

CHAPTER 3A
NATIONAL RESOURCES

National Resources

N1. AMERICAN BRAIN TUMOR ASSOCIATION

2720 River Road, Ste. 146

Des Plaines, IL 60018

(800) 866-2282 or (847) 827-9910, Fax (847) 827-9918

Website: hope.abta.org

Email: info@abta.org

Mission: A national, not-for-profit organization dedicated and committed to funding brain tumor research, providing patient services, and educating people about brain tumors.

N2. AMERICAN CANCER SOCIETY

1599 Clifton Road, NE

Atlanta, GA 30329

Website: www.cancer.org

Mission: Provides research, education, support, etc. for cancer patients.

Services to NCCS patients: Local transportation of families by volunteers for local treatment and hospitalization .

N3. AMERICAN SOCIETY FOR BLOOD AND MARROW TRANSPLANTATION

85 W. Algonquin Rd., Ste. 550

Arlington Heights, IL 60005

(847) 427-0224

Website: www.asbmt.org

Email: mail@asbmt.org

Provides guidelines for clinical centers, guidelines for training, and searchable tests for articles in Biology of Blood and Marrow Transplantation.

N4. BLOOD & MARROW TRANSPLANT INFORMATION NETWORK

2310 Skokie Valley Rd., Ste. 104

Highland Park, IL 60035

(888) 597-5674 or (847) 433-3313, Fax (847) 433-4599

Website: www.bmtinfonet.org

Email: help@bmtinfonet.org

A non-profit organization that produces a newsletter filled with information of concern to bone marrow, peripheral blood stem cell, and cord blood transplant patients and survivors. It includes both technical information, written in lay language, as well as feature stories. If needed, it also offers an attorney referral service and patient-to-survivor link service.

N5. THE BONE MARROW FOUNDATION

337 E. 88th St., Ste. 1B
New York, NY 10128
(800) 365-1336 or (212) 838-3029
Website: www.bonemarrow.org

Resources, information, programs, services about bone marrow and stem cell donation and transplantation.

N6. BONE MARROW TRANSPLANT SUPPORT ONLINE

Website: www.bmtsupport.org
Email: bmt-support@bmtsupport.org

Patient and care giver support group meetings online, link patients with those with similar circumstances for support, information on illnesses treated by BMT.

N7. BRAIN TUMOR FOUNDATION FOR CHILDREN

6065 Roswell Rd. NE, Ste. 505
Atlanta, GA 30341
(404) 252-4107
Website: www.btfcgainc.org
Email: btfc@bellsouth.net

A non-profit organization that provides information, referrals and support to families. Young Leadership Group consisting of survivors, their siblings and friends. Quarterly newsletter.

N8. BRAIN TUMOR SOCIETY

124 Watertown St., Ste 3H
Watertown, MA 02472
(800) 770-8287 or (617) 924-9997, Fax (617) 924-9998
Website: www.tbts.org

A non-profit organization that provides family support and information about brain tumors.

N9. THE CAITLIN RAYMOND INTERNATIONAL REGISTRY OF BONE MARROW DONOR BANKS

UNIVERSITY OF MASSACHUSETTS MEMORIAL MEDICAL CENTER
55 Lake Ave. N.
Worcester, MA 01655
(800) 726-2824, (508) 334-8969, Fax (508) 334-8972
Website: www.crir.org

Email: info@crir.org

Mission: To coordinate international donor searches for patients in need of bone marrow or cord blood transplantation. To provide direct patient advocacy and individual case management.

Services to NCCS patients: Search coordination, patient advocacy and individual case management. Brochures available upon request.

N10. CANCER CARE, INC.

275 Seventh Ave. floor 22

New York, NY 10001

(800) 813-HOPE, Fax (212) 712-8495

Website: www.cancercare.org

Email: infor@cancercare.org

Mission: Dedicated solely to providing support for cancer patients and their families and friends, as well as education for the general public. A non-profit, non-sectarian voluntary agency that offers professional social work, counseling and guidance free of charge.

N11. CANCER INFORMATION SERVICE

NATIONAL CANCER INSTITUTE (NCI)

Regional offices across the U.S.

(800) 4-CANCER

Website: cis.nci.nih.gov

Information on current cancer treatments and clinical trials, online chat to help find information.

N12. CANDLELIGHTERS CHILDHOOD CANCER FOUNDATION

National Office:

P.O. Box 498

Kensington, MD 20895-0498

(800) 366-CCCF or (301) 962-3520, Fax (301) 962-3521

Website: www.candlelighters.org

Email: staff@candlelighters.org

Mission: An information clearinghouse on childhood and adolescent cancer-related issues, periodic newsletters, support groups.

