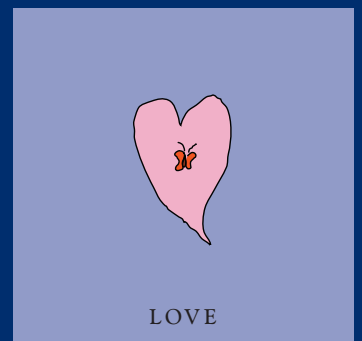
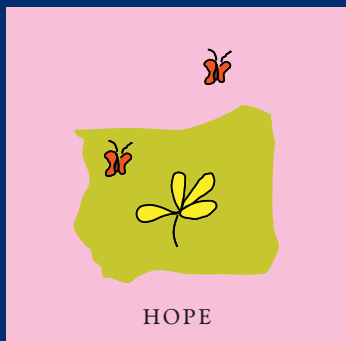


07 RESOURCE DIRECTORY



A GUIDE FOR PATIENTS, FAMILIES AND HEALTH PROFESSIONALS

Dedication

This Resource Directory is dedicated to
brain tumor survivor and NBTF volunteer Jennifer Neale.
Your tremendous spirit and dedication to the brain tumor
community is so very much appreciated.



The National Brain Tumor Foundation

The National Brain Tumor Foundation is a nationwide non-profit organization that serves people whose lives are affected by brain tumors. We are dedicated to promoting a cure for brain tumors, improving the quality of life and giving hope to the brain tumor community by funding meaningful research and providing patient resources, timely information and education.

The National Brain Tumor Foundation offers the following services to patients, their loved ones and health professionals:

- Comprehensive website with information about treatment and coping
- Toll-free Patient Information Line
- Medical Information Nurse
- Nationwide listing of Support Groups
- Patient and Caregiver Support Network via phone and e-mail
- Quarterly newsletter (*Search*) with information about treatments, survivorship, and resources
- Printed information about tumor types, treatment and related issues
- National Caregiver Training Workshops
- Teleconferences and Web Conferences
- Patient Help Fund financial assistance program
- Monthly eNewsletter
- Neuroscience News Network
- Treatment Center Database

National Brain Tumor Foundation

22 Battery Street, Suite 612
San Francisco, CA 94111-5520

Phone: (800) 934-2873

Fax: (415) 834-9980

E-mail: nbtf@braintumor.org

Web: www.braintumor.org

About Our Resource Directory

This **Resource Directory** has been prepared as a public service by the National Brain Tumor Foundation. It contains the names and addresses of various organizations that offer services and products of particular interest to brain tumor patients and their families. The listing is not exhaustive, but does include many of the organizations that NBTF has used over the years. In the event that a listing is no longer current, please use this page to note it and either fax or mail it to us.

This Resource Directory is prepared and distributed with the understanding that NBTF is not rendering any medical, counseling, pharmaceutical or other professional service and is neither endorsing nor recommending any of the individuals, services or organizations listed or described here.

To be added to our mailing list or to update any listings, please mail, fax or e-mail us this information:

Name: _____

Organization/Institution: _____

Address: _____

City: _____ State: _____ Zip: _____

Phone: _____

Fax: _____

E-mail: _____

Are you a patient? yes no

If yes, what was the date of diagnosis? _____ Tumor type: _____

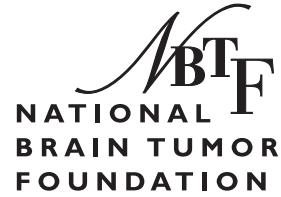
Are you a health professional? no yes Title: _____

Are you a caregiver? no yes

Are you requesting an update for the Resource Directory? yes no

Comments: _____

To order additional copies of the NBTF Resource Directory contact NBTF at (800) 934-2873 or e-mail nbtf@braintumor.org.



Dear Friend,

For the past 25 years, the National Brain Tumor Foundation has been leading the way in responding to needs in the brain tumor community. We receive over 1,000 calls and e-mails every month and provide timely information, support programs, and resource referrals to brain tumor patients, their families and health professionals. This booklet, used as a resource in our office, contains the information we are asked about most frequently.

The NBTF Resource Directory was initially developed by brain tumor survivor and NBTF volunteer Jennifer Neale, who remembered how difficult it was to locate the things she needed during and after treatment. She developed the first NBTF Resource Directory in hopes of making the road a bit easier for those coming behind her, and we have been publishing updated versions since 2002. The Resource Directory includes listings from across the country and the world and has been distributed to thousands. We hope you will find the 2007 Resource Directory useful as well.

This publication, like all NBTF publications, is available free of charge. If you want to order more copies or would like additional information about any of NBTF's programs or services, please call our office or send us an e-mail. We exist to help people like you!

Sincerely,

A handwritten signature in black ink, appearing to read 'Harriet Patterson', written in a cursive style.

Harriet Patterson, MPH
Director of Patient Services

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Section 1

Brain Tumor and Brain Tumor-related Organizations

ACOUSTIC NEUROMA ASSOCIATION

600 Peachtree Parkway, Suite 108
Cumming, GA 30041
Phone: (877) 200-8211
(770) 205-8211
Fax: (770) 205-0239
Web: www.anausa.org
E-mail: info@anausa.org

The Acoustic Neuroma Association provides literature and articles on acoustic neuromas. Their newsletter, *Notes*, is published quarterly. They also hold a national symposium every two years.

AMERICAN BRAIN TUMOR ASSOCIATION

2720 River Road, Suite 146
Des Plaines, IL 60018
Phone: (800) 886-2282
(847) 827-9910
Fax: (847) 827-9918
E-mail: info@abta.org
Web: www.abta.org

The American Brain Tumor Association provides numerous publications and support group listings, funds research, and publishes a newsletter.

BRAIN INJURY ASSOCIATION OF AMERICA

8201 Greensboro Drive, Suite 611
McLean, VA 22102
Phone: (800) 444-6443
(703) 761-0750
Web: www.biausa.org

The Brain Injury Association produces a quarterly newspaper called *TBI Challenge*. They also provide reference books, updated resource information and referrals to nationwide rehabilitation facilities.

BRAIN TRUST

186 Hampshire Street
Cambridge, MA 02139-1320
Phone: (617) 876-2002
Fax: (617) 876-2332
E-mail: info@braintrust.org
Web: www.braintrust.org

The Healing Exchange Brain Trust runs a number of online support groups, including the BRAINTMR Mailing list. Their bulletin board is a place for people to share their experiences with brain tumors. Participants include brain tumor patients, family members, neurosurgeons, nurses, social workers and other health-care professionals.

1

BRAIN TUMOR FOUNDATION FOR CHILDREN, INC.

6065 Roswell Road NE, Suite 505
Atlanta, GA 30328

Phone: (404) 252-4107

Fax: (404) 252-4108

E-mail: btfc@bellsouth.net

Web: www.braintumorkids.org

BTFC provides information and emotional support for families of children with brain tumors. The organization also raises funds for brain tumor research and provides a telephone network system of parents who offer emotional support to other parents. Additionally, it offers educational programs, parent retreats twice a year, and a sibling camp in the summer. Its newsletter, *News Views*, is published several times a year.

BRAIN TUMOUR FOUNDATION OF CANADA

620 Colborne Street, Suite 301
London, Ontario, Canada N6B 3R9

Phone: (800) 265-5106

(519) 642-7755

Fax: (519) 642-7192

E-mail: btfc@btfc.org

Web: www.braintumour.ca

A national, non-profit organization dedicated to providing support services to those affected by brain tumors, educating the public and funding brain tumor research.

BRAIN TUMOR SOCIETY

124 Watertown Street, Suite 3H

Watertown, MA 02472

Phone: (800) 770-8287

(617) 924-9997

Fax: (617) 924-9998

E-mail: info@tbts.org

Web: www.tbts.org

BTS offers support by telephone, information and referrals, a telephone network for patients/family members, and a list of

support groups in the U.S. Its newsletter, *Heads Up*, is published three times a year. BTS is also very active in fundraising for brain tumor research.

THE CENTRAL BRAIN TUMOR REGISTRY OF THE UNITED STATES

244 East Ogden Avenue, Suite 116
Hinsdale, IL 60521

Phone: (630) 655-4786

Fax: (630) 655-1756

E-mail: cbtrus@aol.com

Web: www.cbtrus.org

The Central Brain Tumor Registry is a non-profit resource for gathering and distributing statistics on all primary brain tumors in the United States.

THE CHILDHOOD BRAIN TUMOR FOUNDATION

20312 Watkins Meadow Drive
Germantown, MD 20876

Phone: (877) 217-4166

(301) 515-2900

E-mail: cbtf@childhoodbraintumor.org

Web: www.childhoodbraintumor.org

CBTF provides the Childhood Cancer Ombudsman Program. This free service consists of trained volunteers in the disciplines of medicine, law, and education that provide assistance in: 1) seeking second opinions, 2) access to healthcare, and 3) combating discrimination. This organization also publishes a quarterly newsletter.

THE CHILDREN'S BRAIN TUMOR FOUNDATION, INC.

274 Madison Avenue, Suite 1004
New York, NY 10016

Phone: (866) 228-4673

(212) 488-9494

Fax: (212) 448-1022

E-mail: info@cbtf.org

Web: www.cbtf.org

The Children's Brain Tumor Foundation provides regional support to patients and families. It has a comprehensive resource manual and runs a variety of support services for parents with children in treatment.

THE CHILDREN'S TUMOR FOUNDATION

95 Pine Street, 16th Floor
New York, NY 10005
Phone: (800) 323-7938
(212) 344-6633
Fax: (212) 747-0004
E-mail: info@ctf.org
Web: www.ctf.org

The Children's Tumor Foundation provides information over the telephone and will mail educational and resource materials. Their primary focus is on neurofibromatosis, a.k.a. "Von Recklinghausen's disease," a hereditary disorder characterized by many tumors afflicting the nervous system.

CLINICAL TRIALS AND NOTEWORTHY TREATMENTS FOR BRAIN TUMORS

Web: www.virtualtrials.com

This organization is maintained by the Mussella Foundation for Brain Tumor Research and Information. Their website lists clinical trials in North America by tumor type and geographical location.

CUSHING'S SUPPORT AND RESEARCH FOUNDATION

65 E. India Row, Suite 22B
Boston, MA 02110-3389
Phone: (617) 723-3674
Fax: (617) 723-3674
E-mail: cushinfo@csrf.net
Web: www.csrf.net

This non-profit organization provides information and support to Cushing's patients and their families. Two major CSRF objectives are to put patients in contact

with other patients and to facilitate the sharing of information between members. CSRF also has a quarterly newsletter.

EPILEPSY FOUNDATION OF AMERICA

8301 Professional Place
Landover, MD 20785
Phone: (800) 332-1000
Web: www.efa.org

The Epilepsy Foundation of America's goal is to improve the lives of people with epilepsy. They provide information, advocacy, training and employment placement services, and counseling for people with epilepsy and their families. Their Epilepsy Library and Resource Center provides information to professionals and to the public. EFA provides referrals to local chapters nationwide.

FAMILIAL BRAIN TUMOR REGISTRY

University of Texas – M.D. Anderson
Cancer Center
Department of Epidemiology - Box 189
1515 Holcombe Boulevard
Houston, TX 77030
Phone: (800) 248-4856
(713) 745-4113
Fax: (713) 792-8261
E-mail: mawright@mdanderson.org
Web: www.mdanderson.org

The Familial Brain Tumor Registry is aimed at identifying families who are at high risk for brain tumors and multiple cancers. The registry allows researchers to identify genetic factors associated with the diseases. If you are interested in participating, contact the Registry at the number above.



FLORIDA BRAIN TUMOR ASSOCIATION, INC. (formerly known as South Florida Brain Tumor Association)
P.O. Box 770182
Coral Springs, FL 33077-0182
Phone: (954) 755-4307
(561) 798-9434
E-mail: BtIDiva@aol.com
Web: www.fbta.info

Designed to support and educate those diagnosed with brain tumors and their families, the Florida Brain Tumor Association helps patients, their families and friends in the southern part of the United States.

THE GERRY & NANCY PENCER BRAIN TRUST

22 St. Clair Avenue East, Suite 1104
Toronto, Ontario, Canada M4T 2S3
Phone: (416) 923-2999
Fax: (416) 923-2395
E-mail: info@pencerbraintrust.com
Web: www.pencerbraintrust.com

This non-profit organization provides brain tumor patients and their families with a comprehensive, holistic approach to treatment, education and support in a way that looks at all aspects of families and family life.

HYDROCEPHALUS ASSOCIATION

870 Market Street, Suite 705
San Francisco, CA 94102
Phone: (888) 598-3789
(415) 732-7040
Fax: (415) 732-7044
E-mail: info@hydroassoc.org
Web: www.hydroassoc.org

The Hydrocephalus Association publishes a number of resources about hydrocephalus, the fluid buildup in the brain due to an obstruction of spinal fluid in the ventricles. The association has a parent-to-parent network and provides informational resources on their website.

NATIONAL APHASIA ASSOCIATION

7 Dey Street, Suite 600
New York, NY 10007
Phone: (800) 922-4622
Fax: (212) 989-7777
E-mail: naa@aphasia.org
Web: www.aphasia.org

The National Aphasia Association promotes public education, research, rehabilitation and support services to assist people with aphasia and their families. They publish "The Aphasia Handbook," a guidebook for those living with aphasia, and their website provides listings of community groups and state resources, additional online resources, listings of therapists and updates in research.

NATIONAL BRAIN TUMOR FOUNDATION

22 Battery Street, Suite 612
San Francisco, CA 94111-5520
Phone: (800) 934-2873
(415) 834-9970
Fax: (415) 834-9980
E-mail: nbtf@braintumor.org
Web: www.braintumor.org

The National Brain Tumor Foundation (NBTF) is a non-profit organization that funds research and provides information and support to patients, family members and health professionals. Since 1983, NBTF has awarded over \$4 million in grant funding for research projects. NBTF also provides patient programs, support and information.

