payment). In this type of plan, you might be asked to choose a primary care physician (PCP), but POS plans are usually less restrictive than HMO and PPO plans because you can choose where to be seen at the time you need the service. You can be referred within your network by your PCP, similar to an HMO, or you can choose doctors and hospitals outside the network. If you do choose to go outside the network, your costs will increase because you will have to pay deductibles and coinsurance.

It is important to note that many plans today do not fall strictly into one of these categories. There are many variations. Review your plan and ask questions to find out how your plan works.

Medical savings plans

Health Savings Account (HSA)

AN HSA is a tax-free savings account that can only be used for health expenses. You can use this account for current health expenses, as well as to save for future health expenses. To have an HSA, you must also be covered by a high deductible health insurance policy (HDHP), which has lower premiums than a low deductible policy. The money saved on premiums should also be put into the HSA account, which earns tax-free interest. The savings can then be used to pay for health expenses until your HDHP deductible is met, at which time the HDHP benefits would pay for your health expenses. A person can only withdraw funds that are equal to or less than what is in the plan's account.

Flexible Spending Accounts (FSA)

An FSA is an account that is funded by pre-tax dollars deducted each pay period that can be used to pay for eligible medical expenses. Most plans must be fully used by the end of the calendar year or funds left in the account are not returned. One advantage of an FSA is that a person can access the full amount designated for the year even though they may not have actually contributed the full amount yet.

Supplemental health insurance plans

Supplemental health insurance plans provide additional coverage for specified events, such as cancer, intensive care, accident, etc. They are different from typical health insurance coverage in that the benefits received are paid directly to the policy-holder rather than the doctor or hospital and may be used for any purpose decided by the policy-holder.

Comprehensive health insurance for high-risk individuals

Comprehensive health insurance is sometimes available, even if you are considered a "high-risk" individual. State programs, sometimes called "risk pools," serve people who have been restricted or denied health coverage because of a pre-existing health condition, or who cannot afford the high rates of individual or family insurance. For more information about joining a risk pool, call us at **1-888-999-6743** or the Patient Advocate Foundation at **1-800-532-5274**.

Insurance rights and benefits

You may find that your ability to earn an income and have insurance coverage changes because of your health situation. It's important to know that you have certain rights and benefits (sometimes called "entitlements") under United States law and that you may be eligible for some government programs to help you with your health care costs. The following section is an overview of some of these programs. Your transplant center or clinic social worker can help you access these and other resources. It is a good idea to apply for these programs early, because the application processes can take a long time.

COBRA (Consolidated Omnibus Budget Reconciliation Act of 1985)

COBRA is a federal law (U.S.) that lets individuals of most employer-sponsored group health insurance plans keep their health insurance when they leave their job. COBRA applies to group health plans maintained by employers with 20 or more employees in the prior year. It applies to plans in the private sector and those sponsored by state and local governments. The law does not apply to plans sponsored by the federal government and certain church-related organizations.

You may qualify for COBRA if you leave your job due to termination, layoff or resignation. Under COBRA, the maximum time you can usually keep your health coverage is 18 months from the date of election of coverage.

IMPORTANT: Do not allow a lapse in your health insurance coverage

If you have health care coverage, make sure you maintain "continuous coverage." In order for coverage to be considered continuous, it cannot lapse for more than 63 days between the end of one policy and the beginning of the next one.

- Do not lapse between leaving your job and electing to go on COBRA.
- Do not lapse between when your employer's extended coverage ends under COBRA and replacement coverage begins.

If you have a lapse in coverage, you can be labeled as having a "pre-existing condition" and be excluded under future policies.



However, there are special rules for disabled persons that allow for an 11-month COBRA extension beyond the 18 months. (The Social Security Administration must determine that you are disabled within the first 60 days of electing COBRA. Therefore, it is important to apply for Social Security Disability Insurance/ Supplemental Security Income as soon as you and your physicians determine that you will be unable to work for a minimum of 12 months.) COBRA has many provisions, so it is important to talk to your benefits or human resources representative about the plan.

COBRA is a good option for maintaining continuous coverage, but it can be very expensive. Under COBRA, the entire cost of your insurance premium is your responsibility; your employer will no longer contribute. Because of the expense, you might consider keeping individual COBRA for yourself and researching individual health insurance policies and other options for the rest of the family. Contact your employer (or former employer) to enroll.

HIPAA

The Health Insurance Portability and Accountability Act of 1996 (HIPAA) provides limited protection for working U.S. citizens and their families. HIPAA helps with the following:

- Limits the use of pre-existing condition exclusions
- Prohibits group insurance plans from denying you insurance or charging you
 extra for insurance because of your (or any family member's) past or present
 poor health
- Guarantees the right to purchase health insurance to certain individuals who lose employer-related insurance
- Guarantees, in most cases, that employers, or individuals who purchase health insurance, can renew the coverage regardless of any health conditions of individuals covered under the insurance policy

You must meet certain conditions to qualify as a HIPAA eligible person. If you qualify for Medicaid or Medicare, you will not be HIPAA eligible. If COBRA was an option when you lost your insurance, you must have elected (and exhausted) COBRA benefits before you will qualify as HIPAA eligible. If COBRA was not an option for you, you may qualify as HIPAA eligible as soon as you lose your health insurance, if you meet other eligibility requirements.

If you are not eligible for or have exhausted COBRA and you have a spouse who is covered under an employer plan, you may be eligible for special enrollment onto your spouse's plan. Special enrollment allows you to join your spouse's insurance plan when you lose your insurance, instead of waiting for open enrollment. Find out from the employer if you qualify for special enrollment into that plan (you must have previously turned down your spouse's group insurance plan because you had other coverage). You generally must request special enrollment within 30 days of losing your insurance.

For more information: Contact your state's department of insurance, or visit the HIPAA web site at **cms.hhs.gov/hipaageninfo**.

Medicare

Medicare is a government program that pays for medical care. Many doctors and hospitals accept Medicare. You qualify for Medicare if you are over age 65. You also may qualify for Medicare if you are under the age of 65 and disabled. You are considered disabled if you have been on Social Security Disability (SSD) for 29 months from your deemed date of disability.

Medicare has four parts: A, B, C and D.

- Part A helps pay for inpatient hospital care and certain follow-up services.
- Part B helps pay for doctor's services, outpatient hospital care and other medical care.
- Part C is a managed care option that provides the same coverage as Parts A and B along with the extra coverage of a Medigap insurance policy, also called Medicare Supplement Plan. Coverage is provided by private insurance companies through what are known as Medicare Advantage plans.
- Part D is a stand-alone prescription drug coverage plan.

You must be enrolled in both Part A and Part B to have transplant coverage. However, Medicare does not pay for transplants for all diagnoses.

For more information about Medicare:

Call **1 (800) MEDICARE** (633-4227)

or visit online at medicare.gov

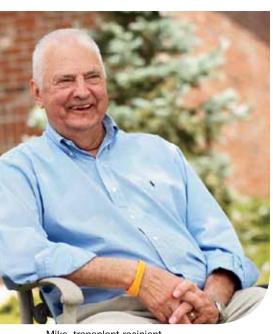
For more information about Medicaid:

Most states have toll-free numbers to answer questions.