N13. CHILDREN'S HOPES & DREAMS FOUNDATION

86 Auble Rd.

Blairstown, NJ 07825

(973) 361-7366, Fax (973) 361-6627

Website: www.childrenswishes.org

Wish fulfillment for seriously ill children, match patients with pen pals.

N14. CHILDREN'S ORGAN TRANSPLANT ASSOCIATION, INC (COTA)

2501 Cota Dr.

Bloomington, IN 47403

(800) 366-2682, Fax (812) 336-8885

Website: www.cota.org

Email: cota@cota.org

Mission: Dedicated to assisting families with children requiring organ and tissue transplants while educating the public to the need for organ and tissue donation. Provide fundraising to pay for bone marrow transplant when no other sources are available.

N15. COPING WITH CANCER

P. O. Box 682268

Franklin, TN 37068-2268

(615) 790-2400, Fax (615) 794-0179

Website: www.copingmag.com click on Coping with Cancer

Email: info@copin gmag.com

Magazine for anyone touched by cancer.

N16. CURE SEARCH

NATIONAL CHILDREN'S CANCER FOUNDATION

4600 East West Hwy., Ste. 600

Bethesda, MD 20814-3457

OR Research Operations Center

440 E. Huntington Dr.

P.O. Box 60012

Arcadia, CA 91066-6012

(800) 458-6223

Website: www.curesearch.org

Email: info@curesearch.org

Mission: A non-profit organization dedicated to the eradication of childhood cancer through research, treatment, education and advocacy. Publishes a newsletter.

N17. CENTER FOR INTERNATIONAL BLOOD AND MARROW TRANSPLANT RESEARCH (CIBMTR)

Health Policy Institute

8701 Watertown Plank Rd.

P.O. Box 26509
Milwaukee, WI 53226 also Minneapolis, MN location
(414) 456-8325, Fax (414) 456-6530
Website: www.cibmtr.org
Email: cibmtr@mcw.edu

Collects and analyzes data on bone marrow and stem cell transplants performed at 300 facilities worldwide. Publications available for patients.

N18. FRIENDS HEALTH CONNECTION

P.O. Box 114
New Brunswick, NJ 08903
(800) 48-friend, (732) 418-1811
Website: www.48friend.org
Email: info@friendshealthconnection.org

Mission: a non-profit communication network whose goal is to alleviate the devastation that illness can bring by providing support from people who have firsthand knowledge of the same health issues. For both patients and their families.

N19. LEUKEMIA AND LYMPHOMA SOCIETY

Home office:
1311 Mamaroneck Ave.
White Plains, NY 10605 has local chapters
(800) 955-4572 or (914) 949-5213
Website: www.leukemia.org

Mission: Provides research, education and support to patients and their families with leukemia and related cancers. Local support groups include children with neuroblastoma and their families.

N20. LEUKEMIA RESEARCH FOUNDATION

2700 Patriot Blvd., Ste. 100
Glenview, IL 60026-8021
(847) 424-0600, Fax (847) 424-0606
Website: www.leukemia-research.org
Email: info@lrfmail.org

Mission: Newsletter, counseling and support groups for patients with leukemia. Financial aid also available.

N21. MAKE-A-WISH FOUNDATION OF AMERICA

3550 N. Central Ave., Ste. 300

Phoenix, AZ 85012-2127 has local chapters

(800) 722-WISH, (602) 279-9474

Website: www.wish.org

Mission: To grant wishes of children with life threatening illnesses. All children with neuroblastoma should qualify.

N22. THE MARROW FOUNDATION

400 Seventh St. NW, Ste. 206

Washington, D.C. 20004

(800) 507-5427, (202) 626-8660, Fax (202)638-0641

Website: www.themarrowfoundation.org

Email: tmf@nmdp.org

Mission: Non-profit organization which works with companies and individuals nationwide on innovative programs to help patients and families.

N23. NATIONAL ASSOCIATION OF HOSPITAL HOSPITALITY HOUSES

44 Merrimon Ave. 1st Floor

Asheville, NC 28801

(800) 542-9730 or (828) 253-1188, Fax (828) 253-8082

Website: www.nahhh.com

Email: helpinghomes@nahhh.org

Referrals to free or low cost lodging near medical facilities.