NATIONAL HYDROCEPHALUS FOUNDATION

12413 Centralia Road
Lakewood, CA 90715-1653
Phone: (888) 857-3434
(562) 924-6666

E-mail: hydrobrat@earthlink.net
Web: www.nhfonline.org

The National Hydrocephalus Foundation focuses on hydrocephalus issues related to education, support, and advocacy.

NATIONAL INSTITUTE OF NEUROLOGICAL DISORDERS AND STROKE

Brain Resources and Information Network
NIH Neurological Institute
P.O. Box 5801
Bethesda, MD 20824
Phone: (800) 352-9424
(301) 496-5751
Web: www.ninds.nih.gov

The National Institute of Neurological Disorders and Stroke provides information regarding biomedical research on disorders of the brain and nervous system.

NATIONAL TUBEROUS SCLEROSIS ALLIANCE

801 Roeder Road, Suite 750
Silver Spring, MD 20910
Phone: (800) 225-6872
(301) 562-9890
Fax: (301) 562-9870
E-mail: info@tsalliance.org
Web: www.tsalliance.org

The National Tuberos Sclerosis Association provides literature and educational materials to patients and families. It has multiple active support groups in the United States. TS is a genetic disease characterized by mental deficiency and multiple tumors of the skin and brain.

THE NEUROBLASTOMA CHILDREN'S CANCER SOCIETY

P.O. Box 957672
Hoffman Estates, IL 60195-7672
Phone: (800) 532-5162
(847) 605-1245

Fax: (847) 605-0705
E-mail: info@neuroblastomacancer.org
Web: www.neuroblastomacancer.org

The Neuroblastoma Children's Cancer Society is a non-profit organization of volunteers dedicated to supporting and advocating for children with neuroblastoma and their families. It also raises money for neuroblastoma research.

NEUROFIBROMATOSIS, INC.

P.O. Box 18246
Minneapolis, MN 55418
Phone: (800) 942-6825
(301) 918-4600
Fax: (301) 918-0009
Web: www.nfinc.org

Neurofibromatosis, Inc. is a non-profit organization that provides patients and families information on the disease, referrals to physicians, service providers, and peer counseling. It also serves professionals, and promotes and supports research in neurofibromatosis and related conditions. Some publications are also available in Spanish.

1

PEDIATRIC BRAIN TUMOR FOUNDATION OF THE UNITED STATES

302 Ridgefield Court
Asheville, NC 28806

Phone: (800) 253-6530
(828) 665-6891

Fax: (828) 665-6894

E-mail: pbtfus@pbtfus.org

Web: www.pbtfus.org

The Pediatric Brain Tumor Foundation of the United States is an organization devoted to raising funds for pediatric brain tumor research. It also helps educate the public about brain tumors in children, and can provide additional information on caregiving resources for parents.

PITUITARY NETWORK ASSOCIATION

P.O. Box 1958
Thousand Oaks, CA 91358

Phone: (805) 499-9973

Fax: (805) 480-0633

E-mail: pna@pituitary.org

Web: www.pituitary.org

The Pituitary Network provides information on pituitary adenomas and related conditions such as acromegaly (gigantism). PNA publishes *The Pituitary Patient Resource Guide*, helps establish support groups for patients and their families, and acts as a patient liaison to the medical community.

THE PSEUDOTUMOR CEREBRI SUPPORT NETWORK

E-mail: ptcduncan@juno.com

Web: www.pseudotumorcerebri.com

The Pseudotumor Cerebri Support Network provides support and information on the disorder and sponsors research. Pseudotumor cerebri, or idiopathic intracranial hypertension, is a neurological

syndrome of increased intracranial pressure that causes headaches and vision loss, yet CT and MRI scans appear normal.

TRIGEMINAL NEURALGIA ASSOCIATION

925 Northwest 56th Terrace, Suite C
Gainesville, FL 32605-6402

Phone: (800) 923-3608
(352) 331-7009

Fax: (352) 331-7078

E-mail: [tnанational@tna-support.org](mailto:tнанational@tna-support.org)

Web: www.tna-support.org

The Trigeminal Neuralgia Association is an information and referral service for patients suffering with this type of facial nerve damage. Also known as Tic Douloureux, this disorder can be common after treatment for Acoustic Neuroma.

VON HIPPEL-LINDAU FAMILY ALLIANCE

2001 Beacon Street, Suite 208
Boston, MA 02135-7787

Phone: (800) 767-4845
(617) 277-5667

Fax: (858) 712-8712

E-mail: info@vhl.org

Web: www.vhl.org

The VHL Family Alliance provides information for families and physicians about this disorder, as well as local self-help support groups for families affected with VHL. Local family support chapters exist across the U.S., and meetings are scheduled periodically. International VHL Support Organizations are established on five continents.



Section 2

Cancer Organizations

NATIONAL CANCER ORGANIZATIONS

AMERICAN BONE MARROW DONOR REGISTRY

P.O. Box 8841
Mandeville, LA 70470-8841

Phone: (800) 745-2452
(985) 626-1749

Fax: (985) 626-7414

E-mail: jakabmdr@bellsouth.net

Web: www.abmdr.org

The American Bone Marrow Donor Registry maintains a list of bone marrow donors and provides information on donor searches and recruitment.

AMERICAN CANCER SOCIETY

1599 Clifton Road NE
Atlanta, GA 30329-4251

Phone: (800) 227-2345

TTY: (866) 228-4327

Web: www.cancer.org

The American Cancer Society (ACS) offers multiple programs, including information and guidance on cancer and its treatments, education for patients and their families, summer camps for children with cancer, and transportation services. Other programs include information and advocacy for people with cancer who

experience job discrimination, rehabilitation programs, home medical equipment rentals, and other specialized services. The ACS also funds cancer research programs. Many of their services and publications are available in Spanish.

AMERICAN SOCIETY OF CLINICAL ONCOLOGY

Phone: (703) 797-1914

Fax: (703) 299-1044

E-mail: asco@asco.org

Web: www.plwc.org

The American Society of Clinical Oncology (ASCO) is a major professional organization representing physicians who treat people with cancer. They have created a website for cancer patients called People Living With Cancer.

2

BLOOD AND MARROW TRANSPLANT INFORMATION NETWORK

2310 Skokie Valley Road, Suite 104
Highland Park, IL 60035
Phone: (888) 597-7674
(847) 433-3313
Fax: (847) 433-4599
E-mail: help@bmtinfonet.org
Web: www.bmtinfonet.org

The Blood and Marrow Transplant Network publishes a quarterly newsletter, *Blood & Marrow Transplant*, for marrow peripheral stem cell and cord blood transplant patients. They also publish eight easy-to-read books, each dealing with undergoing and surviving a transplant. A directory of transplant centers that includes information on types and number of transplants performed and diseases treated, a resource directory, an attorney list to help resolve insurance problems, and a patient-to-survivor telephone link are also available.

CANCER CARE, INC.

275 7th Avenue, 2nd Floor
New York, NY 10001
Phone: (800) 813-4673
(212) 712-8400
Fax: (212) 719-8495
E-mail: info@cancercare.org
Web: www.cancercare.org

Cancer Care, Inc. services include psychological counseling for cancer patients and their families, financial assistance for services such as homemakers, home health aides, housekeepers, transportation for medical appointments and bereavement counseling. Information is also available on other cancer resources in the community. CCI organizes teleconferences that allow patients to discuss specific topics with a national network of brain tumor patients, family members, and health professionals. Additional services are provided for residents in the New York, New

Jersey and Connecticut areas. Support is also available in Spanish.

CANCER FUND OF AMERICA

2901 Breezewood Lane
Knoxville, TN 37921-1099
Phone: (800) 578-5284
(865) 938-5281
Fax: (865) 938-2968
E-mail: info@cfoa.org
Web: www.cfoa.org

The Cancer Fund of America exists to provide supplies to medically indigent cancer patients anywhere in the country, whether or not they already receive public support. It is funded strictly by donations and ships items such as bed pads, diapers and nutritional supplements free of charge to patients. Physician must certify diagnosis and financial need.

CANCER HOPE NETWORK

2 North Road, Suite A
Chester, NJ 07930
Phone: (877) 467-3638
Fax: (908) 879-6518
E-mail: info@cancerhopenetwork.org
Web: www.cancerhopenetwork.org

The Cancer Hope Network is a telephone support network for chemotherapy and/or radiation patients. It has a newsletter that focuses on peer counseling and advocacy.

CANCERSOURCE.COM

280 Summer Street, 9th Floor
Boston, MA 02210-1506
Phone: (617) 399-4483
E-mail: info@cancersource.com
Web: www.cancersource.com

CancerSource.com offers interactive tools and community resources to broaden patients' knowledge and support network. Their website also has a section on alternative health approaches.

CANCERVIVE

11636 Chayote Street
Los Angeles, CA 90049
Phone: (800) 486-2873
(310) 203-9232
Fax: (310) 471-4618
E-mail: cancervivr@aol.com
Web: www.cancervive.org

Cancervive is a non-profit organization that helps cancer survivors deal with the challenges of “life after cancer.” It offers support groups in some states, insurance information and assistance, and patient advocacy. They have also published a coloring book (kids age 3-6), a story/activity book (age 7-11), and a guide for teachers of children with cancer.

THE CANDLELIGHTERS CHILDHOOD CANCER FOUNDATION

P.O. Box 498
Kensington, MD 20895-0498
Phone: (800) 366-2223
(301) 962-3520
Fax: (301) 962-3521
E-mail: staff@candlelighters.org
Web: www.candlelighters.org

The Candlelighters Childhood Cancer Foundation is an informational clearing-house for parents of children with cancer. A quarterly newsletter is published for adults and young people. Services include an Ombudsman program to assist adults who had cancer as a child and are experiencing difficulties with insurance coverage or employment problems. They also offer a reduced-cost prescription drug service. The Foundation has multiple active support groups around the United States and in 30 countries.

CORD BLOOD REGISTRY

1200 Bayhill Drive, Suite 301
San Bruno, CA 94066
Phone: (888) 932-6568
(650) 635-1420
Fax: (800) 844-2202
E-mail: general_questions@cordblood.com
Web: www.cordblood.com

Cord Blood Registry is one of the largest private cord blood banks in the world. It offers parents the opportunity to cryogenically store their newborn’s cord blood in case of future medical need. CBR is committed to education about cord blood and publishes a quarterly newsletter.

CURE SEARCH

4600 East West Highway, Suite 600
Bethesda, MD 20814
Phone: (800) 458-6223
(626) 447-1674
Fax: (626) 447-6359
E-mail: info@curesearch.org
Web: www.curesearch.org

Cure Search is dedicated to the eradication of all childhood cancers through research, treatment, education and advocacy. Its “Children’s Cancer Group” is a network of over 2,800 pediatric cancer specialists that serves to promote cooperation between pediatric medical institutions in the U.S., Canada and Australia. This organization publishes a newsletter called *Heartline*.



LANCE ARMSTRONG FOUNDATION

P.O. Box 161150
Austin, TX 78716-1150
Phone: (512) 236-8820
Fax: (512) 236-8482
Web: www.livestrong.org

The Lance Armstrong Foundation (LAF) exists to enhance the quality of life for those living with, through, and beyond cancer. It hopes to continue to define, refine, and improve cancer survivor services and facilitate the delivery of those services—and a large dose of hope—to the patients, their families, and other loved ones touched by the disease.

LEUKEMIA AND LYMPHOMA SOCIETY OF AMERICA

1311 Mamaroneck Avenue
White Plains, NY 10605
Phone: (800) 955-4572
(914) 949-5213
Fax: (914) 949-6691
Web: www.leukemia.org

This group supports research and provides printed materials on leukemia, lymphoma, myeloma, and Hodgkin's disease. It has information about other resources, as well as a financial assistance program.

LYMPHOMA RESEARCH FOUNDATION

Los Angeles office:
8800 Venice Boulevard, Suite 207
Los Angeles, CA 90034
Phone: (800) 500-9976
(310) 204-7040
Fax: (310) 204-7043

New York office:
111 Broadway, 19th floor
New York, NY 10006
Phone: (800) 235-6848
(212) 349-2910
Fax: (212) 349-2886

E-mail: helpline@lymphoma.org
Web: www.lymphoma.org

This non-profit organization offers assistance to lymphoma patients and family members. Services include support groups, treatment updates, health information and patient advocacy.

NATIONAL BONE MARROW TRANSPLANT LINK

20411 West 12 Mile Road, Suite 108
Southfield, MI 48076
Phone: (800) 546-5268
(248) 358-1886
Fax: (248) 358-1886
E-mail: info@nbmtlink.org
Web: www.nbmtlink.org

The NBMT Link is a non-profit organization specifically serving bone marrow transplant (BMT) patients and families. The NBMT Link works cooperatively with cancer centers, hospitals, health organizations, and other important resources that address the concerns of BMT patients.

NATIONAL CANCER INSTITUTE

6116 Executive Boulevard, Room 3036A
Bethesda, MD 20892-8322
Phone: (800) 422-6237
TDD: (800) 332-8615
Web: www.cancer.gov

NCI offers a national telephone service to provide accurate, up-to-date information to health professionals and the general public. The same information is also available on the website. NCI provides information on prevention, early detection and treatment of cancer, and information on support groups and local community groups. There is also a section dedicated to clinical trials. A questionnaire is available to determine your interest in participating in these trials. Support is also available in Spanish.

NATIONAL CHILDREN'S CANCER SOCIETY

1015 Locust Street, Suite 600
St. Louis, MO 63101
Phone: (800) 532-6459
(314) 241-1600
Fax: (314) 241-1996
E-mail: pfs@children-cancer.org
Web: www.nationalchildrenscancer.org

The National Children's Cancer Society provides financial assistance for children diagnosed before the age of 18 and in need of a bone marrow transplant. Assistance is provided for, but not limited to, donor search, transplant procedure, lost parental income, and living expenses. NCCS will assist in fundraising upon request. It also provides fundraising information and patient advocacy services.