You can find this online at cms.hhs.gov/home/ medicaid.asp

For more information about Social Security:

Call **1 (800) 772-1213** or visit online at ssa.gov



Mike, transplant recipient

Medicaid

Medicaid is a federally (U.S.) funded, but state run, insurance program for individuals with low-income levels. Eligibility is different in each state, but includes pregnant women, children, members of a low-income family, or aged, blind or disabled persons. You must meet state income and resource standards, as well as certain other requirements. Also, you must be a resident of the state, and be a United States citizen or a qualified immigrant. Families with private insurance may be eligible if large hospital bills are only partially covered. Some states cover children who are hospitalized more than 30 days, regardless of income. In most states, if you qualify for Supplemental Security Income (SSI) by meeting the minimum income requirements, you will also be eligible for Medicaid coverage.

You must apply for Medicaid at your local Medicaid office, in the state where you live.

Veterans' benefits

The Veterans Affairs (VA) may offer pensions to veterans who have low-income levels and/or are disabled. Veterans' benefits also provide health care through VA facilities, home loans, disability compensation, life insurance, burial, and other benefits. You can apply through your local Department of Veterans Affairs.

For more information about veterans' benefits:

Contact the U.S. Department of Veterans Affairs at 1 (800) 827-1000 or visit online at va.gov

Disability programs

You may not think of yourself as disabled, but you may qualify as disabled under the government's definition. The government considers a person disabled if they can't work or earn income because of a medically diagnosed condition that doctors expect to last for at least 12 months, or will cause your death. There are two basic types of government-sponsored disability programs run by the Social Security Administration:

Social Security Disability Insurance (SSDI): SSDI is a federal (U.S.) program that pays monthly cash benefits to people who are unable to work for a year or more because of a disability. Eligibility is based on your work history and Social Security taxes you have paid.

Many long term disability policies require a patient to apply for SSDI when applying for long term disability coverage. Note: If a patient returns to work in less than 12 months, then the patient is required to pay back all SSDI payments received. Payments may be considered taxable income for some patients/families, so taxes may be assessed on payments received.

Supplemental Security Income (SSI): SSI is a federal (U.S.) program that provides cash for basic needs. Unlike SSDI, general tax revenues fund this program. SSI is not based on your work history or taxes you have paid. To qualify, you must be disabled or blind and have a limited family income and assets. Both children and adults can apply for SSI. In most states you will also be eligible for Medicaid coverage if you qualify for SSI by meeting the minimum income requirements.

Many disability applications are denied the first time. However, there is an appeals process if you are denied. SSDI benefits can be paid retroactively for up to a year from the date of the official disability application, so it is a good idea to appeal a denial of disability benefits. In order to appeal:

- Your first step would be to file for reconsideration. A different person will review your case than the person who made the initial denial decision. You can also present new evidence at this time.
- If your reconsideration is denied, you can request a hearing. At this point, you might consider hiring a lawyer to assist you in the appeals process.
- If you disagree with the hearing decision, the next step would be Appeals Council.
- If the Appeals Council decision is unsatisfactory, you can file a civil suit in Federal District Court.

The Social Security Administration limits the amount that a lawyer can charge you (unless it reaches the Federal District Court level). You will only have to pay the fee if you win the appeal and qualify for benefits.

Disability waivers

In addition to work-related and government-sponsored disability programs, your auto loan, mortgage or credit cards may have disability waivers to help pay for costs if you are unable to work. Contact the individual companies to see if they have disability waivers as part of the loan.

Other rights and benefits

For information about other benefits you may be entitled to, such as public assistance, senior services, children's medical services, state disability programs, energy assistance programs, or food stamps, you can contact your local or state Department of Human Services or Welfare Unit.

You can also call the U.S. Department of Health and Human Services at **1** (877) 696-6775, or visit online at **hhs.gov**



Dr. Orchard, transplant physician, with Kelsey, his patient and transplant recipient

Understanding your health insurance

In the previous section, you learned about different types of health insurance. The next step is to understand the important features of your policy. You will want to know how your policy defines and treats coverage for pre-existing conditions, deductibles, co-payments, exclusions, and maximum lifetime amounts of coverage.

Clinical trials coverage

Your transplant center may be conducting clinical trials for transplant procedures. These clinical trials might be a way for you to receive state-of-the-art treatment for your medical condition. If you have an opportunity to be part of a clinical trial, you should find out from your health insurance company representative if participation in these trials will reduce the amount of coverage that you receive. If specific tests are required by the trial, ask if they will be covered by your health insurance policy.

If your health insurance company will not approve coverage for clinical trials, then you and your representative from the transplant center will be sent a letter of denial. The letter of denial will outline the reasons you have been denied coverage for clinical trials. Even if this happens, you should not be denied coverage of routine patient care costs for being part of a clinical trial. If you are denied coverage for clinical trials, follow the steps in Chapter Five, "Getting Help with Denials of Coverage and Appeals" on page 34.

Pre-authorization process

Many health insurance policies require you to get approval before you begin a procedure. This is called "pre-authorization." Your doctor or other health care provider will gather information about your case and present it to your health insurance company. The health insurance company either will approve or deny the procedure. If denied, a letter of denial will outline the reasons why the procedure was not approved. If you are denied coverage, take the steps in Chapter Five, "Getting Help with Denials of Coverage and Appeals" to appeal the denial. Preauthorization is not a guarantee of payment.

Second opinions

After you receive a diagnosis or a treatment recommendation from your doctor, you may want to get another opinion from a different doctor. This is known as "getting a second opinion," and it may not be covered under your health insurance policy. You also may find that your health insurance company will only approve second opinions from doctors within the provider network. If you want to get a second opinion and your request has been denied, take the steps in Chapter Five, "Getting Help with Denials of Coverage and Appeals" to appeal the denial.

Coverage for new treatment options

Your transplant center may offer new treatment options. These treatment options may not be covered by your health insurance company. Sometimes health insurance companies don't have enough information yet to make informed decisions about new treatment possibilities. In other cases, your health insurance company representative might not agree with the recommended new treatment. If you have requested that this new treatment be covered and have received a letter of denial, then you should follow the steps for appealing denials that are outlined in Chapter Five, "Getting Help with Denials of Coverage and Appeals."

Learning what your health insurance covers

Not all health insurance policies cover marrow or cord blood transplants. Some policies will cover the transplant, but may not cover all the services that you need before or after the transplant. Some of the indirect costs of a marrow or cord blood transplant may not be covered. Indirect costs are items or services you need in order to get your transplant, but are not part of the actual transplant. These costs may include: tests to find an unrelated donor or cord blood unit, some prescriptions or lodging and transportation to be near the transplant center.

Here's how to find out what your policy does cover. First, you will need a detailed copy of your health insurance policy language. This is different from the short summary of benefits you may have received from the insurance company. You can ask a representative from the health insurance company for the booklet that outlines the coverage guidelines. Once you have read the benefit booklet, call the health insurance company representative and ask questions about coverage for your specific procedure. Before you make the call, complete the worksheet on page 18 about your policy and have it in front of you. Use the worksheet on page 19 to record contact information.



