

A patient checklist

Getting Ready for Your Transplant

This checklist is a guide to help you prepare for your transplant. Some items will not relate to your situation. Although the list is long, please do not let it overwhelm you. You may use this list to help you develop questions for your transplant center coordinator, social worker or financial representative.

Self advocacy

- Identify what works best for you in terms of understanding information on your upcoming treatment. You may want things explained in writing or you may want to have a friend or family member present to hear information with you. A tape recorder is an option if you want to play back important information later.
- Ask your doctor about how long he or she thinks you will need to stay at the transplant center. Identify someone to be your caregiver during and after your inpatient stay at the transplant center. This could include immediate family members or friends. Most transplant centers expect that you have a caregiver to stay with you when you return home.
- To help your caregiver in understanding his or her role, ask your physician what is expected of the caregiver. How long will you need a caregiver? When do they need to be with you? What types of activities will they be asked to perform? Could more than one person serve as a caregiver?

Choosing a caregiver

- Sometimes you do not feel that you have a choice in who will be your caregiver. If you have more than one option, ask yourself how comfortable he/she feels in the hospital/clinic setting.
- Does your caregiver have the patience needed to wait for long periods (i.e., for procedures or doctors' visits)?
- Are you and your caregiver able to resolve differences?
- Will your caregiver understand your health care choices?
- Are there a number of support people within your family/friends network that could rotate the caregiver role?
- Is your caregiver able to get Family Medical Leave for an extended absence from work?
- Discuss with your spouse or significant other the ways in which your relationship might change after the transplant. You will have to depend on him or her for more help with your care. That may put a strain on the relationship. Think about how you can work to make these changes less stressful.

A patient checklist (continued)

Personal care

- Both you and your caregiver may need to complete routine dental and medical appointments prior to transplant if your transplant center is far from home. Your caregiver may need a plan to get prescriptions renewed.
- If you or your caregiver are under a specialist's or therapist's care, discuss the care plan to follow while away and arrange for possible follow-up care near the transplant center. Ask your current doctor what you should do if you need professional care while you are in another city or state.

Family and friends

- Set up family meetings to talk openly about the transplant and the plans you and your family need to make.
- If you have children or grandchildren, explain to them in words they can understand why you are going to the transplant center. You may use books, photos or videos to help them understand.
- Talk to your children about what will happen to them while you are in the hospital. Identify who will be with them, how their schedules will be kept and how you will communicate with them if you are separated. If you want assistance in talking to a child, contact your hospital social worker or child life specialist.
- Discuss your own needs and concerns with your spouse, partner or significant other.
- Consider setting up an appointment with a counselor to assist you and your family in preparing for transplant.
- Participate in a send-off gathering with family and friends. Have pictures taken to bring with you.
- If friends and family want to know how they can help or what they can send, consider long-distance calling cards, snacks, meal certificates, notes of encouragement, videos of family and friends.

A patient checklist (continued)

- Finding support**
- Support groups for adults or family members often help during stressful times by providing answers to commonly asked questions and mutual support from others who have been in similar circumstances. See *Patient resources* on pages 51 through 56 for organizations that provide these resources.
 - Support comes from many sources. Reach out to work colleagues, neighbors, community organizations, religious or spiritual groups, extended family or supportive friends. A group may offer to provide meals for family members at home while you are at the hospital. Others may offer to provide rides for children to school activities.
 - Online support can be found for information, connecting with transplant survivors or talking electronically with others. Remember that medical opinions shared by others or information received over the Internet does not substitute for advice given by your doctor or transplant team.

Financial

- Veterans should contact their Veteran's Administration office to inquire about eligibility for any programs based on service record and disability.
- Fund raising may be done locally on your behalf. You may want the experienced advice of a fund-raising organization if you anticipate uncovered medical expenses (National Foundation for Transplants, 1 (800) 489-3863, or The National Transplant Assistance Fund, 1 (800) 642-8399).
- Some organizations offer limited financial assistance to help with costs not covered by insurance. Check with your transplant center for additional resources.
- The Federal government has two income insurance programs available for adults: Social Security Disability and Supplemental Security Income. Eligibility is based on a determination by your physician that your disability will last one year or longer. You may qualify to start receiving benefits at an earlier date. You should talk to your transplant social worker or contact Social Security at 1 (800) 772-1213. Those who qualify for Supplemental Security Income, (SSI) based on meeting minimum income requirements may also be eligible for Medicaid, which can help cover medical care costs.
- Keep extra checks, deposit slips, and your ATM/debit/cash card on hand. Make sure you and your caregiver know your Personal Identification Number (PIN) number in case you need to access cash from an automated teller machine (ATM). Do not store these things in your hospital room or hotel room. Your caregiver should keep these for you.
- See a financial counselor for longer term financial planning.