NATIONAL COALITION FOR CANCER SURVIVORSHIP

1010 Wayne Avenue, Suite 770
Silver Spring, MD 20910
Phone: (877) 622-7937
(301) 650-9127
Fax: (301) 565-9670
E-mail: info@canceradvocacy.org
Web: www.canceradvocacy.org

The National Coalition for Cancer Survivorship specializes in patient advocacy and assistance with regard to employment issues, job discrimination and insurance concerns. It provides assistance to cancer survivors in locating cancer services and support organizations. NCCS also publishes booklets on topics such as health insurance for cancer survivors, how to talk with your doctor, and employment rights, and has a bibliography of the "Best-Loved Books" of cancer survivors. NCCS provides a quarterly newsletter, *The Networker*.

NATIONAL MARROW DONOR PROGRAM

3100 Broadway Street NE, Suite 500
Minneapolis, MN 55413-1753
Phone: (888) 999-6743 –
Office of Patient Advocacy
Phone: (800) 627-7692
Web: www.marrows.org

This group maintains a registry of bone marrow donors. It provides information on becoming a donor or organizing recruitment drives and provides a patient advocacy program.

NATIONAL ORGANIZATION FOR RARE DISORDERS

55 Kenosia Avenue
P.O. Box 1968
Danbury, CT 06813-1968
Phone: (800) 999-6673
(203) 744-0100
Fax: (203) 798-2291
E-mail: orphan@rarediseases.org
Web: www.rarediseases.org

Since its inception in 1983, the National Organization for Rare Disorders has served as the primary non-governmental agency for those seeking information on over 5,000 rare diseases. There is information on a number of brain tumor types in NORD's library of materials. Reports are \$7.50 each. Patients and families who become members (\$30 per year) have access to a networking program.

ONCOLINK

Web: www.oncolink.com

Oncolink provides cancer information and support. It includes articles, clinical trial lists, PDQ documents, **CANCERNET** publications, and resources.



THE REGIONAL CANCER FOUNDATION

1200 Gough Street, Suite 500
San Francisco, CA 94109
Phone: (415) 775-9956
Fax: (415) 346-8652
E-mail: mail@regionalcancerfoundation.org
Web: www.regionalcancerfoundation.org

The Regional Cancer Foundation offers a second opinion consultation at no charge to individuals diagnosed with cancer. The patient and support team may meet with an interdisciplinary panel of local cancer specialists with expertise in radiation therapy, chemotherapy, surgery, radiology, and pathology.

THE WELLNESS COMMUNITY

919 18th Street NW, Suite 54
Washington, D.C. 20006
Phone: (888) 793-9355
(202) 659-9709
Fax: (202) 659-9301
E-mail: help@thewellnesscommunity.org
Web: www.wellness-community.org

The Wellness Community is designed to assist people in their recovery from cancer through education and support across the country. Its staff helps teach stress management, nutrition, pain control, relaxation and other techniques through many workshops. WC also offers grief counseling.

MINORITY CANCER ORGANIZATIONS

ASIAN & PACIFIC ISLANDER AMERICAN HEALTH FORUM

450 Sutter Street, Suite 600
San Francisco, CA 94108
Phone: (415) 954-9988
Fax: (415) 954-9999
E-mail: healthinfo@apiahf.org
Web: www.apiahf.org

The mission of APIAHF is to enable Asian Americans and Pacific Islanders to attain

the highest possible level of health and well-being. They advocate on health issues and have a cancer survivors' network that provides members the opportunity to connect with experts and other survivors.

CANCER AND CAREERS.ORG

Web: www.cancerandcareers.org

This online resource exists to help women, their employers, coworkers and caregivers deal with their cancer diagnosis in the same way that they have learned to deal with problems at work—strategically, knowledgeably, and effectively. With the right tools—articles, news, charts, checklists, tips and a community of experts, patients, and survivors—many women can continue to work through treatment.

INTERCULTURAL CANCER COUNCIL

6655 Travis, Suite 322
Houston, TX 77030-1312
Phone: (713) 798-4617
Fax: (713) 798-6222
E-mail: info@iccnetwork.org
Web: www.iccnetwork.org

The Intercultural Cancer Council promotes policies, programs, partnerships and research to eliminate the unequal burden of cancer among racial and ethnic minorities and medically underserved populations in the United States and its associated territories.

MAUTNER PROJECT

1707 L Street NW, Suite 230
Washington, D.C. 20036
Phone: (866) 628-8637
(202) 332-5536
Fax: (202) 332-0662
E-mail: mautner@mautnerproject.org
Web: www.mautnerproject.org

This organization offers direct services to lesbians with cancer, their partners

and caregivers. Support is also available in Spanish.

NATIONAL BLACK LEADERSHIP INITIATIVE ON CANCER

311 SP HW m/c 922
2121 West Taylor Street, Room 512
Chicago, IL 60612
Phone: (312) 996-8046
Fax: (312) 996-0064
E-mail: bird@uic.edu
Web: www.uic.edu/UI-Service/programs/UIC168.html

The National Black Leadership Initiative on Cancer (NBLIC) is an outreach initiative of the National Cancer Institute. NBLIC has four regional offices throughout the country whose aims are to make information about cancer incidence, treatment and prevention available to the African American community.

NATIVE AMERICAN CANCER RESEARCH

3022 South Nova Road
Pine, CO 80740-7830
Phone: (303) 838-9359
Fax: (303) 838-7629
E-mail: contact05@natamcancer.org
Web: www.natamcancer.org

Native American Cancer Research is a community-based American Indian non-profit resource. Their mission is to reduce cancer incidence and mortality in Native Americans. They provide resources for patients, survivors, and caregivers through their website, a support network, a newsletter, and a listing of cancer-related events.

YOUNG ADULT CANCER ORGANIZATIONS

BEYOND THE CURE

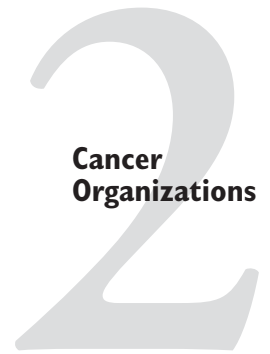
1015 Locust, Suite 600
St. Louis, MO 63101
Phone: (800) 532-6459
(314) 241-1600
Fax: (314) 241-1996
E-mail: survivorship@children-cancer.org
Web: www.beyondthecure.org

Beyond the Cure was created by the National Children's Cancer Society. Its mission is to help children who have survived cancer to celebrate their survivorship and integrate their cancer experience into their new lives.

CANCERVIVE

11636 Chayote Street
Los Angeles, CA 90049
Phone: (800) 486-2873
(310) 203-9232
Fax: (310) 471-4618
E-mail: cancervivr@aol.com
Web: www.cancervive.org

Cancervive is a non-profit organization that helps cancer survivors deal with the challenges of "life after cancer." They offer support groups in some states, insurance information and assistance, and patient advocacy. They have also published a coloring book (kids age 3-6), a story/activity book (age 7-11), and a guide for teachers of children with cancer.



SIGA ADELANTE: LA VIDA DESPUES DEL TRATAMIENTO DEL CANCER is a Spanish language version of Life After Cancer Treatments that highlights issues relevant to Latino survivors. This is available on the web at: www.cancer.gov/espanol/vida-despues-del-tratamiento.

2

GROUP LOOP

The Wellness Community
National Office
Attention: Grouploop
919 18th Street NW, Suite 54
Washington, D.C. 20006
Phone: (888) 793-9355
(202) 659-9709
Fax: (202) 659-9301
E-mail: help@thewellnesscommunity.org
Web: www.grouploop.org

Group Loop is focused on teens with cancer and their parents. It allows teens with cancer to connect with other teens in the same situation. Group Loop also offers support and information for both teens and their parents.

THE LIFELAB

295 Lafayette Street, Suite 501
New York, NY 10012
Phone: (212) 920-3672
Fax: (212) 226-5619
E-mail: info@nylifelab.org
Web: www.nylifelab.org

The NY Lifelab (the “Lifelab”) is a non-profit corporation dedicated to helping young adult cancer survivors rebuild their lives after treatment. It is a support community that provides unique programs, mentors, networking and peer support free of charge to young adult survivors in New York City. Its goal is to help members discover what they would like to do with their lives after cancer, and offer them tools to get there.

OUTLOOK

Phone: (608) 263-6200
Fax: (608) 265-9721
E-mail: jaamond@wisc.edu
Web: www.outlook-life.org

The Outlook website provides information to survivors of childhood cancer and their families to build a bridge of support between current patients and survivors. The University of Wisconsin’s Comprehensive Cancer Center, Children’s Hospital Division of Pediatric Hematology/Oncology and the Medical School’s Biomedical Computing Group worked together to create this web-based information system.

PLANET CANCER

3710 Cedar Street, Box 11
Austin, TX 78705
E-mail: contactus@planetcancer.org
Web: www.planetcancer.org

Planet Cancer is non-profit organization that caters to young adults with cancer. Their website is an online community that allows young adults with cancer to receive and give support and connect with their peers. Planet Cancer provides support and information that helps young adults deal with issues such as dating with cancer, choosing to leave school and loss of fertility.

SURVIVING AND MOVING FORWARD: THE SAMFUND

P.O. Box 35705
Brighton, MA 02135
E-mail: info@thesamfund.org
Web: www.thesamfund.org

The SAMFund is a unique non-profit organization created to assist young adult survivors of cancer with a successful transition into their post-treatment life through the distribution of grants and scholarships.

TIM & TOM GULLIKSON FOUNDATION

8000 Sears Tower
Chicago, IL 60606
Phone: (888) 485-5457
E-mail: info@gulliksonfoundation.org
Web: www.gulliksonfoundation.org

The Tim & Tom Gullikson Foundation assists brain tumor patients and their families in managing the physical, emotional, financial and social challenges presented by the illness. College scholarships for post-high school education are available to brain tumor patients/survivors and/or the children of brain tumor patients/survivors. The program includes accredited four-year colleges, universities, two-year colleges, vocational-technical schools or other institutions of higher learning.

THE ULMAN CANCER FUND FOR YOUNG ADULTS

PMB #505
4725 Dorsey Hall Drive, Suite A
Ellicott City, MD 21042
Phone: (888) 393-3863
(410) 964-0202
E-mail: info@ulmanfund.org
Web: www.ulmanfund.org

The Ulman Cancer Fund is an organization that seeks to provide support programs, education and resources to benefit young adults, their families and friends who are affected by cancer, and to promote awareness and prevention of cancer.

VITAL OPTIONS

4419 Coldwater Canyon Avenue, Suite 1
Studio City, CA 91604-1479
Phone: (800) 477-7666
(818) 508-5657
Fax: (818) 788-5260
E-mail: info@vitaloptions.org
Web: www.vitaloptions.org

Vital Options: Support For Young Adults With Cancer was originally founded in 1983 as the first organization for young adults with cancer. In addition to serving as a resource for this special patient population, Vital Options now provides a variety of cancer communications projects for patients of all ages and disease types, as well as for their families, friends and healthcare providers. In particular, they provide The Group Room[®] radio show, a weekly syndicated cancer talk show that is also simulcast on the web and XM Satellite Radio.

YOUNG ADULTS SURVIVING GLIOBLASTOMA

Web: www.yasg.com

The Young Adults Surviving Glioblastoma website was created to inspire young adults (and beyond) who are diagnosed with this disease. It features biographies, information about different treatments, e-mail addresses of survivors, a message board and live chat.

Specific Support Resources

Caregiver Support Organizations

National Brain Injury Associations

Elderly Healthcare Organizations

Minority Healthcare Organizations

Hospice and Homecare Organizations

Hospitality Organizations

Home Improvement Organizations

Section 3

Specific Support Resources

CAREGIVER SUPPORT ORGANIZATIONS

AMERICAN CANCER SOCIETY

1599 Clifton Road NE
Atlanta, GA 30329
Phone: (800) 227-2345
Web: www.cancer.org

In addition to other services (see NBTF Directory Section 2 – Cancer Organizations and Resources), the American Cancer Society has a booklet entitled *Caring for the Patient with Cancer At Home: A Guide for Patients and Families*.

CAREGIVER.COM

Phone: (800) 829-2734
(954) 893-0550
Fax: (954) 893-1779
E-mail: info@caregiver.com
Web: www.caregiver.com

Caregiver.com is an online resource for caregivers that provides topic-specific newsletters, online discussion lists, back issue articles of *Today's Caregiver* magazine, chat rooms and an online store.

DRUG INFONET

5760 Commons Park Drive
East Syracuse, NY 13057
Phone: (315) 671-0801
Fax: (201) 313-3377
Web: www.druginfonet.com

Drug Infonet provides information on many drugs (searchable by brand or generic name), and has links to medical schools and libraries, disease information, healthcare news, etc.

FAMILY CAREGIVER ALLIANCE

180 Montgomery Street, Suite 1100
San Francisco, CA 94104
Phone: (800) 445-8106
(415) 434-3388
Fax: (415) 434-3508
E-mail: info@caregiver.org
Web: www.caregiver.org

The Family Caregiver Alliance is an information clearinghouse for caregiver resources, respite care, and professional referrals throughout California. It publishes educational materials and medical updates by specific illness, and offers workshops and training seminars on all aspects of caregiving. There are 15 chapters throughout the state of California.

**THE HEALING EXCHANGE
BRAIN TRUST**

186 Hampshire Street
Cambridge, MA 02139
Phone: (617) 876-2002
Fax: (617) 876-2332
E-mail: info@braintrust.org
Web: www.braintrust.org

The Healing Exchange Brain Trust runs a number of online support groups, including the BRAINTMR Mailing list. Their bulletin board is a place for people to share their experiences with brain tumors. Participants include brain tumor patients, family members, neurosurgeons, nurses, social workers and other health-care professionals.

**NATIONAL BRAIN TUMOR
FOUNDATION**

22 Battery Street, Suite 612
San Francisco, CA 94111
Phone: (800) 934-2873
(415) 834-9970
Fax: (415) 834-9980
E-mail: nbtbf@braintumor.org
Web: www.braintumor.org

The National Brain Tumor Foundation (NBTF) is a non-profit organization that funds research and provides information and support to patients, family members and health professionals. Since 1983, NBTF has awarded over \$4 million in grant funding for research projects. NBTF also provides patient programs, support and information.