N24. NATIONAL BONE MARROW TRANSPLANT LINK

20411 W. 12 Mile Rd., Ste. 108

Southfield, MI 48076

(800) LINKBMT, [(800) 546-5268]

Website: www.nbmtlink.org

Email: myrajacobs@nbmtlink.org

Mission: Educational and emotional support, link patients with survivors.

N25. NATIONAL BRAIN TUMOR FOUNDATION

22 Battery St. Ste. 612

San Francisco, CA 94111-5520

(800) 934-CURE (2873), Fax (415) 284-0209

Website: www.braintumor.org

Email: nbtf@braintumor.org

Publications, support group referrals, phone support, fund raising events.

N26. NATIONAL CANCER INSTITUTE

(800) 4-CANCER [800-422-6237]

NCI Public Inquiries Office

6116 Executive Blve. Rm. 3036A

Bethesda, MD 20892-8322

Website: www.cancer.gov

Email: cancergovtstaff@mail.nih.gov

Mission: Federal gov't agency offering wealth of information on cancers, treatment options, clinical research projects, online support.

NCCS patients: Provides the most current clinical research studies on neuroblastoma (updated every 30 days). Also provides numerous brochures, also in Spanish.

N27. NATIONAL CHILDREN'S CANCER SOCIETY

1015 Locust, Ste. 600

St. Louis, MO 63101

(800) 5-FAMILY or (314) 241-1600, Fax (314) 446-5264

Website: www.nationalchildrenscancersociety.com

Email: pfs@children-cancer.com

Mission: To ensure no child seeking a bone marrow transplant should be denied quality medical care or other resources to sustain child and family through the process.

NCCS patients: BMT, donor harvest, donor recruitment, tissue typing and emergency ancillary. Will intercede with insurance companies. Also send team or provide guidance for fundraisers. Several free brochures available upon request.

N28. NATIONAL COALITION FOR CANCER SURVIVORSHIP (NCCS)

1010 Wayne Ave., Ste. 770

Silver Spring, MD 20910

(877) NCCS-YES [877-622-7937], or (301) 650-8868, Fax (301) 565-9670

Website: www.cansearch.org

Email: info@canceradvocacy.org

Mission: To inform, serve and advocate on behalf of this country's cancer survivors in order to maximize their potential for living the best quality of life possible following a diagnosis of cancer.

NCCS patients: numerous brochures and newsletter.

N29. NATIONAL FOUNDATION FOR TRANSPLANTS

1102 Brookfield, Ste. 200

Memphis, TN 38119

(800) 489-3863, (901) 684-1697, Fax (901) 684-1128

Website: www.transplants.org
Email: info@transplants.org

Fundraising assistance.

N30. NATIONAL MARROW DONOR PROGRAM

3001 Broadway St. NE, Ste. 500
Minneapolis, MN 55413-1753
(800) 627-7692, Fax (612) 627-5877
Office of Patient Advocacy: (888) 999-6743
Website: www.marrow.org

Mission: A registry of bone marrow donors. Provides information on becoming a donor and organizing donor recruitment drives. A patient advocate is available to help with questions.
NCCS patients: provides help in finding bone marrow donors.

N31. NATIONAL ORGANIZATION FOR RARE DISORDERS (NORD)

55 Kenosia Ave.
P.O. Box 1968
Danbury, CT 06813-1968
Voicemail: (800) 999-6673, phone (203) 744-0100, Fax (203) 798-2291
Website: www.rarediseases.org
Email: orphan@rarediseases.org

Mission: The federation of voluntary health organizations dedicated to helping people with rare (orphan) diseases and assisting the organizations that serve them. NORD is committed to the identification, treatment, and cure of rare disorders through education, advocacy, research and service.
NCCS patients: can provide current information on neuroblastoma.

N32. NEUROBLASTOMA CHILDREN'S CANCER SOCIETY

P.O. Box 957672
Hoffman Estates, IL 60195
(800) 532-5162, (847) 605-1245, Fax (847) 605-0705
Website: www.neuroblastomacancer.org
Email: info@neuroblastomacancer.org

Mission: The primary focus of the organization is to raise money to assist local research in neuroblastoma cancer, and to raise national awareness to focus additional research and funding until a cure can be found.

N33. R.A. BLOCH CANCER FOUNDATION INC.

4400 Main St.

Kansas City, MO 64111

(800) 433-0464, (816) 932-8453, Fax (816) 931-7486

Website: www.blochcancer.org

Email: hotline@hrblock.com

Links to treatment, step-by-step guide, emotional support, link patients with survivors.