Kelsey, transplant recipient, with her mom and caregiver, Stacy

Health Insurance Worksheet

Information about your heal	th insurance company and disability plan:
My health insurance company is:	
Contact information:	
My disability plan is:	
Contact information:	
Information your health insu	urance company representative may need:
Member number:	
Policy-holder's employer:	
Policy-holder's name:	
Policy-holder's Social Security or ID number:	
Policy number:	
Group number:	
Effective date for policy-holder and/or dependents:	

Contact Worksheet

The health insurance company representative I talked to is: Name: My insurance case manager is: Name: Phone:

Find out what your policy covers

E-mail:

Fax:

Other:

The worksheet on the following pages offers questions you can ask to learn more about your exact coverage. When benefits are quoted, representatives often give general coverage guidelines and this information should not be considered a guarantee of coverage. Ensure that you are working with someone who is authorized and knowledgeable about your specific situation and your specific coverage. Work with your transplant center and/or your insurance case manager and have them help you verify in writing what is covered.



Danielle, transplant recipient

Keep good records

Always take notes when you talk to health insurance company representatives or health care providers. Be sure to write down the name of the person you talked to and the date of the call. Take notes during the conversation and keep these notes or record the conversation if possible. You may need this information later if you try to appeal a denial from a health insurance company. The person you speak to may offer an interpretation of the policy over the phone. Most insurance companies do not consider a verbal interpretation as a guarantee of payment. If you do receive a verbal interpretation, be sure to also ask for it in writing.

Policy Coverage Worksheet

Questions to Ask	Yes or No	Comments
Am I covered for treatment of my medical diagnosis under my policy?	□Yes □No	
Does my policy have a pre-existing condition clause? If so, how is it defined?	□Yes □No	
Is my diagnosis considered a pre- existing condition?	□Yes □No	
Does my policy have a deductible and coinsurance amounts? If yes, for what and how much?	□Yes □No	
Does my policy have co-payments? If yes, for what and how much?	□Yes □No	
Does my policy have a co-payment for prescriptions? Are there different tiers of prescription coverage? If yes, how much?	□Yes □No	
Is there a maximum amount of money out-of-pocket that I would be responsible for each year? If yes, how much?	□Yes □No	
Which costs are considered for my out-of-pocket maximum?		
Does my policy have a maximum amount (a lifetime amount) it will pay out in charges? If yes, how much?	□Yes □No	
Are there any coverage exclusions in my policy? If yes, how long is coverage excluded?	□Yes □No	
Does my policy cover unrelated marrow or cord blood transplant for my diagnosis?	□Yes □No	
If my policy covers a marrow or cord blood transplant, does it include outpatient as well as inpatient services?	□Yes □No	

Policy Coverage Worksheet (continued)

Questions to Ask	Yes or No	Comments
Does my policy cover expenses for testing to find a matched donor or cord blood unit?	□Yes □No	
If my policy covers testing to find a matched donor or cord blood unit, are there any limits or exclusions to this coverage? If so, what are they?	□Yes □No	
Does my policy cover the costs to obtain stem cells from an unrelated donor or cord blood unit? If yes, are there limits?	□Yes □No	
Does my policy have a limit to the number of transplants I can receive in my lifetime?	□Yes □No	
Does my policy cover costs for clinical trials? If yes, are there limits?	□Yes □No	
Does my policy have any restrictions on which transplant centers I can use ("centers of excellence")? If so, how do the restrictions affect my coverage?	□Yes □No	
Are the transplant centers I'm considering in my provider network?	□Yes □No	
What criteria does my policy use in selecting providers?		
Will my policy provide coverage for me at an out-of-network provider? If yes, will my out-of-pocket expenses be higher?	□Yes □No	
Does my policy cover a consultation at one or more transplant centers?	□Yes □No	

Policy Coverage Worksheet (continued)

Questions to Ask	Yes or No	Comments
Is pre-authorization necessary for treatment? If so, who may request this approval? If so, to whom should the request be made?	□Yes □No	
Will my policy pay for a second opinion?	□Yes □No	
Does my policy cover indirect expenses for me, my family, and/ or my caregiver, such as travel, food, and lodging costs while I am at the transplant center? If yes, how much will it pay?	□Yes □No	
Does my policy cover outpatient medications?	□Yes □No	
If yes, is there an approved list of covered prescriptions? If yes, how do I get a copy of the list?	□Yes □No	
If there is an approved list for prescriptions, can the health insurance company ever make an exception? If yes, how do I request this exception?	□Yes □No	
If I have a complaint, or want to appeal my coverage, how do I do that?		
Is there a time limit for making a complaint or appeal?	□Yes □No	
Is there a limit to the number of appeals that can be made on my behalf? If yes, what is it?	□Yes □No	

Chapter Three

Determining your financial position

Before you begin the transplant procedure, you will need to assess your financial position by:

- Calculating your current living expenses
- Taking a financial inventory that includes assets such as savings and personal property, and disability or mortgage insurance

This information will help you determine how much money you have and how much you might need to make up the difference. This will help you develop a budget for managing medical costs and living expenses.

Elias, transplant recipient, with his mom, Sheila

Cost assessment

Use the answers about coverage for your transplant to estimate your out-of-pocket costs for the procedure. You will also need to estimate indirect costs—costs related to the transplant that are not part of the medical procedure. An example of an indirect cost would be temporary living arrangements for you and your family to be near the transplant center. Once you have completed the worksheets in this section, you'll know how much money you will need to have for your transplant and its related, indirect costs. You'll also know if you need to raise money for the transplant.

Your transplant center staff will assist you in gathering cost information. They will initiate benefits inquiries with your health insurance company once you and the transplant center staff decide to search the NMDP's Be The Match Registry for an unrelated donor or cord blood unit. You should also work closely with the transplant center staff to discuss payment options.

Current living costs

Use the Monthly Expenses Worksheet on page 31 in Chapter Four, "Developing a Financial Plan," to calculate your current living costs.

Indirect transplant costs

The costs listed on page 24 are indirectly related to the transplant procedure. They are related to the overall cost of your transplant, however, and need to be part of your total financial plan. You may have covered some of these costs when you talked to the health insurance company representative. These are often large costs that are sometimes covered, but often are not. Be sure not to overlook these costs in your financial plan.

Seeking assistance

Elias and his family had to relocate to another state to get his transplant. His young parents' income was reduced to nothing—but their expenses increased greatly as a result of the transplant. Even though Elias' transplant was covered by insurance, many transplant-related costs were not. They worked closely with the social work staff at the transplant center to learn if they were eligible for any assistance.