**NATIONAL FAMILY CAREGIVERS
ASSOCIATION**

10400 Connecticut Avenue, Suite 500
Kensington, MD 20895-3944
Phone: (800) 896-3650
(301) 942-6430
Fax: (301) 942-2302
E-mail: info@thefamilycaregiver.org
Web: www.thefamilycaregiver.org

The National Family Caregivers Association provides information and support for caregivers, including educational materials, a resource guide, respite care and a person-to-person network for emotional support. It publishes a quarterly newsletter called *Take Care*. Support is also available in Spanish.

**SPOUSES OF BRAIN TUMOR
PATIENTS**

Web: www.bradsupdates.com/care

A website that features message boards, a chat room and bios for spouses of brain tumor patients. Spouses of Brain Tumor Patients was created out of a need for people to have a place to come and vent free from judgment, to find support, and to be able to connect with others who understand the emotions and frustrations that they are going through.

WELLSPOUSE ASSOCIATION

63 West Main Street, Suite H
Freehold, NJ 07728
Phone: (800) 838-0879
(732) 577-8899
Fax: (732) 577-8644
E-mail: info@wellspouse.org
Web: www.wellspouse.org

The Wellspouse Association is a non-profit national self-help organization serving the “well spouse” of the chronically ill. Members help each other develop coping and survival skills through local support groups (including bereavement), letter and telephone networks, and personal outreach. The foundation publishes a bimonthly newsletter called *Mainstay* and holds West and East Coast regional conferences for spouses.

3

NATIONAL BRAIN INJURY ASSOCIATIONS

Alabama

Phone: (205) 823-3818

Alaska

Phone: (800) 444-6443

Arizona

Phone: (602) 323-9165
(888) 500-9165

Arkansas

Phone: (800) 235-2443
(501) 374-3585

California

Phone: (888) 824-6724

Colorado

Phone: (800) 955-2443
(303) 355-9969

Connecticut

Phone: (800) 278-8242
(860) 721-8111

Delaware

Phone: (800) 411-0505
(302) 537-5770

Florida

Phone: (800) 992-3442
(954) 786-2400

Georgia

Phone: (678) 937-1555

Hawaii

Phone: (808) 454-0699

Idaho

Phone: (888) 374-3447
(208) 342-0999

Illinois

Phone: (800) 699-6443
(312) 726-5699

Indiana

Phone: (866) 854-4246
(317) 356-7722

Iowa

Phone: (800) 475-4442
(319) 272-2312

Kansas

Phone: (800) 783-1356
(816) 842-8607

Kentucky

Phone: (800) 592-1117 ext 223
(502) 493-0609

Louisiana

Phone: (504) 619-9989
(800) 444-6443

Maine

Phone: (800) 275-1233
(207) 861-9900

Maryland

Phone: (800) 221-6443
(410) 448-2924

Massachusetts

Phone: (800) 242-0030
(508) 475-0032

Michigan

Phone: (800) 772-4323
(810) 229-5880

Minnesota

Phone: (800) 669-6442
(612) 378-2742

Mississippi

Phone: (800) 641-6442
(601) 981-1021

Missouri

Phone: (800) 377-6442
(314) 426-4024

Montana

Phone: (800) 241-6442
(406) 541-6442

Nebraska

Phone: (800) 444-6443

Nevada

Phone: (800) 444-6443

New Hampshire

Phone: (800) 773-8400
(603) 225-8400

New Jersey

Phone: (800) 669-4323
(732) 738-1002

New Mexico

Phone: (888) 292-7415
(505) 292-7414

New York

Phone: (800) 228-8201
(518) 459-7911

North Carolina

Phone: (800) 377-1464
(919) 833-9634

North Dakota

Phone: (800) 444-6443
(701) 845-1124

Ohio

Phone: (866) 644-6242
(614) 481-7100

Oklahoma

Phone: (580) 233-4363

Oregon

Phone: (800) 544-5243
(503) 413-7707

Pennsylvania

Phone: (866) 635-7097
(717) 657-3601

Rhode Island

Phone: (888) 824-8911
(401) 461-6599

South Carolina

Phone: (800) 290-6461
(803) 731-0588

South Dakota

Phone: (800) 444-6443
(605) 472-0521

Tennessee

Phone: (877) 757-2428
(615) 248-2541

Texas

Phone: (800) 392-0040
(512) 326-1212

Utah

Phone: (800) 281-8442
(801) 484-2240

Vermont

Phone: (802) 985-8440
(877) 856-1772

Virginia

Phone: (800) 334-8443
(804) 355-5748

Washington

Phone: (800) 523-5438
(425) 895-0047

West Virginia

Phone: (800) 356-6443
(304) 766-4892

Wisconsin

Phone: (800) 882-9282
(262) 790-9660

ELDERLY HEALTH CARE ORGANIZATIONS

BENEFITS CHECKUP

300 D Street SW, Suite 801
Washington, D.C. 20024
Phone: (202) 479-1200
Fax: (202) 479-0735
E-mail: info@ncoa.org
Web: www.benefitscheckup.org

This is a service of the National Council on Aging and helps locate programs for seniors that may pay for some of their costs of prescription drugs, health care, utilities and other essential items or services.

ELDERCARE LOCATOR

Phone: (800) 677-1116
Fax: (202) 296-8134
Web: www.eldercare.gov

The Eldercare Locator can put you in touch with state and local information that enables older persons to find help to remain independent in their homes. The staff locates a wide variety of services such as meals, home care, transportation, housing alternatives, home repair, recreation, social activities, legal and other community services. Spanish-speaking services are also available.

NATIONAL ASSOCIATION OF STATE UNITS ON AGING

1201 15th Street NW, Suite 350
Washington, D.C. 20005
Phone: (202) 898-2578
Fax: (202) 898-2583
E-mail: info@nasua.org
Web: www.nasua.org

The National Association of State Units on Aging (NASUA) provides many services for adults, including health insurance, counseling and advocacy, in-home personal care, nutrition and volunteer programs, adult day health care, cooking and shopping, foster grandparents and senior companion programs. In addition, it provides a program that trains elderly people for possible reentry into the work force. The organization also advocates for those in nursing homes and boarding care. Call to obtain your local listing.

MINORITY HEALTHCARE ORGANIZATIONS

African-American Healthcare Organizations

MINORITY HEALTH PROFESSIONS FOUNDATION

100 Edgewood Avenue, Suite 1020
Atlanta, GA 30303
Phone: (678) 904-4217
Fax: (678) 904-4518
E-mail: mail@minorityhealth.org
Web: www.minorityhealth.org

THE MEDICARE RIGHTS CENTER (MRC) is a national, non-profit organization that helps ensure that older adults and people with disabilities receive affordable health care. The center has an education department and they are actively engaged in policy/advocacy for Medicare reform. Contact them at (212) 869-3850 or www.medicarerights.org.



**NATIONAL ASSOCIATION OF
BLACK SOCIAL WORKERS**

2305 Martin Luther King Avenue SE
Washington, D.C. 20020
Phone: (202) 678-4570
Fax: (202) 678-4572
E-mail: nabsw.harambee@verizon.net
Web: www.nabsw.org

**NATIONAL BLACK NURSES
ASSOCIATION, INC.**

8630 Fenton Street, Suite 330
Silver Spring, MD 20910-3803
Phone: (800) 575-6298
(301) 589-3200
Fax: (301) 589-3223
E-mail: nbna@erols.com
Web: www.nbna.org

**BLACK WOMEN'S
HEALTH IMPERATIVE**

1420 K Street NW, Suite 1000
Washington, D.C. 20005
Phone: (202) 548-4000
Fax: (202) 543-9743
E-mail: nbwhp@nbwhp.org
Web: www.blackwomenshealth.org

**Asian & Pacific Islander Healthcare
Organizations**

**ASIAN AND PACIFIC ISLANDER
AMERICAN HEALTH FORUM**

Main Office:

450 Sutter Street, Suite 600
San Francisco, CA 94108
Phone: (415) 954-9988
Fax: (415) 954-9999

Washington, D.C. Office:

1001 Connecticut Avenue NW, Suite 530
Washington, D.C. 20036
Phone: (202) 466-7772
Fax: (202) 466-6444
E-mail: healthinfo@apiahf.org
Web: www.apiahf.org

ASIAN HEALTH SERVICES

818 Webster Street
Oakland, CA 94607
Phone: (510) 986-6830
Fax: (510) 986-6890
Web: www.ahschc.org

**Native American Healthcare
Organizations**

**ADMINISTRATION FOR NATIVE
AMERICANS**

8th Floor, West Aerospace Center
370 L'Enfant Promenade
Washington, D.C. 20447
Phone: (877) 922-9262
Web: www.acf.dhhs.gov/programs/ana

**A GATHERING OF
CANCER SUPPORT**

P.O. Box 83
Santo Domingo Pueblo, NM 87052
Phone: (505) 465-0325
Fax: (505) 465-2688

**Hispanic and Latino Healthcare
Organizations**

**NATIONAL ALLIANCE FOR
HISPANIC HEALTH**

1501 16th Street NW
Washington, D.C. 20036
Phone: (202) 387-5000
E-mail: alliance@hispanichealth.org
Web: www.hispanichealth.org

**NATIONAL ASSOCIATION OF
HISPANIC NURSES**

1501 16th Street NW
Washington, D.C. 20036
Phone: (202) 387-2477
Fax: (202) 483-7183
Web: www.thehispanicnurses.org

HOSPICE AND HOMECARE ORGANIZATIONS

BRAIN HOSPICE

E-mail: brainhospice@earthlink.net
 Web: www.brainhospice.com

Brain Hospice is a support website for caregivers of brain tumor patients who are considering hospice and need information on what to expect, questions to ask and things to consider. The site also has a guest book and stories from other caregivers of brain tumor patients.

CHILDREN'S HOSPICE INTERNATIONAL

901 King Street, Suite 360
 Alexandria, VA 22314

Phone: (800) 242-4453
 (703) 684-0330

Fax: (703) 684-0226

E-mail: info@chionline.org
 Web: www.chionline.org

Children's Hospice International is a non-profit organization that works to improve hospice care for children. Services include an information and referral service for childcare, counseling, support groups, pain management, professional education, and research. This is a membership group, with a membership fee for other services.

GEORGE MARK CHILDREN'S HOUSE

2121 George Mark Lane
 San Leandro, CA 94578

Phone: (866) 897-4624
 (510) 346-4624

Fax: (510) 346-4620

E-mail: info@georgemark.org
 Web: www.georgemark.org

George Mark Children's House is the first freestanding children's respite and end-of-life care facility in the United States. The

House, located in San Leandro, California, offers respite support (round-the-clock), transitional care, and end-of-life care for children with life-limiting or terminal illnesses. All care is informed by the principles of palliative care. Additional support services are available to all family members. Services are provided regardless of a family's ability to pay.

HOSPICE FOUNDATION OF AMERICA

2001 S. Street NW, Suite 300
 Washington, D.C. 20009

Phone: (800) 854-3402
 (202) 638-5419

Fax: (202) 638-5312

E-mail: info@hospicefoundation.org
 Web: www.hospicefoundation.org

The Hospice Foundation of America is a non-profit organization that promotes hospice care through educational material. It provides grief and bereavement services and organizes an annual bereavement teleconference.

HOSPICE EDUCATION INSTITUTE

3 Unity Square
 P.O. Box 98

Machiasport, ME 04655-0098

Phone: (800) 331-1620
 (207) 255-8800

Fax: (207) 255-8008

E-mail: info@hospiceworld.org
 Web: www.hospiceworld.org

The Hospice Education Institute provides patients and professionals with information about hospice and palliative care. It has a nationwide toll-free information and referral service, as well as regional seminars, professional education, advice and assistance.

3

NATIONAL ASSOCIATION FOR HOME CARE AND HOSPICE

228 7th Street SE
Washington, D.C. 20003
Phone: (202) 547-7424
Fax: (202) 547-3540
E-mail: hospice@nahc.org
Web: www.nahc.com

This is a trade association representing various home care, hospice and health aid organizations. The National Association for Home Care and Hospice also publishes a pamphlet entitled *How to Select a Home Care Agency*.

NATIONAL HOSPICE AND PALLIATIVE CARE ORGANIZATION/CARING CONNECTIONS

1700 Diagonal Road, Suite 625
Alexandria, VA 22314
Phone: (800) 658-8898
(703) 837-1500
Fax: (703) 837-1233
E-mail: caringinfo@nhpco.org
Web: www.nhpco.org
Web: www.caringinfo.org

The National Hospice and Palliative Care Organization represents the individual hospice service providers in the United States. Customer services include information on local hospice providers and services. Support is also available in Spanish. Caring Connections, a program of the National Hospice and Palliative Care Organization, is a national consumer engagement initiative to improve care at the end of life, supported by a grant from The Robert Wood Johnson Foundation. Caring Connections provides free resources and information to help people make decisions about end-of-life care and services before a crisis.

VISITING NURSE ASSOCIATIONS OF AMERICA

99 Summer Street, Suite 1700
Boston, MA 02110
Phone: (617) 737-3200
Fax: (617) 737-1144
E-mail: vnaa@vnaa.org
Web: www.vnaa.org

VNAA is an agency that represents independent VNA units across the United States. Each VNA unit may vary in its services, but most provide skilled nursing, physical therapy, occupational therapy, speech therapy, and home health aid services.

HOSPITALITY ORGANIZATIONS

NATIONAL ASSOCIATION OF HOSPITAL HOSPITALITY HOUSES

P.O. Box 18087
Asheville, NC 28814-0087
Phone: (800) 542-9730
(828) 253-1188
Fax: (828) 253-8082
E-mail: helpinghomes@nahhh.org
Web: www.nahhh.org

The National Association of Hospital Hospitality Houses is a clearinghouse for information on over 100 non-profit organizations which provide family-centered lodging and support services to families and loved ones that are receiving medical treatment far from home. They offer inexpensive accommodations (usually \$5 to \$20, sometimes free) during hospitalizations, before and after surgery, and during repeated outpatient visits. Many of the homes serve special populations, such as pediatric outpatients or military personnel.