A patient checklist (continued)

Employment

- Contact your employer to make arrangements regarding absence from work. Seek out your employee human resources representative to help you understand your benefits and responsibilities in order to qualify for disability and continuation of insurance. Know your rights regarding COBRA insurance benefits, work disability and Family Medical Leave.
- If you are covered under your employer's disability plan (short or long term), the employer will assist you in determining when to apply for Social Security Disability.

Legal

- Many employers have employee assistance programs that include access to legal advice. You may be interested in completing a will, a trust, planning guardianship (if you are a single parent), completing a living will or designating power of attorney. If you do not share a joint checking account, you may want to designate someone to handle your financial affairs temporarily.
- Depending on how complicated your financial or legal affairs are, you may want to consult a financial or family law attorney. Contact your local bar association for referral.
- You may want to know your rights under the Americans with Disabilities Act, which protects you against discrimination upon your return to work.
- If you have children under the age of 18 who will be separated from both parents, you need to give permission for another adult to take them for medical care (emergency or routine) in your absence. Generally, a signed statement will suffice, but you should check with your child's doctor.

Travel & lodging

- Check with your insurance carrier to see if your benefits cover travel, meals and lodging for yourself and a caregiver.
- Ask your transplant center about lodging resources near the transplant center. Ask for costs and whether you need to put your name on a waiting list. The National Association of Hospital Hospitality Houses Inc. may also list lodging options in the area. Call 1 (800) 542-9730.
- If you will have to travel to a transplant center, make travel arrangements. You may want to ask family members if they have frequent flyer miles available to assist you. If you need assistance for travel, you may contact the National Patient Travel Helpline at 1 (800) 296-1217 for resource information or patienttravel.org.
- Angel Flight America offers free trips on small planes for distances less than 1,000 miles for patients who meet medical and financial guidelines. Call 1 (877) 858-7788 or visit angelflightamerica.org for more information.

A patient checklist (continued)

Faith and spirituality

- If consistent with your beliefs, arrange ways to keep in touch with your faith community. Other members may want your address to send cards and give encouragement.
- Many faith communities have rituals for healing or have other important ways of offering support. You may want to discuss this with your faith leader.
- There may be connections to your faith community in the city where your transplant will take place. You may want to make a local contact for additional support.

Before leaving home

- Prepare a packing list. Think of clothes for different temperatures and seasons, if appropriate. Include some family photos or posters that may brighten your hospital room or temporary living space.
- Bring phone lists, addresses, e-mail addresses and a phone card to use for long-distance calls while you are away from your home phone.
- Arrange for someone to look after your home or apartment while you are away.
- Consider how bills will be paid in your absence. When possible, pay ahead. You may consider checking with certain loans (such as car, student loan, etc.) about the possibility of temporary deferment (grace period) of payments due to medical disability.
- Have your mail forwarded, or arrange to have someone screen your mail for you while you are away.
- Make arrangements for someone to care for your pet during your intensive treatment. Most temporary lodging facilities do not have accommodations for pets.

The National Marrow Donor Program's Office of Patient Advocacy would like to acknowledge the contributions of the BMT social workers, patients, and families at Fairview-University Medical Center at the University of Minnesota and the Patient Services Committee of the NMDP in the development of this checklist.

For further assistance, please contact the Office of Patient Advocacy toll-free at **1 (888) 999-6743** or **(612) 627-8140**.

A parent checklist

Getting Ready for Your Child's Transplant

This checklist is a guide to help prepare for your child's marrow or cord blood transplant and stay at a transplant center. Although the list is long, please do not let it overwhelm you. Some of the suggestions may not apply to your circumstances and others will simply help you to think of preparations not listed here. This list is not all-inclusive. Please contact your hospital social worker if you need assistance or clarification.

Your child

- Talk honestly with your child about the hospital stay and change in location (if changing hospitals or cities). Explain in words your child will understand. You may use books, videos or pictures to help tell the story.
- Talk with your child about the plan. You may include details of how you will travel, who will be coming along, what will happen with siblings or pets who will be staying home.
- Talk with your child (in words he or she will understand) about what will happen upon your arrival at the transplant center. You may include information about where you will be living, where he or she will receive medical care and what the schedule will be like.
- Reassure your child that Mom, Dad or an identified caregiver will be there or available and will help with whatever needs the child has.
- Help your child to make a list of items he or she would like to take along.
- If you want help in talking with your child, contact your hospital social worker or child life specialist.
- Talk with your child's teacher/principal about the plan of absence and ways to keep your child connected with the school both academically and socially.
- Children may benefit from being connected to others in their age group who have a family member being treated for cancer. The American Cancer Society and the Leukemia and Lymphoma Society have children's groups in many locations. Your local hospital social worker may refer you to other groups. Kids Connected offers a Web site (www.kidsconnected.org) or toll-free line (1-800-899-2866) with simple instructions to aid in talking with children about cancer.