Indirect Transplant Costs Worksheet

Costs	Estimate	Amount covered by insurance
Testing to find a matched donor or cord blood unit	\$	\$
Donor costs	\$	\$
IV Neupogen [®] injections	\$	\$
Procurement of stem cells from the donor or cord blood unit	\$	\$
Harvest/storage fees prior to transplant	\$	\$
Backup collection of stem cells	\$	\$
Travel expenses to and from the transplant center for patient and/or caregiver	\$	\$
Temporary lodging expenses near the transplant center for patient and/or caregiver	\$	\$
Food costs while staying near the transplant center (including eating at the hospital cafeteria)	\$	\$
Parking costs	\$	\$
Wigs	\$	\$
Child-care costs	\$	\$
Office visits coverage	\$	\$
Home health care	\$	\$
Mental health coverage	\$	\$
Clinical trials	\$	\$
Sperm/egg storage	\$	\$
Insurance premiums when patient is not employed	\$	\$
Prescriptions for post-transplant discharge or outpatient medications	\$	\$
Fees for post-transplant home-preparation (carpet and drapery cleaning, replacing filters on heaters, air conditioning cleaning)	\$	\$
Change in cost of living after transplant (different food needs, for example)	\$	\$
Total	\$	\$

Calculating additional transplant expenses

Online tool

Patients and family members often find it helpful to budget for the indirect expenses related to a marrow or cord blood transplant. Our online tool, in addition to the worksheets in this handbook, can help you develop a combined estimate of your indirect transplant costs and household expenses.

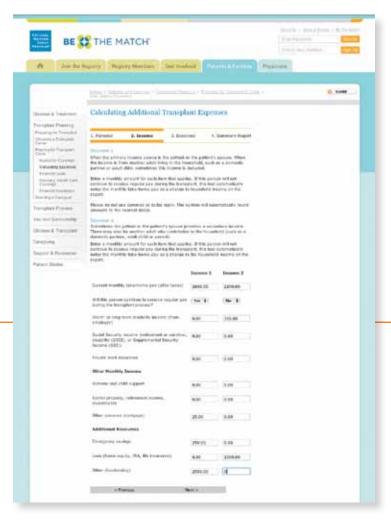
The free and confidential tool provides step-by-step instructions for collecting and entering data to create a personalized financial report. Patients and caregivers can use the report to discuss household financial

needs with transplant center staff, insurance providers or financial advisors. Patients who prefer using the online tool, may access it at **BeTheMatch.org/planAhead**.

You can use this free and confidential planning tool to:

- Summarize current monthly income and expenses
- Estimate expenses not covered by insurance
- Identify factors that affect transplantrelated expenses
- List financial planning resources







Everett, transplant recipient

Once you know the total cost of the transplant procedure and how much you have to cover, ask a financial representative of the transplant center the following questions:

- How can I break the cost into payments?
- What is the amount of each payment?
- When is each payment due?
- Will interest be added to my balance?

Transplant center estimates and payment requirements

Use the table below to estimate the total costs and coverage at the transplant center. Call your transplant center staff and ask them to provide you with a cost estimate for your transplant. Once you know how much your transplant will cost and how much your insurance company pays, you will know how much to plan for. Your transplant center staff will assist you in gathering this information. Ask to speak to the transplant center financial representatives. They will work with you on payment options.

Cost and Coverage Worksheet

Costs	Amount
Requested initial deposit	\$
Estimate of indirect costs (see page 24)	+ \$
Estimate of uncovered costs	+ \$
Estimate of total cost	= \$
Estimate of covered costs	- \$
Balance Remaining	= \$

Taking your financial inventory

A financial inventory is a list of your assets (what you own) and your liabilities (what you owe). If you subtract your liabilities from your assets, you will know your net worth. Use the worksheet on page 28 to list your assets and liabilities. The worksheet will help you calculate your net worth.

Examples of assets:

Personal savings and investments

Checking and savings accounts in a bank or credit union, money market funds, mutual funds, stocks or bonds, or any other financial assets you own.

Personal property

Real estate, such as houses or land, furniture, cars, artwork, jewelry, collections or other valuables.

Retirement benefits

Money you have in 401(k) or 403(b) plans, Individual Retirement Accounts (IRAs) and pension plans.

Life insurance

Either term (set period of time) or permanent coverage. Term insurance does not have a cash surrender value. It pays money to your beneficiary when you die. If you stop paying premiums, coverage ends. Permanent (whole life) insurance builds up cash value as you make payments. This cash value is an investment feature of a permanent policy because you can borrow against it if needed. It is also the key factor in making the policy capable of lasting a lifetime.

Viatical life settlements

A viatical insurance settlement is an agreement in which a third party pays the life insurance policy holder for the right to be the legal beneficiary of the policy. In most cases viaticals and viatical providers will pay a large percentage of the cash value of the policy, and in most cases they agree to continue to pay the premium on the existing life insurance policy until the death of the insured.

Long-term care insurance

Long-term care insurance pays for care in a long-term facility, such as a nursing home. Or, it may pay for home health care, adult day care, and sometimes respite care so the caregiver can take a break.

Mortgage insurance

Mortgage insurance comes in many forms. It may be a life insurance policy that pays an amount adequate to pay off a mortgage when the insured dies. Or it may make payments on your mortgage if you are sick or disabled.

Disability programs

Disability programs offer coverage that pay a portion of your income if you are unable to work. Having some kind of disability coverage may be one of your main sources of income during the time you are recovering from your transplant, so it is important to understand your coverage.

There are different categories of disability programs: work related, personal and government sponsored. Work-related programs usually fall into two categories: short-term and/or long-term coverage. There are two types of government programs, Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI). See the "Disability programs" information starting on page 14.



Personal assets are those assets that belong to you. In general, an asset is property that has value. Assets can be sold or used up over a period of time.

Calculating your net worth

Using this table as a guideline, make a list of what you own (assets). Next make a list of what you owe (debts or liabilities). Subtract what you owe from what you own to estimate your net worth.

*Note: List assets at liquidation value rather than replacement value. Liquidation value is the value at which the items can be sold; replacement value is the cost to replace the item with a new one.

Net Worth Worksheet

Assets	Value
Home	\$
Car	\$
Checking account(s)	\$
Savings account(s)	\$
Other investments (mutual funds, stocks, bonds, etc.)	\$
Retirement plan(s)	\$
Life insurance cash values	\$
Furniture and artwork	\$
Jewelry and collections	\$
Rental property	\$
Business	\$
Other	\$
Total Assets	\$

Liabilities	Amount Owed
Home mortgages(s)	\$
Car loan balance	\$
Credit card debt(s)	\$
Other loans	\$
Other debts	\$
Total Liabilities	\$
Net Worth (Assets minus Liabilities)	\$

Chapter Four

Developing a Financial Plan

After you complete your financial inventory, you can develop a financial plan. This plan will include how much money you bring in, how much you owe, how much you spend, and how much is available to put toward transplant. It will also help determine if additional funding is needed.

Spending plans

A spending plan is a budget. It helps you manage your money and frees you from worrying about unexpected financial events.

Your spending plan helps you keep track of how much money comes in each month and how most of the money is spent. It also helps identify spending leaks – those small purchases that add up over time. Following a spending plan can give you peace of mind about monthly expenses.