JOE'S HOUSE

50 Lexington Avenue, Suite 10H
New York, NY 10010
Phone: (877) 563-7468
E-mail: info@joeshouse.org
Web: www.joeshouse.org

Joe's House is a housing resource for cancer patients and their families who must travel away from home for medical treatment. The website lists cancer treatment centers and details on nearby lodging facilities, amenities and rates.

RONALD MCDONALD HOUSE CHARITIES

One Kroc Drive
Oak Brook, IL 60523
Phone: (630) 623-7048
Fax: (630) 623-7488
Web: www.rmhc.com

The Ronald McDonald House and the Ronald McDonald Family Room are focused on providing a "home away from home" for families of seriously ill children receiving treatment at nearby hospitals. The Ronald McDonald Care Mobile program brings cost effective, high-quality medical, dental and health education services directly to underserved children in both rural and urban areas around the world.

HOME IMPROVEMENT ORGANIZATIONS

ABLEDATA

8530 Fenton Street, Suite 930
Silver Spring, MD 20910
Phone: (800) 227-0216
(301) 608-8998
Fax: (301) 608-8958
E-mail: abledata@orcmacro.com
Web: www.abledata.com

Abledata provides information about and descriptions of more than 20,000

products for people with physical, sensory, or cognitive disabilities. Information Specialists are available to help provide specific information about a particular device, type of device, and manufacturers and distributors of assistive technology.

NATIONAL RESOURCE CENTER ON SUPPORTIVE HOUSING AND HOME MODIFICATION

Andrus Gerontology Center
University of Southern California
3715 McClintock Avenue
Los Angeles, CA 90089-0191
Phone: (213) 740-1364
Fax: (213) 740-7069
E-mail: homemods@usc.edu
Web: www.homemods.org

The National Resource Center on Supportive Housing and Home Modification is a university-based, non-profit organization dedicated to promoting aging in place and independent living for persons of all ages and abilities. The website offers a national directory of home modification resources, information on home modification, and links to other home modification websites.

UNIVERSAL DESIGN SPECIALISTS, INC.

42 Greenfield Avenue
San Anselmo, CA 94960
Phone: (415) 457-8765
Fax: (415) 457-9606
Web: www.universaldesignspecialists.com

This organization helps patients with physical limitations by offering innovative and modern designs to provide new freedom to people whose mobility has been negatively impacted. In addition to the use of wider doorways and reduced countertop height, appliances, shelves and sinks may be adjusted automatically.



**Children's
Organizations
and Resources**

Children's Brain Tumor
Organizations
Other Pediatric,
Teen and Young Adult
Organizations

Section 4

Children's Organizations & Resources

CHILDREN'S BRAIN TUMOR ORGANIZATIONS

BRAIN TUMOR FOUNDATION FOR CHILDREN, INC.

6065 Roswell Road NE, Suite 505

Atlanta, GA 30328

Phone: (404) 252-4107

Fax: (404) 252-4108

E-mail: btfc@bellsouth.net

Web: www.braintumorkids.org

BTFC provides information and emotional support for families of children with brain tumors. The organization also raises funds for brain tumor research and provides a telephone network system of parents who offer emotional support to other parents. Additionally, it offers educational programs, parent retreats twice a year, and a sibling camp in the summer. Its newsletter, *News Views*, is published several times a year.

THE CHILDHOOD BRAIN TUMOR FOUNDATION

20312 Watkins Meadows Drive

Germantown, MD 20876

Phone: (877) 217-4166

(310) 515-2900

E-mail: cbtfc@childhoodbraintumor.org

Web: www.childhoodbraintumor.org

CBTF provides the Childhood Cancer Ombudsman Program. This free service consists of trained volunteers in the disciplines of medicine, law, and education that provide assistance in: 1) seeking second opinions, 2) access to healthcare, and 3) combating discrimination. This organization also publishes a quarterly newsletter.

THE CHILDREN'S BRAIN TUMOR FOUNDATION, INC.

274 Madison Avenue, Suite 1301

New York, NY 10016

Phone: (866) 228-4673

(212) 448-9494

Fax: (212) 448-1022

E-mail: info@cbtf.org

Web: www.cbtf.org

The Children's Brain Tumor Foundation provides regional support to patients and families. It has a comprehensive resource manual and runs a variety of support services for parents with children in treatment.

LIGHTHOUSE SOS

Phone: (515) 965-1443
E-mail: cneilson@lighthousesos.org
Web: www.lighthousesos.org

Lighthouse SOS provides emotional comfort, information and opportunities for families in Iowa and surrounding states. Support is offered for children ages 0-20 who have been newly diagnosed, are in treatment, living beyond treatment and those bereaved.

MAKING HEADWAY FOUNDATION, INC.

115 King Street
Chappaqua, NY 10514-1615
Phone: (914) 238-8384
Fax: (914) 238-1693
E-mail: request@makingheadway.org
Web: www.makingheadway.org

This organization is dedicated to the care, comfort and cure of children with brain and spinal cord tumors and other catastrophic neurological illnesses. Support groups are available in the New York and New Jersey areas.

THE NEUROBLASTOMA CHILDREN'S CANCER SOCIETY

P.O. Box 957672
Hoffman Estates, IL 60195-7672
Phone: (800) 532-5162
(847) 605-1245
Fax: (847) 605-0705
E-mail: info@neuroblastomacancer.org
Web: www.neuroblastomacancer.org

The Neuroblastoma Children's Cancer Society is a non-profit organization of volunteers dedicated to supporting and advocating for children with neuroblastoma and their families. It also raises money for neuroblastoma research.

PEDIATRIC BRAIN TUMOR FOUNDATION OF THE UNITED STATES

302 Ridgefield Court
Asheville, NC 28806
Phone: (800) 253-6530
(828) 665-6891
Fax: (828) 665-6894
E-mail: pbtfus@pbtfus.org
Web: www.pbtfus.org

The Pediatric Brain Tumor Foundation of the United States is an organization devoted to raising funds for pediatric brain tumor research. It also helps educate the public about brain tumors in children, and can provide additional information on caregiving resources for parents.

WECAN PEDIATRIC BRAIN TUMOR NETWORK

P.O. Box 614
Manhattan Beach, CA 90266
Phone: (310) 739-3433
Fax: (310) 545-8315
E-mail: gigi@wecan.cc
Web: www.wecan.cc

WeCan is a parent-initiated group based in Los Angeles that provides an opportunity for parents of children with brain tumors to meet each other, share information and experiences, and better equip themselves to manage their children's treatment and recovery. Meetings typically involve a brief presentation by a carefully chosen expert, a question and answer session, and personal group discussion. The life situations of WeCan members range from families with young children still in treatment and acute recovery to parents of adult children treated more than a decade ago.

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OTHER PEDIATRIC, TEEN & YOUNG ADULT ORGANIZATIONS

ADOLESCENT HEALTH PROGRAM AND INSTITUTE FOR HEALTH AND DISABILITY

Division of General Pediatrics and Adolescent Health
Department of Pediatrics
McNamara Alumni Center
200 Oak Street SE, Suite 260
Minneapolis, MN 55455-2002
Phone: (800) 276-8642
(612) 626-2820
Fax: (612) 624-0997
E-mail: kdwb-univ@umn.edu
Web: www.allaboutkids.umn.edu/cfahad/

The Center's mission is to improve the health and social functioning of youth with disabilities through technical assistance and consultation, disseminating information, etc. There is a regularly published newsletter, *Connections*. Video and book listings include: *Legal Issues for Adolescents with Chronic Illnesses and Disabilities and Their Families*; *Developing Self Esteem: Issues for Adolescents With Chronic Illness & Disabilities* and *Developing Social Skills*; and *Issues for Adolescents With Chronic Illness and Disabilities*.

BEYOND THE CURE

1015 Locust, Suite 600
St. Louis, MO 63101
Phone: (800) 532-6459
(314) 241-1600
Fax: (314) 241-1996
E-mail: survivorship@children-cancer.org
Web: www.beyondthecure.org

Beyond the Cure was created by the National Children's Cancer Society. Its mission is to help children who have survived cancer celebrate their survivorship and integrate their cancer experience into their new lives.

CANCERVIVE

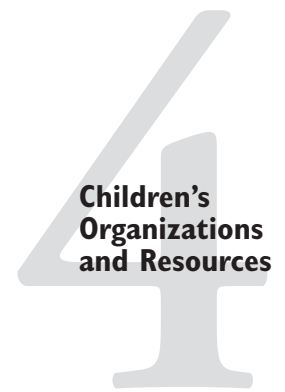
11636 Chayote Street
Los Angeles, CA 90049
Phone: (800) 486-2873
(310) 203-9232
Fax: (310) 471-4618
E-mail: cancervivr@aol.com
Web: www.cancervive.org

Cancervive is a non-profit organization that helps cancer survivors deal with the challenges of "life after cancer." They offer support groups in some states, insurance information and assistance, and patient advocacy. They have also published a coloring book (kids age 3-6), a story/activity book (age 7-11), and a guide for teachers of children with cancer.

THE CANDLELIGHTERS CHILDHOOD CANCER FOUNDATION

P.O. Box 498
Kensington, MD 20895-0498
Phone: (800) 366-2223
(301) 962-3520
Fax: (301) 962-3521
E-mail: staff@candlelighters.org
Web: www.candlelighters.org

The Candlelighters Childhood Cancer Foundation is an informational clearinghouse for parents of children with cancer. A quarterly newsletter is published for adults and young people. Services include an Ombudsman program to assist adults who had cancer as a child and are experiencing difficulties with insurance coverage or employment problems. They also offer a reduced-cost prescription drug service. The Foundation has multiple active support groups around the United States and in 30 countries.



CHILDREN'S HOSPICE INTERNATIONAL

901 King Street, Suite 360
Alexandria, VA 22314

Phone: (800) 242-4453
(703) 684-0330

Fax: (703) 684-0226

E-mail: info@chionline.org

Web: www.chionline.org

Children's Hospice International is a non-profit organization that works to improve hospice care for children. Services include an information and referral service for childcare, counseling, support groups, pain management, professional education, and research. This is a membership group, with a membership fee for other services.

CURE SEARCH

4600 East West Highway, Suite 600
Bethesda, MD 20814-3457

Phone: (800) 458-6223
(626) 447-1674

Fax: (626) 447-6359

E-mail: info@curesearch.org

Web: www.curesearch.org

Cure Search is dedicated to the eradication of all childhood cancers through research, treatment, education and advocacy. Its "Children's Cancer Group" is a network of over 2,800 pediatric cancer specialists that serves to promote cooperation between pediatric medical institutions in the U.S., Canada and Australia. This organization publishes a newsletter called *Heartline*.

THE DOUGY CENTER FOR GRIEVING CHILDREN AND FAMILIES

3909 SE 52nd Avenue

P.O. Box 86852

Portland, OR 97286

Phone: (866) 775-5683

(503) 775-5683

Fax: (503) 777-3097

E-mail: help@dougy.org

Web: www.grievingchild.org

The Dougy Center is a non-profit organization whose goal is to help people who are grieving a death by providing a way to share experiences with healing. It also provides support and local training to individuals and organizations seeking to assist children in grief.

FRIENDS OF KAREN

118 Titicus Road

P.O. Box 190

Purdys, NY 10578-0190

Phone: (800) 637-2774

(914) 277-4547

Fax: (914) 277-4967

E-mail: info@friendsofkaren.org

Web: www.friendsofkaren.org

Friends of Karen is dedicated to helping terminally and catastrophically ill children and their families in the New York/New Jersey metropolitan area. Their social workers provide advocacy and assistance in locating public and private resources, and they will meet additional need with direct financial assistance for medical care, transportation expenses, home care and child care. They also provide bereavement support, assistance with funeral arrangements, counseling referrals, and weekend retreats for bereaved families.



**GEORGE MARK
CHILDREN'S HOUSE**

2121 George Mark Lane
San Leandro, CA 94578
Phone: (866) 897-4624
(510) 346-4624
Fax: (510) 346-4620
E-mail: info@georgemark.org
Web: www.georgemark.org

George Mark Children's House is the first freestanding children's respite and end-of-life care facility in the United States. The House, located in San Leandro, California, offers respite support (round-the-clock), transitional care, and end-of-life care for children with life-limiting or terminal illnesses. All care is informed by the principles of palliative care. Additional support services are available to all family members. Services are provided regardless of a family's ability to pay.

GROUP LOOP

The Wellness Community
National Office
Attention: Grouploop
919 18th Street NW, Suite 54
Washington, D.C. 20006
Phone: (888) 793-9355
(202) 659-9709
Fax: (202) 659-9301
E-mail: help@thewellnesscommunity.org
Web: www.grouploop.org

Group Loop is focused on teens with cancer and their parents. It allows teens with cancer to connect with other teens in the same situation. Group Loop also offers support and information for both teens and their parents.

KIDS CANCER NETWORK

P.O. Box 4545
Santa Barbara, CA 93140
E-mail: info@kidscancernetwork.org
Web: www.kidscancernetwork.org

Kids Cancer Network provides support to children with cancer through their publication of *Funletter*, a nationally distributed activities letter. The network also provides personal letters and phone calls of support and family networking resources.

THE LIFELAB

295 Lafayette Street, Suite 501
New York, NY 10012
Phone: (212) 920-3672
Fax: (212) 226-5619
E-mail: info@nylifelab.org
Web: www.nylifelab.org

The NY Lifelab (the "Lifelab") is a non-profit corporation dedicated to helping young adult cancer survivors rebuild their lives after treatment. It is a support community that provides unique programs, mentors, networking and peer support free of charge to young adult survivors in New York City. Its goal is to help members discover what they would like to do with their lives after cancer, and offer them tools to get there.

THE NEUROPSYCHOLOGY CENTRAL WEBSITE offers information regarding Pediatric Textbooks, Children's Learning and Communication Disorders, and Pediatric Neuropsychology E-Groups. Contact them at: www.neuropsychologycentral.com.