Parents and caregivers

- Make necessary arrangements with your employer for your absence. Use paid or unpaid leave of absence. Talk with your employer or Human Resources Department about the Family Medical Leave Act.
- You may consider maintaining some level of paid work, if possible, by using telephone, fax or computer.
- Arrange how your home will be looked after while you are away.

A parent checklist (continued)

Family members and caregivers continued

- Consider how bills will be paid in your absence. When possible, pay ahead.
- Have your mail forwarded or arrange to have someone collect it for you while you are away.
- Discuss your own needs and concerns with your spouse, partner or significant other.
- If you are a single parent with more than one child, you may want to discuss legal arrangements for your other children if you go out of state for your child's treatment. An important consideration is who will be able to give consent for your children's medical treatment while you are away. Discuss this with your child's doctor and other involved parties.
- Begin to think about ways you can take care of yourself so that you will be better able to care for your child.
- Complete your own routine physical and dental appointments if due in the near future.
- Make sure you refill your own prescriptions if needed. Make sure you will be able to have prescriptions refilled while you are away from home.
- If you are under a physician's or therapist's care, discuss the care plan you will follow while out of state. Arrange, if necessary, for medical or psychological care at or near your transplant center.
- Consider having a family photograph taken. Bring a copy along and leave a copy with any family members (such as siblings or grandparents) at home.

Siblings

- Talk with your children to tell them what will be happening within the family while their sibling is going through a transplant. It is important to be honest and use words that your children will understand.
- If children are staying at home, talk with them about who will take care of them. Reassure them they will be taken care of during this time and that you love them. Tell them you will make plans for all the family members.
- Discuss if there will be planned family visits to the transplant center.
- If siblings are coming along, talk with them about who will take care of them. Let children know that different friends or family members may be taking turns caring for them while you are caring for their brother or sister.
- School enrollment may be available at the hospital, Ronald McDonald House or in the community. Talk with your transplant center social worker to see if this option is available.
- Bring your child's books and assignments along to the transplant center.
- Bring the school's address and telephone number and the teacher's name.

A parent checklist (continued)

Faith and spirituality

- If consistent with your beliefs, consider informing your faith leader and community of your temporary address. You may wish to establish a plan of communication (e.g. e-mail, cards, visitation, telephone tree for information updates) with them.
- You may ask your faith or community leader to offer special prayers, anointing services or other healing rituals for you and your family.
- Provide a time and opportunity to talk with your family about what each of you believe. Consider talking about what gives you comfort and strength as you and your family prepare for your child's transplant.

Travel and lodging

- Make travel arrangements. You may want to ask family members if they have frequent flyer miles available to assist you. If you need assistance for travel, you may contact the National Patient Travel Helpline at 1 (800) 296-1217 for resource information or patienttravel.org.
- Check with the Ronald McDonald House near your transplant center to see what prior arrangements can be made for lodging.
- Ask your transplant center contact about other lodging resources near the transplant center. Ask for costs and whether you need to put your name on a waiting list. The National Association of Hospital Hospitality Houses Inc. may also list lodging options in the area. Call 1 (800) 542-9730.

Family and friends

- Participate in a send-off gathering with family and friends.
- If friends and family want to know how they can help or what they can send, consider long-distance calling cards, snacks, meal certificates, notes of caring and encouragement, videos of family and friends, and items that you or your child might enjoy.

A parent checklist (continued)

Financial

- Check with your insurance case manager to learn if there is coverage for your housing, travel and meal expenses related to your child's transplant.
- If you receive medical assistance via your county, talk with your case worker about financial assistance for travel, housing and meals for patient and caregiver.
- You may consider participating in fund-raising activities for uncovered expenses related to the transplant. If you receive Medicaid or Supplemental Security Income (SSI), talk to your case worker or home hospital social worker about how to process any money that is raised so that it does not affect your eligibility for medical assistance or state-funded disability support.
- Keep extra checks, deposit slips and your ATM/debit/cash card on hand. Do not store these things in the hospital room or hotel room.

Communication

- Plan for how you will stay in touch with family members and friends back home.
- Bring long-distance telephone cards.
- Bring telephone/address directory and e-mail addresses.
- Consider using video or audiotapes to maintain contact with separated siblings or parents.