Use the following monthly income and monthly expenses worksheets to record your household's sources of income and all of your anticipated expenses for the month. You might want to make copies of these worksheets to keep track of your income and expenses for several months. If either your income or your expenses change, adjust the amounts on the worksheets.



Ed, transplant recipient with his wife, Rosemarie

Keep in mind that you may not be able to work while you are recovering from your transplant. Having a financial plan in place will allow you to focus on your healing instead of worrying about money.



Trevin and Brayden, both transplant recipients, with their parents, Regina and Martin.

Raising funds

Out-of-pocket costs, before and after transplant, often exceed available resources. This can result in large medical debts for transplant patients and their families. Fundraising can help.

The best time to raise money through fundraising is **before** the transplant takes place. See chapter 6, "Fundraising," on page 38 for more information.

Monthly Household Income Worksheet

Income	Per Month
After-tax wages	\$
Tips or bonuses	\$
Child support	\$
Alimony/maintenance payment	\$
Unemployment compensation	\$
Social Security or Supplemental Security Income	\$
Retirement plan(s) (pensions)	\$
Disability insurance payments	\$
Public assistance	\$
Food stamps	\$
Interest/dividends	\$
Other	\$
Total Income	\$

Now you know how much you have coming in each month. Next, calculate how much you spend each month. Using the worksheet on the next page, list all your monthly household expenses. You may have extra medical expenses some months, depending on what treatment you are receiving. You may need to revise this worksheet each month to include additional medical expenses.

Monthly Household Expenses Worksheet

Expense	Per Month
Rent or mortgage	\$
Heat/air conditioning and electricity	\$
Water/sewer	\$
Telephone/Internet	\$
Cell phone	\$
Groceries	\$
Prescription drugs	\$
Car payments	\$
Car repairs and gas	\$
Other transportation payments (bus fare, taxis, train)	\$
Homeowner's or renter's insurance	\$
Car insurance	\$
Health insurance	\$
Dental insurance	\$
Doctor bills	\$
Dentist bills	\$
Hospital bills	\$
Child care	\$
Loan or credit card payments	\$
Entertainment (eating out, movies, cable, satellite)	\$
Miscellaneous (gifts, classes, vacations)	\$
Savings or IRA contributions	\$
Taxes (other than wage withholding)	\$
Other (pet care, for example)	\$
Total Expenses	\$

Write down everything you spend, no matter how small an amount, except for your medical bills. Even write down those cups of coffee and bags of chips. At the end of each month, you can look at your record and see where you spend your money.



Gloria, transplant recipient

Accessing posttransplant assistance

When Gloria was diagnosed, her mate Jeff gave up his job to be her caregiver, greatly reducing the couple's income. "They tell you to avoid stress, but all you have is stress. You are very sick AND you have to worry about whether or not you'll go broke," says Gloria.

Their family was there for them with emotional and caregiving support. "When it strikes, it happens to the whole family," Jeff says. It was hard for them to ask for financial assistance, but encouraged to do so by social work staff at the transplant center, they were able to access financial resources that provided some relief.

Now, compare your monthly household income with your monthly household expenses using the following worksheet:

Compare Income and Expenses Worksheet

Income/Expenses	Amount
Monthly income from the Monthly Household Income Worksheet (page 30)	\$
Monthly expenses from the Monthly Household Expenses Worksheet (page 31)	\$
Subtract expenses from income and write the amount here	\$

If your spending is more than your income each month, you will end up with debt. The next section provides information to help you manage your debt.

Pre- and post-transplant debt management

If you are in debt, try not to get discouraged or feel overwhelmed. Even if you don't usually have a lot of debt, because of your medical treatment, you may have new bills now that are adding to your regular monthly expenses. If you or your caregiver are unable to work while recovering, you might have less income each month than you did before, too. You can take steps to help manage your expenses, reduce your debt and feel more in control of your situation.

Call your creditors (the people to whom you owe money) and explain your situation. Many creditors will understand and will work with you. Your medical expenses, rent or mortgage, utilities, and taxes should be at the top of your bill-paying list. Try to negotiate lower payments with your creditors and stick to the agreements you make with them. You also may have disability waivers for your major loans, such as mortgage or cars, and for credit cards. These disability waivers may provide relief from your monthly loan payments while you are unable to work during your recovery process.

Another way to decrease your spending is to plug your spending leaks. Keep a record of all your expenses for three months. Do you see certain trends? This information will help you think about areas where you can decrease your spending.

If you need help working out lower payments with creditors, contact a nonprofit consumer credit counseling service. These organizations will help you establish a budget. They also will work with your creditors to come up with a payment plan. Call **1 (800) 388-2227** or visit the National Foundation for Credit Counseling at **nfcc.org** for more information.

Taxes

You may be able to save money on your income taxes by claiming the medical expense deduction. See Internal Revenue Service (IRS) publication 502 for more information on what qualifies for this income deduction. You can order a free copy of the form from the IRS by calling **1-800-829-1040**, or you can download a copy from the IRS Web site at irs.gov (click on "Forms and Publications").

If you file an itemized tax return, you can deduct medical expenses that exceed a certain percentage of your income. Save all bills and receipts for medications, parking fees, gas, and transportation costs for doctor's visits. Keep track of your mileage to and from the doctor's office or hospital, which is deductible to the extent allowed by law. Even overnight stays in hotels may be deductible, provided the stay is primarily for and essential to medical care. Ask your doctor to write a prescription for medications, wheelchairs, splints, or any special equipment that you need. When prescribed, these items generally will be tax deductible.

A scooter or a walker is generally deductible, as are medically related adaptations to your home or car. Keep all medical receipts with your records, and discuss them with a financial planner or accountant.



Michelle, transplant recipient

Keep all of your medical receipts and other important documents together. You may even want to store them in a special box or binder so they are all in one place. Be sure to discuss them with a financial planner or accountant.

IMPORTANT: Each health insurance company has an identified appeal process - often times the health insurance policy limits the numbers of appeals that can be made. It is important to contact the health insurance company directly to learn their process and work with your transplant center on any appeals.

Chapter Five

Getting Help with Denials of Coverage and Appeals

If you have received a denial of coverage, staff at your transplant center can work with your health insurance company to help you understand the reason for the denial. They can also guide you through the appeals process, if necessary. Our patient services coordinators can also help. Call 1 (888) 999-6743 or e-mail patientinfo@nmdp.org for one-on-one support.

Coverage decisions

The people who review your request for coverage use the guidelines established by the health insurance company. If you have a self-funded policy, go to your employer or Third Party Administrator for a decision. The reviewer will base his or her decision on answers to the following questions:

- What is the severity of your illness?
- What type of treatment will you receive?
- Is the treatment the "standard of care" for your circumstance?
- What is the extent of the care that you will receive?
- Does the anticipated treatment meet the policy's guidelines?
- Does the treatment setting or center meet the policy's guidelines?

If the reviewer believes that your request does not fall within the guidelines established by the policy, the reviewer will deny coverage for the procedure. If you receive a letter of denial for treatment and/or you begin treatment without approval, your insurance company will not pay for this treatment.