**NATIONAL CHILDREN'S
CANCER SOCIETY**

1015 Locust, Suite 600
St. Louis, MO 63101
Phone: (800) 532-6459
(314) 241-1600
Fax: (314) 241-1996
E-mail: pfs@children-cancer.org
Web: www.nationalchildrenscancer.org

The National Children's Cancer Society provides financial assistance for children diagnosed before the age of 18 and in need of a bone marrow transplant. Assistance is provided for, but not limited to, donor search, transplant procedure, lost parental income, and living expenses. NCCS will assist in fundraising upon request. It also provides fundraising information and patient advocacy services.

**NATIONAL DISSEMINATION
CENTER FOR CHILDREN
WITH DISABILITIES**

P.O. Box 1492
Washington, D.C. 20013
Phone: (800) 695-0285
(202) 884-8200
Fax: (202) 884-8441
E-mail: nichcy@aed.org
Web: www.nichcy.org

The National Dissemination Center for Children with Disabilities is a clearinghouse of information for parents and professionals. It helps parents become advocates in getting the best education for their disabled children up to age 21. The agency has various publications for parents and a newsletter called the *News Digest*.

**NATIONAL STUDENTS OF
AILING MOTHERS AND FATHERS
SUPPORT NETWORK**

Web: www.studentsofamf.org
National Students of AMF Support Network is a national, non-profit organization whose mission is to support all grieving college students, empower all college students to get involved in service, and raise awareness about the needs of grieving college students. They provide support online, award scholarships, distribute research grants, conduct conferences and hold fundraising events.

OKIZU FOUNDATION CAMPS

16 Digital Drive
Novato, CA 94949-6115
Phone: (415) 382-9083
Fax: (415) 382-8384
E-mail: info@okizu.org
Web: www.okizu.org

The Okizu Foundation runs family camp programs for children who have cancer and their families, and for children who have or had a parent with cancer.

OUTLOOK

Phone: (608) 263-6200
Fax: (608) 265-9721
E-mail: jaamond@wisc.edu
Web: www.outlook-life.org

The Outlook website provides information to survivors of childhood cancer and their families to build a bridge of support between current patients and survivors. The University of Wisconsin's Comprehensive Cancer Center, Children's Hospital Division of Pediatric Hematology/Oncology and the Medical School's Biomedical Computing Group worked together to create this web-based information system.

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PLANET CANCER

3710 Cedar Street, Box 11
Austin, TX 78705
E-mail: contactus@planetcancer.org
Web: www.planetcancer.org

Planet Cancer is non-profit organization that caters to young adults with cancer. Their website is an online community that allows young adults with cancer to receive and give support and connect with their peers. Planet Cancer provides support and information that helps young adults deal with issues such as dating with cancer, choosing to leave school, and loss of fertility.

PROJECT ASSIST NEVADA

P.O. Box 70247
Reno, NV 89570-0247
Phone: (800) 522-0066
(775) 688-2819
E-mail: assist@govmail.state.nv.us
Web: <http://health2k.state.nv.us/Beis/resource.htm>

Project Assist is an information and referral service that maintains a database of over 500 listings for disability resources. It specializes in Nevada organizations, but also has information about national organizations that serve children and youth with disabilities up to 21 years old.

RONALD MCDONALD HOUSE CHARITIES

One Kroc Drive
Oak Brook, IL 60523
Phone: (630) 623-7048
Fax: (630) 623-7488
Web: www.rmhc.com

The Ronald McDonald House and the Ronald McDonald Family Room are focused on providing a “home away from home” for families of seriously ill children receiving treatment at nearby hospitals. The Ronald McDonald Care Mobile

program brings cost effective, high-quality medical, dental and health education services directly to underserved children in both rural and urban areas around the world.

STARLIGHT STARBRIGHT CHILDREN'S FOUNDATION

5757 Wilshire Boulevard, Suite M100
Los Angeles, CA 90036
Phone: (800) 315-2580
(310) 479-1212
Fax: (310) 479-1235
E-mail: info@starlight.org
Web: www.starlight.org

Starlight Starbright's mission is to soften the hard edges of what a family experiences when a child has a serious illness. They build playrooms and teen lounges in hospitals so kids can play games, e-mail, chat with friends, and even do their homework from their hospital bed. When the kids get to go home, they keep them connected through online chat rooms and special outings for the entire family. They also provide information about illnesses and treatments on their website and through videos and games.

SURVIVING AND MOVING FORWARD: THE SAMFUND

P.O. Box 35705
Brighton, MA 02135
E-mail: info@thesamfund.org
Web: www.thesamfund.org

The SAMFund is a unique non-profit organization created to assist young adult survivors of cancer with a successful transition into their post-treatment life through the distribution of grants and scholarships.

TIM & TOM GULLIKSON FOUNDATION

8000 Sears Tower
Chicago, IL 60606
Phone: (888) 485-5457
E-mail: info@gulliksonfoundation.org
Web: www.gulliksonfoundation.org

The Tim & Tom Gullikson Foundation assists brain tumor patients and their families in managing the physical, emotional, financial and social challenges presented by the illness. College scholarships for post-high school education are available to brain tumor patients/survivors and/or the children of brain tumor patients/survivors. The program includes accredited four-year colleges, universities, two-year colleges, vocational-technical schools or other institutions of higher learning.

THE ULMAN CANCER FUND FOR YOUNG ADULTS

PMB 505
4725 Dorsey Hall Drive, Suite A
Ellicott City, MD 21042
Phone: (888) 393-3863
(410) 964-0202
Fax: (410) 964-0402
E-mail: info@ulmanfund.org
Web: www.ulmanfund.org

The Ulman Cancer Fund is an organization that seeks to provide support programs, education and resources to benefit young adults, their families and friends who are affected by cancer, and to promote awareness and prevention of cancer.

VITAL OPTIONS

4419 Coldwater Canyon Avenue, Suite 1
Studio City, CA 91604-1479
Phone: (800) 477-7666
(818) 508-5657
Fax: (818) 788-5260
E-mail: info@vitaloptions.org
Web: www.vitaloptions.org

Vital Options: Support For Young Adults With Cancer was originally founded in 1983 as the first organization for young adults with cancer. In addition to serving as a resource for this special patient population, Vital Options now provides a variety of cancer communications projects for patients of all ages and disease types, as well as for their families, friends and healthcare providers. In particular, they provide The Group Room[®] radio show, a weekly syndicated cancer talk show that is also simulcast on the web and XM Satellite Radio.

WRIGHTS LAW

Web: www.wrightslaw.com

This website provides updated and accurate information on special education laws.

YOUNG ADULTS SURVIVING GLIOBLASTOMA

Web: www.yasg.com

The Young Adults Surviving Glioblastoma website was created to inspire young adults (and beyond) who are diagnosed with this disease. It features biographies, information about different treatments, e-mail addresses of survivors, a message board and live chat.

Section 5

Complementary Therapy Organizations

AN OVERVIEW OF COMPLEMENTARY AND ALTERNATIVE MEDICINE THERAPIES (CAM)

“Complementary” describes a therapy used “in addition to” or “to complement” a conventional therapy. For brain tumor patients, conventional therapy generally means surgery, radiation and chemotherapy. An alternative therapy is one that is used “instead of” conventional therapy. The more contemporary term “integrative” refers to the combination of unconventional and conventional therapies.

The National Institutes of Health (NIH) and the National Center for Complementary and Alternative Medicine (NCCAM) describe the following seven categories of CAM:

ALTERNATIVE SYSTEMS OF MEDICAL CARE include Naturopathy, Ayurvedic Medicine, Traditional Chinese Medicine and others. They stress patient responsibility and combine different techniques that influence the body, mind and spirit.

BIOELECTROMAGNETIC THERAPIES include the use of acupuncture, magnets and others. These therapies are primarily complementary and may be helpful for symptom management. Acupuncture is one proven therapy in this category that has positive results in pain management.

DIET, NUTRITION AND LIFESTYLE include the use of special nutritional programs or diets and exercise to influence health and well-being.

HERBAL MEDICINE is the use of herbs for medicinal purposes, including Gingko Biloba, Echinacea, St. John’s Wort and others.

MANUAL HEALING METHODS are complementary therapies that include massage, therapeutic touch, Reiki, reflexology and others. The benefits of these therapies seem obvious to the patients using them, but research is limited.

MIND-BODY MEDICINE uses the mind and spirit to influence the body and includes yoga, biofeedback, creative art therapies and more.

PHARMACOLOGICAL AND BIOLOGICAL THERAPIES include unproven therapies most often accessed as “alternative.” These include shark cartilage, laetrile and others.

COMPLEMENTARY AND ALTERNATIVE THERAPY ORGANIZATIONS

ALTERNATIVE MEDICINE FOUNDATION

P.O. Box 60016
Potomac, MD 20859
Phone: (301) 340-1960
Fax: (301) 340-1936
E-mail: info@amfoundation.org
Web: www.amfoundation.org

The Alternative Medicine Foundation provides responsible and reliable information about alternative medicine to the public and health professionals regarding non-traditional approaches to health and well-being. It offers both free and fee-based information services and resources.

ALTERNATIVE MEDICINE HOMEPAGE

Web: www.pitt.edu/~cbw/altm.html

Alternative Medicine Homepage offers links to information on unconventional, unproven, alternative, complementary, and integrative therapies. It is maintained by the Falk Library of Health Sciences at the University of Pittsburgh. It also provides links to organizations and alternative medicine practitioners.

AMERICAN CANCER SOCIETY

1599 Clifton Road NE
Atlanta, GA 30329-4251
Phone: (800) 227-2345
Web: www.cancer.org

The American Cancer Society (ACS) provides a wealth of information on complementary and alternative therapies that includes topics such as: mind, body and spirit; manual healing and physical touch; herbs, vitamins and minerals; diet and nutrition; and pharmacological and biological treatments.

AMERICAN HOLISTIC HEALTH ASSOCIATION

P.O. Box 17400
Anaheim, CA 92817-7400
Phone: (714) 779-6152
E-mail: mail@ahha.org
Web: www.ahha.org

The American Holistic Health Association is a national clearinghouse for self-help resources that promote health and well-being. AHHA offers resources, networking lists and a newsletter. This is a volunteer-run non-profit educational association.

AMERICAN HOLISTIC MEDICAL ASSOCIATION

P.O. Box 2016
Edmonds, WA 98020
Phone: (425) 967-0737
Fax: (425) 771-9588
E-mail: ahma@holisticmedicine.org
Web: www.holisticmedicine.org

The American Holistic Medical Association (AHMA) is a professional organization established to explore and promote holistic health care. The association has a network of regional groups and publishes a quarterly magazine, *Holistic Health*. It also offers brochures entitled *Choosing a Holistic Health Practitioner* and *The Most Asked Questions About Holistic Health & Holistic Medicine* and a national directory of AHMA member physicians.



COMMONWEAL

P.O. Box 316
Bolinas, CA 94924
Phone: (415) 868-0970
Fax: (415) 868-2230
E-mail: commonweal@commonweal.org
Web: www.commonweal.org

Commonweal is an organization that studies alternative and complementary cancer therapies. Its purpose is to assist people who have been diagnosed with cancer who are seeking physical, emotional, and spiritual healing. It has workshops and retreats focusing on deep relaxation, meditation, imagery, yoga and massage.

DRUG DIGEST

Web: www.drugdigest.org

Drug Digest is the consumer health and drug information website of Express Script, Inc., a pharmaceutical site. Drug Digest is designed to offer reference materials regarding drugs, vitamins and herbs.

HEALTHWORLD ONLINE

4049 Lyceum Avenue
Los Angeles, CA 90066
Web: www.healthy.net

HealthWorld Online believes individuals should be major players in their own health care. Conventional and alternative therapies for common health conditions are listed side-by-side for easy comparison.

HOLISTIC HEALING WEB PAGE

Web: www.holisticmed.com

A resource for holistic medicine that includes articles, web links and internet discussion groups.

INTEGRATIVE MEDICAL ARTS GROUP, INC.

P.O. Box 671
Beaverton, OR 97075
Phone: (503) 641-6060
Fax: (503) 643-4633
E-mail: ima@ibismedical.com
Web: www.ibismedical.com

The IBIS site is a source for Integrated Medicine and Natural Health. Their approach involves respect for the integrity of ancient systems of healing, while staying in touch with the latest in medical research. They feature information on the Integrative BodyMind Information System, drug herb/nutrient interactions, and a natural health hotline.

NATIONAL CENTER FOR COMPLEMENTARY AND ALTERNATIVE MEDICINE

National Institutes of Health
9000 Rockville Pike
Bethesda, MD 20892
Phone: (888) 644-6226
(301) 519-3153
Fax: (866) 464-3616
E-mail: info@nccam.nih.gov
Web: www.nccam.nih.gov

The mission of the National Center for Complementary and Alternative Medicine (NCCAM) is to explore CAM healing practices in the context of rigorous science, train CAM researchers, and provide authoritative information to the public and professionals. Their website has a wealth of information on different CAM topics and therapies, what to look for in a CAM practitioner, and a listing of clinical trials that use CAM.

ADDITIONAL SPECIALITY ORGANIZATIONS

Acupuncture/Oriental Medicine

THE AMERICAN ACADEMY OF MEDICAL ACUPUNCTURE

4929 Wilshire Boulevard, Suite 428
Los Angeles, CA 90010
Phone: (323) 937-5514
E-mail: jdowden@prodigy.net
Web: www.medicalacupuncture.org

AMERICAN ASSOCIATION OF ORIENTAL MEDICINE

P.O. Box 162340
Sacramento, CA 95816
Phone: (866) 455-7999
(916) 443-4770
Fax: (916) 443-4766
E-mail: execdir@aaom.org
Web: www.aaom.org

Allopathic (M.D.) & Osteopathic (D.O.) Medicine

AMERICAN HOLISTIC MEDICAL ASSOCIATION

P.O. Box 2016
Edmonds, WA 98020
Phone: (425) 967-0737
Fax: (425) 771-9588
E-mail: ahma@holisticmedicine.org
Web: www.holisticmedicine.org

AMERICAN MEDICAL ASSOCIATION

515 North State Street
Chicago, IL 60610
Phone: (800) 621-8335
Web: www.ama-assn.org

AMERICAN OSTEOPATHIC ASSOCIATION

142 East Ontario Street
Chicago, IL 60611
Phone: (800) 621-1773
Fax: (312) 202-8200
Web: www.osteopathic.org

Art Therapy

AMERICAN ART THERAPY ASSOCIATION, INC.

