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.btfcqainc.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 REGISTRTY 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: info@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@copingmag.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.
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
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
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.