Even if your doctor believes the procedure is medically necessary, this does not guarantee that it is authorized by the health insurance company. The reviewers for the policy may feel that the procedure is experimental and not supported by established medical research. Or, the reviewer may approve the treatment but believe it would be better implemented at a different hospital or transplant center than the one you requested. The guidelines for treatment may vary from policy to policy, so a procedure or treatment center approved under one policy may not be approved under another one. Getting approval may take extra efforts, but may improve your chances of having your request for treatment funded. Your transplant center will help you.

The appeals process

You may have been denied coverage for any of the reasons listed on the previous page or for other reasons. However, you don't have to accept the reviewer's first answer as their final answer. You can appeal a denial of coverage. The appeals process may take time and effort, but it can help you get the coverage you request for a medical procedure.

Use whatever support you can to help you through this process so you can focus on health and healing.

- The transplant center financial representatives and coordinator will help you work with your health insurance company representatives to try to get coverage. Be sure to speak with them about any concerns with your coverage or appeals.
- Friends and family can make phone calls and keep records during the appeals process. Be sure you have signed a release to let someone else speak on your behalf.
- You can also contact Be The Match patient services for help with the appeals process at 1 (888) 999-6743, or e-mail patientinfo@nmdp.org.

Appealing denials

If you and your transplant center receive a letter of denial, be sure to get the following information from your health insurance company:

- A specific reason for the denial
- A detailed explanation of the guidelines that were used in the decision to deny your treatment request

After you receive this information, speak with your transplant center staff to help you with the appeals process.



Herschel, transplant recipient

The appeals process may take time and effort, but it can help you get the coverage that you request for a medical procedure.



Getting legal counsel

You can find a lawyer several ways. You can contact the bar association in your city or state for referrals. You also can contact The American Association for Justice (formerly the Association of Trial Lawyers of America) for referrals in your area at **1 (800) 424-2725** or **justice.org**. The "Patient Resources" section on pages 38–44 also contains other sources to help with legal issues.

Getting legal advice or taking legal action

If you have been unsuccessful in the initial appeals process, you will need to decide what steps to take next. The available alternatives will largely depend upon the terms of your insurance policy. This could mean, among other things, pursuing a second appeal or filing a grievance with the insurance company, or perhaps even taking formal legal action in the courts. In any case, you should always act as quickly as possible in order to avoid missing a deadline established by the insurance company or by law.

Making these decisions means finding out what rights you have to challenge the insurance company's decision and how and when you can exercise those rights. Because this can be very complex, you might want to hire a lawyer to assist you. Be aware, though, that legal action can be time consuming and expensive. It also can be emotionally draining. You should be well informed before you decide to take legal action.

The process

To help make the process go as smoothly and quickly as possible, it's important to ask the right questions when you meet with a lawyer.

Examples of questions you might ask:

- Have you handled health insurance cases in the past?
- Have you handled health insurance cases in my state?
- Have you dealt with my health insurance company before?
- Have you handled marrow or cord blood transplant cases before?
- Have you handled health insurance cases similar to this one? Have you handled cases with this diagnosis, specific treatment or disputed area of coverage?
 (Disputed areas of coverage might include donor or cord blood unit search costs, procurement costs or actual marrow or cord blood transplant admission costs.)
- How were these cases resolved? (Also, ask the lawyer how he or she compares to other lawyers handling similar cases.)
- How do you charge? Can you estimate total charges, including expenses? Will you take the case on a contingency basis? (A contingency basis means the lawyer gets paid from the money recovered by the health insurance company. If the lawyer does not win the case, he or she does not get paid. Note that if the lawyer takes a percentage of the settlement or judgment, the patient must raise that amount to finish paying for the transplant.)

When you meet with a lawyer

Remember to bring as much information about your case as possible, including:

- Notes about phone conversations with health insurance company representatives, including the person you spoke to and the date of your conversation
- Copies of your health insurance policy language and related policy information
- Copies of denial letters from the health insurance company, appeal letters that you sent, and any letters you sent or received from the company about your case
- Medical documentation that justifies your need for a transplant

After you meet with your lawyer and review your materials, you can decide whether or not to go ahead with legal action. You should also decide if you feel comfortable with this lawyer. Ask yourself, "Can I work with this person if I choose him/her to represent me?"

You are not alone

Whether you are working with Be The Match patient services or with representatives from your transplant center, or talking with friends and family, remember that you are not alone. Use this booklet to gather information and seek help from the sources available to you.

Finally, please remember that while the purpose of this booklet is to provide helpful information for understanding insurance coverage, the information contained in this booklet is not a substitute for the legal judgment and advice of a qualified attorney. We encourage anyone with legal questions to contact a licensed attorney for assistance.





Nick, transplant recipient with his wife, Ra-Young

"Many costs were not covered by our insurance. Through fundraising, we were able to afford the extra expenses we couldn't foresee—and it was much easier than expected. With my friends' energy and help, we raised more than we had ever dreamed possible."

- Nick

Chapter Six

Fundraising—Doing It the Right Way

One way to help pay for your transplant, and transplantrelated expenses, is to raise money. Even if you have coverage for transplant, fundraising is a good way to help with indirect costs, such as prescriptions and temporary housing.

Finding fundraising help

It's okay to ask for help, and you may find that many people are happy to help if you let them. Find a family member or close friend to take charge of the fundraising campaign. Co-workers, neighbors, members of a faith community and others can all find satisfaction in doing what they can to help you and your family.

A number of experienced fundraising organizations are available to help you launch a successful fundraising campaign. It is a good idea to use these experts, rather than try to go it alone. They can provide support for the entire process.

The "Patient Resources" section starting on page 40 offers suggestions for locating fundraising organizations. You can also find information about fundraising from your transplant center, hospitals or Be The Match patient services.

Basic fundraising guidelines

If you decide to raise funds on your own, use the following guidelines:

- Never mix donated money with personal or family funds.
- Establish a separate trust account in a bank with an administrator to oversee it.
- Work with a tax-exempt organization if you want contributions to be tax deductible for the donors.
- Follow the Internal Revenue Services (IRS) guidelines on the requirements for tax exempt donations and how these funds can be used.
- Work with a tax advisor to be sure that you are following IRS guidelines.

Protect your other benefits

Before you begin to raise funds on your own, check with representatives from such programs as Medicaid or the Supplement Security Income (SSI) portion of Social Security to make sure you won't lose the benefits you have now.

Tax laws

Make sure you understand the tax laws related to fundraising. As mentioned previously, you need to keep all donated funds in a separate bank account. Keep records for this bank account, including the donors' names and the amount donated by each donor. If you'd like donations to be tax deductible, you will have to work with a tax-exempt organization, or a 501(c)(3). Fundraising organizations can help you do this correctly.

Be sure to follow the IRS guidelines on how tax-exempt donations can be used. If you are not sure if you can use donated money for a certain purchase, ask before you spend it. Write down what you bought with the donated money and when it was purchased. Keep receipts for all expenditures using donated money. These receipts include hospital and doctor bills as well as those for medical equipment.

Fundraising organizations can help you find answers to the questions you have about using tax-exempt donated funds.