5999 Stevenson Avenue
Alexandria, VA 22304
Phone: (703) 212-2238
E-mail: info@arttherapy.org
Web: www.arttherapy.org

Bodywork

AMERICAN MASSAGE THERAPY ASSOCIATION

500 Davis Street, Suite 900
Evanston, IL 60201-4695
Phone: (877) 905-2700
(847) 864-0123
Fax: (847) 864-1178
E-mail: info@amtamassage.org
Web: www.amtamassage.org

ASSOCIATED BODYWORK AND MASSAGE PROFESSIONALS

1271 Sugarbush Drive
Evergreen, CO 80439-9766
Phone: (800) 458-2267
(303) 674-8478
Fax: (800) 667-8260
E-mail: expectmore@abmp.com
Web: www.abmp.com





Chiropractic

AMERICAN CHIROPRACTIC ASSOCIATION

1701 Clarendon Boulevard
Arlington, VA 22209
Phone: (800) 986-4636
(703) 276-8800
Fax: (703) 243-2593
E-mail: memberinfo@acatoday.org
Web: www.amerchiro.org

INTERNATIONAL CHIROPRACTIC ASSOCIATION

1110 North Glebe Road, Suite 650
Arlington, VA 22201
Phone: (800) 423-4690
(703) 528-5000
Fax: (703) 528-5023
Web: www.chiropractic.org

Herbal Therapy

AMERICAN HERBALISTS GUILD

141 Nob Hill Road
Cheshire, CT 06410
Phone: (203) 272-6731
Fax: (203) 272-8550
E-mail: ahgoffice@earthlink.net
Web: www.americanherbalistsguild.com

Homeopathic Therapy

NATIONAL CENTER FOR HOMEOPATHY

801 North Fairfax Street, Suite 306
Alexandria, VA 22314
Phone: (877) 624-0613
(703) 548-7790
Fax: (703) 548-7792
E-mail: info@homeopathic.org
Web: www.homeopathic.org

Hypnosis

HYPNOSIS ASSOCIATION FOR CERTIFIED HYPNOTHERAPISTS

4110 Edgeland, Suite 800
Royal Oak, MI 48073-2285
Phone: (800) 257-5467
Phone: (248) 549-5594
Fax: (248) 549-5421
Web: www.infinityinst.com

Mind/Body

THE CENTER FOR MIND/BODY MEDICINE STUDIES

5225 Connecticut Avenue NW, Suite 414
Washington, D.C. 20015
Phone: (202) 966-7338
Fax: (202) 966-2589
E-mail: center@cmbm.org
Web: www.cmbm.org

THE MIND/BODY MEDICAL INSTITUTE

824 Boylston Street
Chesnut Hill, MA 02467
Phone: (866) 509-0732
(617) 991-0102
Fax: (617) 991-0112
E-mail: mbmi@caregroup.harvard.edu
Web: www.mbmi.org

Music Therapy

AMERICAN MUSIC THERAPY ASSOCIATION, INC.

8455 Colesville Road, Suite 1000
Silver Spring, MD 20910
Phone: (301) 589-3300
Fax: (301) 589-5175
E-mail: info@musictherapy.com
Web: www.musictherapy.com



Naturopathy

AMERICAN ASSOCIATION FOR NATUROPATHIC PHYSICIANS (AANP)

4435 Wisconsin Avenue NW, Suite 403

Washington, D.C. 20016

Phone: (866) 538-2267

(202) 237-8150

Fax: (202) 237-8152

E-mail: member.services@naturopathic.org

Web: www.naturopathic.org

Nutrition

AMERICAN HEALTH SCIENCE UNIVERSITY AND THE NATIONAL INSTITUTE OF NUTRITIONAL EDUCATION (NINE)

1010 S. Joliet Street, Suite 107

Aurora, CO 80012

Phone: (800) 530-8079

(303) 340-2054

Fax: (303) 367-2577

E-mail: admin@ahsu.edu

Web: www.ahsu.edu

Nursing

AMERICAN HOLISTIC NURSES ASSOCIATION

P.O. Box 2130

Flagstaff, AZ 86003-2130

Phone: (800) 278-2462

Fax: (520) 526-2752

E-mail: info@ahna.org

Web: www.ahna.org

Qigong

QIGONG FOUNDATION FOR SOCIAL ONCOLOGY

P.O. Box 72

Eureka, MT 59917

Phone: (406) 889-3966

E-mail: info@socialoncology.com

Web: www.socialoncology.com

QIGONG INSTITUTE

561 Berkeley Avenue

Menlo Park, CA 94025

Phone: (650) 323-1221

Fax: (650) 323.1221

E-mail: qi@qigonginstitute.org

Web: www.qigonginstitute.org

CONSUMER HEALTH PROTECTION SITES tackle health fraud as a public health concern. They feature articles written by physicians, nurses, scientific and legal professionals regarding fraudulent traditional and alternative therapies. These two organizations are helpful resources in learning more:

National Council Against Health Fraud

Phone: (978) 532-9383 • www.ncahf.org

Quackwatch

www.quackwatch.com



**Disability and
Anti-Discrimination
Organizations**

Disability Assistance
Organizations

Anti-Discrimination
Assistance Organizations

State Protection and
Advocacy Agencies

Section 6

Disability and Anti-Discrimination Organizations

DISABILITY ASSISTANCE ORGANIZATIONS

ADOLESCENT HEALTH PROGRAM AND INSTITUTE FOR HEALTH AND DISABILITY

Division of General Pediatrics and
Adolescent Health
Department of Pediatrics
McNamara Alumni Center
200 Oak Street SE, Suite 260
Minneapolis, MN 55455-2002
Phone: (800) 276-8642
(612) 626-2820
Fax: (612) 624-0997
E-mail: kdwb-univ@umn.edu
Web: www.allaboutkids.umn.edu/cfahad

The Center's mission is to improve the health and social functioning of youth with disabilities through technical assistance and consultation, disseminating information, etc. There is a regularly published newsletter, *Connections*. Video and book listings include: *Legal Issues for Adolescents with Chronic Illnesses and Disabilities and Their Families*; *Developing Self Esteem: Is-*

sues for Adolescents With Chronic Illness & Disabilities and Developing Social Skills; and *Issues for Adolescents With Chronic Illness and Disabilities*.

AMERICAN HEALTH INFORMATION MANAGEMENT ASSOCIATION

233 North Michigan Avenue, Suite 2150
Chicago, IL 60601-5800
Phone: (800) 335-5535 – Product Sales
(312) 233-1100
Fax: (312) 233-1090
(312) 233-1500 – Product Orders
E-mail: info@ahima.org
Web: www.ahima.org

This national association can provide information on patients' rights on a state-by-state basis, as well as answer general questions about medical record-keeping.

DISABILITY RESOURCES, INC.

4 Glatter Lane
Centereach, NY 11720-1032
Phone: (631) 585-0290
Fax: (631) 585-0290
E-mail: info@disabilityresources.org
Web: www.disabilityresources.org

Disability Resources, Inc. is a non-profit organization established to promote and improve awareness, availability and accessibility of information that can help people with disabilities live, learn, love, work and play independently. This group disseminates information about books, pamphlets, magazines, newsletters, videos, databases, government agencies, non-profit organizations, telephone hotlines and online services that provide free, inexpensive or hard-to-find information to help people with disabilities live independently.

DISABILITY RIGHTS, EDUCATION AND DEFENSE FUND, INC.

2212 Sixth Street
Berkeley, CA 94710
Phone: (510) 644-2555 (Voice/TDD)
Fax: (510) 841-8645
E-mail: dred@dredf.org
Web: www.dredf.org

The Disability Rights, Education and Defense Fund, Inc. (DREDF) is a law and policy center for people of all ages with all types of disabilities. Its purpose is to further the civil rights of persons with disabilities. DREDF provides information and referrals, legal advocacy and representation for adults and children with disabilities in both individual and class action cases. It also provides training and speakers to the community, public entities, and private businesses about the Americans with Disabilities Act (ADA) and its relationship to other state and federal laws.

HANDINET

Warren King HandiNet
800 Archway Court #102
Virginia Beach, VA 23455
Fax: (757) 490-9236
E-mail: warking@handinet.org
Web: www.handinet.org

HandiNet is dedicated to advancing the issues of the disability community, especially that of Virginia, through grass-roots activism, public education, and advocacy. The website includes a listserv, an online disability guide, disability links, and other resources.

NATIONAL COUNCIL ON DISABILITY

1331 F Street NW, Suite 850
Washington, D.C. 20004-1107
Phone: (202) 272-2004
TDD: (202) 272-2074
Fax: (202) 272-2022
E-mail: mquigley@ncd.gov
Web: www.ncd.gov

The National Council on Disability is an independent federal agency that works with the President and Congress to increase the inclusion, independence and empowerment of Americans with disabilities. The Council is involved in policy-making issues, conducts hearings, and holds forums and conferences. Patient education materials are also available. Its monthly publication, *NCD Bulletin*, provides information on the latest issues and news impacting people with disabilities.



NATIONAL INFORMATION CENTER FOR CHILDREN WITH DISABILITIES

P.O. Box 1492
Washington, D.C. 20013
Phone: (800) 695-0285 (Voice/TDD)
Fax: (202) 884-8441
E-mail: nichcy@aed.org
Web: www.nichcy.org

The National Information Center for Children with Disabilities is a clearinghouse of information for parents and professionals. It helps parents become advocates in getting the best education for their disabled children up to age 21. NICHCY has various publications for parents and a newsletter called the *News Digest*.

NATIONAL JOB ACCOMMODATION NETWORK

P.O. Box 6080
Morgantown, WV 26506-6080
Phone: (800) 526-7234 (Voice/TDD)
Fax: (304) 293-5407
E-mail: jan@jan.wvu.edu
Web: www.jan.wvu.edu

The National Job Accommodation Network is an international information service for people with disabilities or their employers. It provides information about the implementation of workplace accommodations (e.g. job restructuring, assistive devices, etc.), as well as resources to promote an awareness of functional limitations associated with disability.

NATIONAL LEGAL CENTER FOR THE MEDICALLY DEPENDENT AND DISABLED, INC.

7 South Sixth Street, Suite 208
Terre Haute, IN 47807
Phone: (812) 238-0769
Fax: (812) 232-0260
E-mail: tmarzen@aol.com

The National Legal Center is committed

to defending the rights of vulnerable persons threatened by infanticide, euthanasia, assisted suicide, non-voluntary withdrawal/withholding of essential medical treatment and care, and discrimination in health care financing. Its goal is to provide direct delivery, technical assistance, training, and publications on legal issues concerning the treatment of the critically or terminally ill, handicapped and medically dependent poor persons.

NATIONAL ORGANIZATION ON DISABILITY

910 16th Street NW, Suite 600
Washington, D.C. 20006
Phone: (202) 293-5960
Fax: (202) 293-7999
E-mail: ability@nod.org
Web: www.nod.org

The National Organization on Disability consumer advocacy group attempts to take a grassroots, community-based approach toward educating and supporting those with disabilities. They provide numerous educational pamphlets on disability rights.

PARAQUAD, INC.

5240 Oakland Avenue
St. Louis, MO 63110
Phone: (314) 289-4200
TDD: (314) 289-4252
Fax: (314) 289-4201
Web: www.paraquad.org

Paraquad provides support and empowerment to individuals with disabilities who are seeking to increase their independence. They offer information and referrals via a hotline, peer consultation, independent living skills training, and advocacy regarding rights and responsibilities.

PATIENT ADVOCATE FOUNDATION

700 Thimble Shoals Boulevard, Suite 200
Newport News, VA 23606
Phone: (800) 532-5274
Fax: (757) 873-8999
E-mail: help@patientadvocate.org
Web: www.patientadvocate.org

The Patient Advocate Foundation serves as an active liaison between the patient and their insurer, employer and/or creditors to resolve insurance, job discrimination and/or debt crisis matters relative to their diagnosis through case managers, doctors and attorneys.

PROJECT ASSIST NEVADA

P.O. Box 70247
Reno, NV 89570-0247
Phone: (800) 522-0066
(775) 688-2819
E-mail: assist@govmail.state.nv.us
Web: <http://health2k.state.nv.us/Beis/resource.htm>

Project Assist is an information and referral service that maintains a database of over 500 listings for disability resources. It specializes in Nevada organizations, but also has information about national organizations that serve children and youth with disabilities up to 21 years old.

SPECIAL NEEDS PROJECT WORLDWIDE

324 State Street, Suite H
Santa Barbara, CA 93101
Phone: (800) 333-6867
Fax: (805) 962-5087
E-mail: books@specialneeds.com
Web: www.specialneeds.com

Special Needs Project Worldwide offers thousands of books, audiotapes, videos, magazines and directories about various disabilities and illnesses, as well as psychological health and caregiving issues.

THROUGH THE LOOKING GLASS

2198 Sixth Street, Suite 100
Berkeley, CA 94710-2204
Phone: (800) 644-2666
(800) 804-1616
TDD: (510) 848-1112
Fax: (510) 848-4445
E-mail: tlg@lookingglass.org
Web: www.lookingglass.org

Through the Looking Glass is a nationally recognized community-based non-profit organization that has pioneered research, training, and services for families in which a child, parent or grandparent has a disability or medical issue.

ANTI-DISCRIMINATION ASSISTANCE ORGANIZATIONS

AMERICAN CANCER SOCIETY

1599 Clifton Road NE
Atlanta, GA 30329-4251
Phone: (800) 227-2345
TDD: (866) 228-4327
Web: www.cancer.org

The American Cancer Society personnel can assist with job or insurance questions. Educational materials are also available. See page 7 for additional information.