Packing List

- Make your own packing list as you think of items you want to bring.
- Think of small personal belongings to bring that are a source of comfort to you and your child.
- Consider bringing photos of home, pets, family and friends to decorate the hospital room or your temporary housing.
- Pack clothing items for changing seasons and temperatures, if appropriate.

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Transplant team phone list

As you know, a search is being conducted on your behalf for an unrelated donor through the National Marrow Donor Program Registry. During the search process, the following members of the transplant team are available to assist you. Please contact them with any questions or concerns.

Fill in names and phone numbers of your transplant team.

Transplant Team Member	Name	Phone Number	Type of Assistance
Transplant Doctor			Example: For help with medical and treatment questions
Transplant Center Coordinator			Example: For updates on progress of search
Financial Representative			Example: For insurance questions
Social Worker			Example: For assistance with preparation such as transportation, lodging and resources
Patient Advocate			Example: For help with problem resolution

Patient resources

Many organizations are available to help you and your family. The following list will help you locate resources and information that you might need.

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 the NMDP Web site at marrow.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

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
E-mail: 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
E-mail: 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.

Caring Bridge

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

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
E-mail:
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
E-mail: 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.

(S)= Spanish language support

Patient resources (continued)

BMT Support Online

P.O. Box 10303
Dothan, AL 36304
(586) 575-9910
Fax: (810) 277-5118
Web site: www.bmtsupport.org
E-mail: 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 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
E-mail: 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
E-mail: 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
E-mail: 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

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
E-mail: 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

Patient resources (continued)

Fanconi Anemia

(S) Fanconi Anemia Research Fund, Inc.

1801 Williamette Street #200
Eugene, OR 97401
(800) 828-4891
(541) 687-4658
Fax: (541) 687-0548
Web site: www.fanconi.org
E-mail: 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
E-mail: 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
E-mail: 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
E-mail: 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
E-mail: 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
E-mail: theIMF@myeloma.org

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

Multiple Myeloma Research Foundation

51 Locust Ave, Suite 201
New Canaan, CT 06840
(203) 972-1250
Web site: www.multiplemyeloma.org
E-mail: 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
E-mail: 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.

(S)= Spanish language support

Patient resources (continued)

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
E-mail: 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.

Chai Lifeline

(877) 242-4543 (CHAI LIFE)
Fax: (292) 465-0949
Web site: www.chailifeline.org
E-mail: 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
E-mail: 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 Konnected

27071 Cabot Road, Suite 102
Laguna Hills, CA 92653
(800) 899-2866
Web site: www.kidskonnected.org
E-mail: info@kidskonnected.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.nationalchildrenscancersociety.com
E-mail: 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
E-mail: 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
E-mail: 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

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.

(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
E-mail: 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
E-mail: jennifer@cota.org

Provides fund-raising 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 fund-raising programs.

(S)= Spanish language support

Patient resources (continued)

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
E-mail: helpinghomes@nahhh.org

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

National Foundation for Transplants

1102 Brookfield Road, Suite 200
Memphis, TN 38119
(800) 489-3863
Fax: (901) 684-1128
Web site: www.transplants.org
E-mail: 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
E-mail: ntaf@transplantfund.org

Assists with fund raising 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

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

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

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

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

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.

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
E-mail: 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
E-mail: 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.

(S) = Spanish language support

Patient resources (continued)

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
E-mail: info@canceradvocacy.org

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

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
E-mail: orphan@rarediseases.org

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

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.

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
E-mail: 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
E-mail: nln@lymphnet.org

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

Insurance

Medicare

7500 Security Blvd.
Baltimore, MD 21244-1850
(800) MEDICARE
Web site: 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
E-mail: 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

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

(S)= Spanish language support

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.

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.

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.

Autologous Blood

One's own blood, collected for one's own use.

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, Venous Catheter

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. See apheresis, peripheral blood stem cell (PBSC) donation.

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.

Confirmatory HLA Testing (CT)

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

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.

Filgrastim

A man-made version of a normal human protein that increases the number of blood-forming cells in the bloodstream. It is given to donors who have agreed to donate peripheral blood cells. See Apheresis, Peripheral Blood Stem Cell (PBSC) Donation.

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.

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.

Glossary of terms (continued)

HLA Typing

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

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 (GVHD).

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. See Histocompatibility, HLA, HLA Typing.

Molecular HLA Typing

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

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-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. See apheresis, central line, filgrastim.

Platelet

A blood cell that helps control bleeding.

Relapse

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

Remission

When signs and symptoms of disease are gone after treatment.

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.

T cell

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

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.

Notes

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.



Mary, transplant recipient (far right) with her family

National Marrow Donor Program®

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

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