What you need to know about fundraising and charitable organizations

Several national charitable organizations help with fundraising for transplant procedures. Answer the questions below to help ensure that the group is reputable and uses an ethical approach to fundraising.

Evaluating eligibility and legitimacy

Before you begin working with a fundraising organization, be sure it is legitimate. Make sure it has tax-exempt status so the donations are tax deductible. Use the following questions to evaluate the tax-exempt eligibility and the legitimacy of a fundraising organization:

- Is the organization willing to make public its budget and complete an annual report?
- Is the organization willing to make public an audit by an independent accountant?
- Are the fundraising and administrative costs reasonable? Are fees disclosed?
- Is a list of the organization's management team made public?
- Does the group ensure that none of the information it distributes is misleading, deceptive or inaccurate?
- If the group claims tax-exempt status, is it willing to produce its 501(c)(3) credentials?

Getting the answers to these questions might not tell you everything about the group, but this information will help you learn about the ethics and procedures of the organization.



Ajani, transplant recipient, with his mom and caregiver, Risa

It's difficult to ask for money, but you may be surprised by how many of your family members and friends want to help. Fundraising is a great way to get them involved.



Ashley, transplant recipient

Patients preparing for a marrow or cord blood transplant have many resources available to help them with their insurance and financial concerns.

Patient Resources

Accessing additional information

The following pages contain general information about organizations and programs that may help you with your insurance or financial concerns.

Marrow and cord blood transplants are expensive. There are many extra expenses following transplant as well, especially if you do not live close to your transplant center. Because of all these added expenses, if you are considering transplant, you also need to think about your insurance coverage and financial situation. It is important to understand your coverage and prepare for these expenses as soon as possible. Insurance and financial concerns can be very frustrating, but knowing what resources are available can help you through the transplant process.

Use this as a starting point to help you find the assistance you need. Contact each organization directly to verify availability and eligibility, including a timeline for eligibility after transplant and apply for assistance. Your transplant center or clinic social worker can help you locate other resources.

Our web site, **BeTheMatch.org/patient**, contains additional financial and insurance information. Please contact our patient services team at **1 (888) 999-6743** or **patientinfo@nmdp.org** if you have questions or need additional information.

Advocacy Resources

Name	Who they help	How they can help	Learn more at
BMT InfoNet	Transplant patients	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	Phone: 1 (888) 597-7674 Web site: bmtinfonet.org
National Association of State Comprehensive Health Insurance Plans	Uninsured patients	Provides information about high- risk insurance pools, as well as a central listing of states with high-risk insurance pools	Web site: naschip.org
National Bone Marrow Transplant Link (NBMTLink)	Transplant patients	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	Phone: 1 (800) 546-5268 Web site: nbmtlink.org
Patient Advocate Foundation	All patients	Helps patients resolve insurance, employment, and/or debt crisis disputes related to their diagnosis	Phone: 1 (800) 532-5274 Web site: patientadvocate.org

Financial Aid

American Cancer Society	Cancer patients	Some individual chapters provide limited grants	Phone: 1 (800) ACS-2345
Caricer Society	patients	iiiiiited grants	Web site: cancer.org
CancerCare	Cancer patients	Small grants; information and resources about financial assistance	Phone: 1 (800) 813-H0PE 1 (800) 813-4673 Web site: cancercare.org
Cancer Financial Assistance Coalition (CFAC)	Cancer Patients	Provides a central listing of financial assistance organizations	Web site: cancerfac.org

Financial Aid (continued)

	Time real file (continued)		
Name	Who they help	How they can help	Learn more at
First Hand Foundation	Pediatric patients (under 18)	Income based grants for clinical expenses, durable medical goods, relocation expenses, and some vehicle modification expenses	Phone: 1 (816) 201-1569 Web site: cerner.com/ firsthand
HealthWell Foundation	Patients with some diagnoses (includes MDS and multiple myeloma)	Provides financial assistance with prescription drug coinsurance, copayments, and deductibles, health insurance premiums; income-based eligibility	Phone: 1 (800) 675-8416 Web site: healthwell foundation.org
Leukemia & Lymphoma Society	Patients with: leukemia, lymphoma, multiple myeloma or MDS	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)	Phone: 1 (800) 955-4572 Web site: leukemia-lymphoma.org
Lymphoma Research Foundation	Lymphoma patients	Small financial grants for some uncovered expenses, such as child care, travel, medical aids/devices, camps, wigs, and hygiene products	Phone: 1 (800) 500-9976 Web site: lymphoma.org
National Children's Cancer Society	Children with cancer	Provides direct financial assistance for medical and non-medical expenses related to treatment for children with cancer	Phone: 1 (800) 5-FAMILY 1 (800) 532-6459 Web site: nationalchildrens cancersociety.org
Patient Access Network Foundation	Patients with specific conditions, including non- Hodgkins lymphoma, MDS, multiple myeloma	Provides financial assistance for deductibles, co-payments and coinsurance	Phone: 1 (866) 316-7263 Web site: panfoundation.org
Patient Services Incorporated	Patients with chronic diagnoses (includes CML)	Provides financial assistance for insurance premiums, and co-pays; determines eligibility for financial hardship waiver programs	Phone: 1 (800) 366-7741 Web site: uneedpsi.org

Financial Planning

Name	Who they help	How they can help	Learn more at
Certified Financial Planner Board of Standards, Inc.	Anyone wanting to verify a financial planner's CFP certification	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.	Phone: 1 (800) 487-1497 Web site: cfp.net
Financial Planning Association	Anyone who needs to find a financial planner	Connects you with certified financial planners (CFPs)	Phone: 1 (800) 322-4237 Web site: fpanet.org
National Endowment for Financial Education (NEFE)	People with questions about money	Provides articles, tools and resources to help people learn how to manage their money	Phone: 1 (303) 741-6333 Web site: nefe.org or smartaboutmoney.org
National Foundation for Credit Counseling	People with questions about financial planning and debt	Provides consumer counseling and education on budgeting and debt reduction	Phone: 1 (800) 388-2227 Web site: nfcc.org

Fundraising

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

Housing Information

Name	Who they help	How they can help	Learn more at
National Association of Hospital Hospitality Houses	Patients who need temporary housing	Provides information on all known patient housing	Phone: 1 (800) 542-9730 Web site: nahhh.org

Legal Resources

American Association for Justice	All patients	Provides referrals to a lawyer who appeals denials from health care companies	Phone: 1 (800) 424-2725 Web site: justice.org
Cancer Legal Resource Center	Cancer patients	Provides information about patients' rights, and resources to help with insurance coverage, employment issues, medical care questions, and estate planning	Phone: 1 (866) 843-2572 Web site: disabilityrights legalcenter.org

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.

