

MAPPING *the* MAZE

A Personal Financial Guide to Blood Stem Cell Transplant

About Blood Stem Cells

The National Marrow Donor Program® (NMDP) facilitates blood stem cell transplants for patients worldwide.

Blood stem cells are present in bone marrow, peripheral (circulating) blood, and umbilical cord blood. Living adults donate marrow and peripheral blood stem cells, and cord blood is collected from the discarded umbilical cord and placenta after a baby is born. Thousands of healthy adults and birth mothers have voluntarily provided these donations in the hope of saving the life of a patient with a life-threatening disease.

The collection of cord blood stem cells is an accepted medical practice. The National Marrow Donor Program does not use embryonic stem cells. The NMDP will only consider sources of stem cells subject to applicable law and national policy.



NATIONAL ENDOWMENT FOR
FINANCIAL EDUCATION

Partnering for Financial Well-Being



**National Marrow
Donor Program®**

THE **MARROW** FOUNDATION®

This handbook is meant to provide general financial information; it is not meant to substitute for, or to supersede, professional, legal, or medical advice.

The National Endowment for Financial Education® does not intend to provide any advice regarding treatments discussed in this material. Medical treatments and related health issues should be discussed with a qualified medical professional.

Note: 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 contact the NMDP Office of Patient Advocacy at 1-888-999-6743.

©2003 National Endowment for Financial Education. All rights reserved.

CONTENTS

Introduction	iii
Understanding the terms	1
Finding help	1
Chapter One: Managing Your Records	2
What basic records should I maintain?	3
What if I need help managing my records?	3
Chapter Two: Assessing Your Financial Position	4
Take a look at your health-care coverage	5
Private insurance	6
Self-funded plan	6
Managed care	7
COBRA (Consolidated Omnibus Budget Reconciliation Act of 1985)	9
Medicare	10
Medicaid	10
Veterans benefits	11
Disability programs	11
Comprehensive health insurance for high-risk individuals	13
Understanding your health-care plan	13
Clinical trials coverage	15
Pre-authorization process	15
Second opinions	15
Coverage for new treatment options	16
Costs assessment	21
Current living costs	21
Indirect transplant costs	22
Transplant Center estimates and payment requirements	24
Taking your financial inventory	25
Personal savings and investments	25
Personal property	25
Retirement benefits	25
Life insurance	25
Long-term care insurance	25
Mortgage insurance	25
Disability programs	25
Calculating your net worth	26



Chapter Three: Developing a Financial Plan	28
Spending plans	29
Pre- and post-transplant debt management	34
Taxes	35
Chapter Four: Helping Yourself	36
If you're denied coverage	37
The appeals process	38
Appealing denials	39
Sample appeal letters	40
Appeal Letter: Your health-care plan will not cover the unrelated donor search or blood stem cell procurement process	40
Appeal Letter: Your health-care plan believes the procedure is not medically necessary	42
Chapter Five: Fund Raising—Doing It the Right Way	44
Finding fund-raising help	45
Determining specific needs and amounts	46
Protect your other benefits	46
Tax laws	46
What you need to know about fund-raising and charitable organizations ..	47
Evaluating eligibility and legitimacy	47
Chapter Six: Seeking Help	48
Getting legal advice or taking legal action	49
You are not alone	51
Patient Resources	52
Financial assistance resources	53
Advocacy resources	55
Travel and housing resources	56
Fund-raising organizations	56
Debt consolidation	57
Legal resources	57
Financial planners	57
Glossary	58
Acknowledgments	60

INTRODUCTION



The prospect of planning for a blood stem cell transplant may seem overwhelming for patients and their families. Add to that thoughts of how to pay for such an expensive medical treatment and it's easy to see how patients and their loved ones can feel helpless—lost in what seems to be a maze of new and unfamiliar concerns.



Finding help

It is important to understand that you are not alone, and you are not powerless. There are ways to negotiate your way through this maze of insurance information, health-care coverage options, and financial decisions. Many resources are available to help guide you in this process—including this booklet, which is intended to:

- ✦ Help you know what questions you might need to ask
- ✦ Answer many of the questions you might have
- ✦ Help you develop a financial plan as you explore your treatment options
- ✦ Tell you about the resources that may help you along this journey

Understanding the terms

If you're just beginning to learn more about your treatment options, you may hear the treatment described two ways: "bone marrow transplant" and "blood stem cell transplant." Actually, stem cells are found in human bone marrow, human blood, and the umbilical cord blood of a newborn baby. In this booklet, we will be using the words "blood stem cell transplant" regardless of the source of the stem cells (marrow, peripheral blood, or umbilical cord blood).

Most of the information in this booklet is intended for patients facing an unrelated stem cell transplant. Much of the information, however, also is helpful to patients facing a related stem cell transplant.

Remember, you don't have to face your treatment alone. Many people are waiting to help you. Just ask. In addition to talking with trusted financial advisors and family members, you will want to work closely with your Transplant Center staff. They have helped many patients through the same hard times that you are facing right now. They have a lot of information and can help you.

Additionally, The Marrow Foundation® works with the National Marrow Donor Program (NMDP) to offer financial assistance to patients in need of an unrelated stem cell transplant. Patient Assistance Funds are available if you qualify. You can ask your NMDP Transplant Center staff more about this process. The Transplant Center must apply for these funds on your behalf. More information about The Marrow Foundation's services is available at www.themarrowfoundation.org.

The NMDP has an Office of Patient Advocacy (OPA) staffed with people trained to help answer questions that you or your caregiver(s) may have. They specialize in information about unrelated blood stem cell transplants. The OPA services are free of charge. Please call them toll free at 1-888-999-6743 or direct at 1-612-627-8140 between the hours of 8 a.m. and 5 p.m. Central Time. You also may find information on the NMDP Web site at www.marrows.org.