NeedyMeds	Patients without prescription coverage, based on income level	Provides information about patient assistance programs that provide free or discounted prescription medications	Web site: needymeds.com
Partnership for Prescription Assistance	Patients without prescription coverage, based on income level	Provides information about how qualified patients can get free or nearly free medications	Phone: 1 (888) 4PPA-NOW 1 (888) 477-2669 Web site: pparx.org

Travel Assistance

Name	Who they help	How they can help	Learn more at
Air Care Alliance	All patients	Provides a central listing of free air transportation services	Phone: 1 (888) 260-9707 Web site: aircareall.org
Aplastic Anemia & MDS International Foundation	AA or MDS patients who are in a clinical trial	Provides families up to \$500 for travel expenses to participate in a clinical trial	Phone: 1 (800) 747-2820 Web site: aamds.org
National Patient Air Transport HELPLINE	All patients	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.	Phone: 1 (800) 296-1217 Web site: patienttravel.org



Betsy, transplant recipient (lower right), with her family

Community Service Organizations

Many community service and faith organizations provide assistance to patients and families in need. Look in your local yellow pages under Social Service Organizations, Human Service Organizations and Community Organizations. The following are examples of organizations that may be in your community:

- American Legion
- Elks Club
- Jaycees
- Kiwanis Club
- Knights of Columbus
- Lions and Rotary Clubs
- Masons
- Thrivent Financial Chapters
- United Way
- Veterans of Foreign Wars

Glossary of terms

The following terms may help you review and understand the information provided in this booklet.

Appeal

A request to an insurance company to ask for an exception, after a treatment or service has been denied.

Clinical trial

A series of carefully controlled scientific studies using a limited number of patients.

Coinsurance

The percentage of expense that you pay. For example, the health insurance company may pay up to 80% of the approved cost of a treatment. The insured person would then have to pay the remaining 20%.

Co-payment (co-pay)

A set amount that is owed by the insured person for each medical visit, procedure or prescription. Co-pays for emergency care, medical treatment and hospital stays are generally higher (see Tiered prescription coverage).

Deductible

An amount the insured person must pay for a treatment or service before the health insurance coverage begins. Not all treatments or services may require a deductible.

Denial

Same as exclusion. Treatments or services that are not paid for by a health insurance company.

Drug formulary

A list of drugs that are paid by your health insurance company.

Exclusions

Same as denial. Treatments or services that are not paid for by a health insurance company.

Experimental treatment

A type of treatment that is still under medical study. Many health insurance companies will not pay the costs of experimental treatments.

Explanation of Benefits (EOB)

A written statement showing what the health insurance company paid, what the insured person needs to pay and/or any action that still needs to be taken.

Fair and reasonable charges

Costs that a health insurance company believes are normal and appropriate for a specific medical service or product. Any charges above this amount must be paid by the insured person. Also called "usual and customary" charges.

Family and Medical Leave Act (FMLA)

The Family and Medical Leave Act (FMLA) gives covered employees the right to an unpaid leave of absence for up to 12 weeks within a 12-month period for the birth, adoption or placement of a child, or a serious medical condition affecting them or a family member. The FMLA only applies to employees who work for a company with more than 50 employees.

Fee-for-service

What the health care provider is paid for each individual service or procedure they did, as shown in the bill.

Lifetime maximum payment

A limit to the amount your health insurance company will pay during your life or for certain conditions.

Network provider/participating provider

A doctor, hospital or other health care provider who has an agreement with a health insurance company to provide services to members for specific rates. These rates are usually lower than those of providers outside of the network. Out-of-network providers may be available at a higher out-of-pocket cost to the insured, or none of their charges may be paid by the health insurance company. Also see "Fair and Reasonable" or "Usual and Customary" charges.

Out-of-pocket costs

Health care costs that the insured person must pay on their own. Examples: co-payments, deductibles and coinsurance.

Out-of-pocket limit

The most that you would have to spend per person, per year. This amount will vary according to your policy.

Pre-certification/ pre-authorization/ prior authorization

Approval given by a health insurance company before the insured person starts treatment. The patient must notify the health insurance company before admission to the hospital, to give the company time to decide if the treatment or procedure is covered.

Pre-existing clause

A period of time when a health insurance company will not cover an illness (pre-existing condition) that a person had before they joined. This only exists if a person did not have health insurance coverage for more than 63 (continuous coverage) days before joining a new health insurance company.

Pre-existing condition

An illness a person had before they joined a new health insurance company.

Premium

The cost of health insurance. A person may pay all of it, or the cost may be shared between a person and their employer.

Standard of care

An accepted mode of treatment for a given disease or condition.

Tax-exempt organization

Section 501(c)(3) of the Internal Revenue Code. This designation states that an organization must meet the criteria of the IRS to be exempt from federal income tax. Donations to such an organization are tax deductible.

Third party payor

A health insurance carrier, health maintenance organization (HMO), managed care organization or an organized delivery system.

Tiered prescription coverage

A covered prescription drug is usually put into one of several categories. Each category has a different tier of cost. Copayments for each drug vary depending on the tier, starting with tier one drugs which have the lowest co-payment. See Co-payment (co-pay).

Usual and customary charges

Costs that a health insurance company believes are normal and appropriate for a specific medical service or product. Any charges above this amount must be paid by the insured person. Also called "fair and reasonable" charges.

Notes



Mary, transplant recipient

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National Endowment for Financial Education

Partnering for Financial Well-Being

The National Endowment for Financial Education (NEFE) partnered with Be The Match to produce the original *Mapping the Maze: A Personal Financial Guide to Blood Stem Cell Transplant* and were content reviewers for this publication.

The National Endowment for Financial Education (NEFE) is an independent, private nonprofit foundation committed to educating Americans about personal finance and empowering them to make positive and sound decisions to reach financial goals. The National Endowment for Financial Education, NEFE, and the NEFE logo are federally registered service marks of the National Endowment for Financial Education. For more information about the National Endowment for Financial Education, visit **nefe.org.**

Be The Match has a team dedicated to supporting patients, caregivers and families before, during and after transplant.

We offer you confidential one-on-one support, financial guidance and free educational resources-DVDs, booklets, online tools and more. Our goal is to get you what you need, when you need it. We can help you learn more about transplant as a treatment option, plan for a transplant, and learn what to expect after transplant.

We offer support in more than 100 languages, including Spanish bilingual staff, and translated materials.

■ Learn: BeTheMatch.org/patient

Request information: BeTheMatch.org/request

E-mail: patientinfo@nmdp.org

Call: 1 (888) 999-6743



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 1888 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.

Every individual's medical situation, transplant experience, and recovery is unique. You should always consult with your own transplant team or family doctor regarding your situation. This information is not intended to replace, and should not replace, a physician's medical judgment or advice.



Patient Services, National Marrow Donor Program 3001 Broadway St. N.E., Minneapolis, MN 55413-1753

Be The Match helps patients with leukemia, lymphoma and other diseases who need a marrow or umbilical cord blood transplant. People can join the Be The Match Registry® — the largest listing of potential marrow donors and donated cord blood units — contribute financially and volunteer.

Patients and their families can also turn to Be The Match for support and resources before, during and after transplant. Be The Match is operated by the National Marrow Donor Program® (NMDP), a nonprofit organization that matches patients with donors, educates health care professionals and conducts research so more lives can be saved. Learn more at BeTheMatch.org/patient or call 1 (888) 999-6743.