EQUAL EMPLOYMENT OPPORTUNITY COMMISSION

1801 L Street NW
Washington, D.C. 20507
Phone: (800) 669-4000
(800) 669-6820 (Voice/TDD)
(202) 663-4900
Fax: (703) 997-4890
E-mail: info@ask.eeoc.gov
Web: www.eeoc.gov

The Equal Employment Opportunity Commission (EEOC) can provide information on employment discrimination and



assists consumers with complaints or questions. The Commission can provide information on the Americans With Disabilities Act, in addition to educational materials. Support is also available in Spanish.

NATIONAL COALITION FOR CANCER SURVIVORSHIP

1010 Wayne Avenue, Suite 770
Silver Spring, MD 20910
Phone: (887) 622-7937
(301) 650-9127
Fax: (301) 565-9670
E-mail: info@canceradvocacy.org
Web: www.canceradvocacy.org

The National Coalition for Cancer Survivorship specializes in patient advocacy and assistance regarding employment issues, job discrimination and insurance concerns. The NCCS provides assistance to cancer survivors in locating cancer services and support organizations. The NCCS has a quarterly newsletter, *The Networker*.

STATE PROTECTION AND ADVOCACY AGENCIES FOR PEOPLE WITH DISABILITIES

are part of the Americans With Disabilities Act of 1990. All states are obligated to provide basic services for people with disabilities.

These services include employment assistance, public services such as transportation, accommodations and telecommunications. Additional services may vary from state to state, so please call the appropriate office for local referrals.

Headquarters may be reached at:
Phone: (202) 690-6590
Fax: (202) 690-6904

PLEASE NOTE: The 800 numbers listed on the next page do not always work when called from outside of the state. This information can be found on the internet at: www.acf.hhs.gov/programs/add/states/pas.html.

STATE PROTECTION AND ADVOCACY AGENCIES

Alabama

Phone: (205) 348-4928
(800) 826-1675
TDD: (205) 348-9484

Alaska

Phone: (907) 565-1002
TDD: (800) 478-1234

American Samoa

Phone: (684) 633-2441

Arizona

Phone: (602) 274-6287

Arkansas

Phone: (501) 296-1775
(800) 482-1174
TDD: (501) 296-1775

California

Phone: (916) 488-9955

Colorado

Phone: (303) 722-0300
(800) 288-1376
TDD: (303) 722-0300

Connecticut

Phone: (860) 297-4300
(800) 842-7303
TDD: (860) 566-2102

Delaware

Phone: (302) 575-0660

District of Columbia

Phone: (202) 547-0198

Florida

Phone: (850) 488-9071
(800) 342-0832
TDD: (800) 346-4127

Georgia

Phone: (404) 885-1234
(800) 537-2329
TDD: (404) 885-1234

Guam

Phone: (671) 477-9811

Hawaii

Phone: (808) 949-2922
TDD: (808) 949-2922

Idaho

Phone: (208) 336-5353
(866) 262-3462
TDD: (208) 336-5353

STATE PROTECTION AND ADVOCACY AGENCIES (continued)

Illinois

Phone: (312) 341-0022
(800) 537-2632
TDD: (800) 610-2779

Indiana

Phone: (317) 722-5555
(800) 622-4845
TDD: (317) 722-5555

Iowa

Phone: (515) 278-2502
(800) 779-2502
TDD: (515) 278-0571

Kansas

Phone: (785) 273-9661

Kentucky

Phone: (502) 564-2967
TDD: (800) 372-2988

Louisiana

Phone: (504) 522-2337
TDD: (800) 960-7705

Maine

Phone: (207) 626-2774 x104
TDD: (800) 452-1948

Maryland

Phone: (410) 727-6352
(800) 233-7201
TDD: (410) 727-6387

Massachusetts

Phone: (617) 723-8455
(800) 872-9992
TDD: (617) 723-8455

Michigan

Phone: (517) 487-1755
(800) 288-5923
TDD: (517) 487-1755

Minnesota

Phone: (612) 332-1441
(800) 292-4150

Mississippi

Phone: (601) 981-8207
(800) 772-4057

Missouri

Phone: (373) 893-3333
(800) 392-8667
TDD: (800) 735-2966

Montana

Phone: (406) 449-2344
(800) 245-4743
TDD: (406) 449-2344

Nebraska

Phone: (402) 474-3183
(800) 422-6691
TDD: (402) 474-3183

Nevada

Phone: (702) 257-8150
TDD: (702) 257-8160

New Hampshire

Phone: (603) 228-0432
(800) 834-1721
TDD: (603) 228-0432

New Jersey

Phone: (609) 292-9742
(800) 922-7233

New Mexico

Phone: (505) 256-3100
(800) 432-4682
TDD: (505) 256-3100

New York

Phone: (518) 388-2892
TDD: (800) 624-4143

North Carolina

Phone: (919) 733-9250
(800) 821-6922
TDD: (919) 733-9250

North Dakota

Phone: (701) 328-2950
(800) 472-2670
(800) 642-6694

Ohio

Phone: (614) 466-7264
(800) 282-9181
TDD: (614) 466-7264

Oklahoma

Phone: (405) 525-7755
(800) 880-7755

Oregon

Phone: (503) 243-2081
(800) 452-1694
TDD: (800) 556-5351

Pennsylvania

Phone: (717) 236-8110
(800) 692-7443
TDD: (717) 236-8110

Puerto Rico

Phone: (787) 721-4299
(800) 981-4125
TDD: (787) 725-2333

Rhode Island

Phone: (401) 831-3150
TDD: (401) 831-5335

South Carolina

Phone: (803) 782-0639
(866) 275-7273
TDD: (803) 782-0639

South Dakota

Phone: (605) 224-8294
(800) 658-4782
TDD: (605) 224-8294

Tennessee

Phone: (615) 298-1080
(800) 287-9636
TDD: (615) 298-2471

Texas

Phone: (512) 454-4816
(800) 252-9108
TDD: (512) 454-4816

Utah

Phone: (801) 363-1347
(800) 662-9080

Vermont

Phone: (802) 229-1355
(800) 834-7890

Virginia

Phone: (804) 225-2042
(800) 552-3962
TDD: (804) 225-2042

Virgin Islands

Phone: (340) 772-1200
TDD: (340) 772-4641

Washington

Phone: (206) 324-1521
(800) 562-2702
TDD: (206) 324-1521

West Virginia

Phone: (304) 346-0847
(800) 950-5250
TDD: (304) 346-0847

Wisconsin

Phone: (608) 267-0214
(800) 928-8778
TDD: (608) 267-0214

Wyoming

Phone: (307) 632-3496
(800) 624-7648

7

Financial and Insurance Organizations

Financial Assistance Organizations

Financial Disability and Assistance Organizations

General Insurance Organizations

State Health Insurance Assistance Programs

Scholarship Information

Section 7

Financial and Insurance Organizations

FINANCIAL ASSISTANCE ORGANIZATIONS

BTS CARES

Brain Tumor Society
124 Watertown Street, Suite 3H
Watertown, MA 02472
Phone: (800) 770-8287
(617) 924-9997
Fax: (617) 924-9998
E-mail: info@tbts.org
Web: www.tbts.org

The BTS CARES Financial Assistance Program was created to provide supplementary financial assistance to individuals experiencing financial need. This program covers specific non-medical costs related to a primary brain tumor diagnosis, and does not cover direct medical expenses. Grants of up to \$2,000 dollars, per family, per year, are available to assist with the costs of local transportation, home health assistance, home adaptations and child care.

CANCER CARE, INC.

275 7th Avenue
New York, NY 10001
Phone: (800) 813-4673
(212) 712-8400
E-mail: info@cancercare.org
Web: www.cancercare.org

Cancer Care, Inc. services include financial assistance for services such as homemakers, home health aides, and housekeepers, as well as transportation for medical appointments.

CANCER FUND OF AMERICA

2901 Breezewood Lane
Knoxville, TN 37921-1099
Phone: (800) 578-5284
(865) 938-5281
E-mail: info@cfoa.com
Web: www.cfoa.org

The Cancer Fund of America exists to provide supplies to medically indigent cancer patients anywhere in the country, whether or not they already receive public support. It is funded strictly by

donations and ships items such as bed pads, diapers and nutritional supplements free of charge to patients. Physician must certify diagnosis and financial need.

THE CANDLELIGHTERS CHILDHOOD CANCER FOUNDATION

P.O. Box 498
Kensington, MD 20895-0498
Phone: (800) 366-2223
(301) 962-3520
Fax: (301) 962-3521
E-mail: staff@candlelighters.org
Web: www.candlelighters.org

The Candlelighters Childhood Cancer Foundation is an informational clearing-house for parents of children with cancer. A quarterly newsletter is published for adults and young people. Services include an Ombudsman program to assist adults who had cancer as a child and are experiencing difficulties with insurance coverage or employment problems. They also offer a reduced-cost prescription drug service. The Foundation has multiple active support groups around the United States and in 30 countries.

GENENTECH ACCESS TO CARE FOUNDATION

1 DNA Way MS #13A
South San Francisco, CA 94080
Phone: (800) 530-3083
Fax: (650) 225-1366
Web: www.spoconline.com

Genentech has established the Genentech® Access to Care Foundation for each of its marketed products to make them available to qualified uninsured patients, patients deemed uninsured due to denial by payers, or underinsured patients in the United States. Products include Avastin, Herceptin, Rituxan, and Tarceva.

HILL-BURTON FREE HEALTH CARE

5600 Fishers Lane, Room 10-105
Rockville, MD 20857
Phone: (800) 638-0742
(301) 443-3376
Fax: (301) 443-1989
Web: www.hrsa.gov

Administered by the Department of Health and Human Services, this federal program includes medical facilities, hospitals and nursing homes, providing low-income persons with free or low-cost care. Eligibility standards vary between facilities, depending on income and family size—some will accept income up to three times the poverty level. Facilities may not discriminate against Medicare or Medicaid patients. Medicare deductions and insurance co-payments are not covered.

NATIONAL ASSOCIATION FOR THE TERMINALLY ILL

P.O. Box 368
Shelbyville, KY 40066
Phone: (888) 847-0390
E-mail: info@terminallyill.org
Web: www.terminallyill.org

The National Association for the Terminally Ill offers financial aid to children and families who are dealing with a terminal illness. Confidential financial assistance is offered via a special online link.

NATIONAL CHILDREN'S CANCER SOCIETY

1015 Locust Street, Suite 600
St. Louis, MO 63101
Phone: (800) 532-6459
Fax: (314) 241-1996
E-mail: pfs@children-cancer.com
Web: www.children-cancer.com

The National Children's Cancer Society provides financial assistance for children diagnosed before the age of 18 and in need of a bone marrow transplant.



**Financial and
Insurance
Organizations**

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Assistance is provided for, but not limited to, donor search, transplant procedure, lost parental income, and living expenses. NCCS will assist in fundraising upon request. It also provides fundraising information and patient advocacy services.

PATIENT ADVOCATE FOUNDATION (PAF)

700 Thimble Shoals Boulevard, Suite 201
Newport News, VA 23606

Phone: (800) 532-5274

(866) 512-3861 (Co-Pay Relief)

Fax: (757) 873-8999

Web: www.patientadvocate.org
www.copays.org

PAF is a non-profit organization that seeks to safeguard patients through effective mediation assuring access to care, maintenance of employment and preservation of their financial stability. PAF introduced its Co-Pay Relief Program in 2003. The program provides co-payment assistance to insured Americans who qualify financially and medically, including those diagnosed with a brain tumor.

FINANCIAL DISABILITY AND ASSISTANCE ORGANIZATIONS

MEDICAID

Medicaid is a federally funded program that provides medical insurance to persons who receive Aid to Families with Dependent Children (AFDC) and Supplemental Security Income (SSI). Each state has different requirements and programs; call your local Department of Social Services to receive more information or check with your hospital social worker.

MEDICARE

To qualify for Medicare - Federal Health Insurance program:

You qualify at any age if you have kidney failure or are blind;

or

You have received Social Security Disability (SSDI/SSA) benefits for 24 months;

or

You are 65 years old or more.

SOCIAL SECURITY

ADMINISTRATION offers two programs – Social Security Disability and Supplemental Security Income – for people who are considered disabled.

To qualify for Social Security Disability (SSD):

You must be disabled—defined as “any medical condition whether physical or mental—that prevents or is expected to prevent you from working for at least 12 months.”

If you are over 31, you must also have paid a minimum amount into the Social Security system during five of the past ten years before becoming disabled.

If you are under 31, this requirement is lower—paying into the system means that you must have worked in a job or jobs where Social Security taxes (FICA) were withheld from your paycheck, or you must have worked as a self-employed person who paid self-employment taxes.

If you are applying for a minor, ask your Social Security Administration office for special requirements for disabled minors.

Contact the **NATIONAL ORGANIZATION OF SOCIAL SECURITY CLAIMANTS REPRESENTATIVES (NOSSCR)** if you have questions regarding qualifications required for Social Security and Supplemental Security Income. Call (800) 341-2804 or visit www.nosscr.org.

THE DEPARTMENT OF HEALTH AND HUMAN SERVICES

offers answers to questions about disability benefits, State Disability Insurance (SDI), Supplemental Security Income (SSI), Medicaid, Medicare, permanent retirement, and survivor benefits.

Phone: (800) 772-1213

THE NATIONAL ELDERCARE LOCATOR

is an organization with information on over 1,800 centers, programs and associations across the country. See their listing in Section 3 – Elderly Healthcare Organizations, page 19.

Phone: (800) 677-1116

BENEFITS CHECKUP

is a service of the National Council on Aging, listed in Section 3 – Elderly Healthcare Organizations.

Phone: (202) 479-1200

To apply for Social Security Disability (SSD):

You should apply as soon as you become disabled and are no longer working to allow plenty of time for your application to be processed.

Begin the process by contacting SSD at (800) 772-1213 Monday – Friday to schedule a telephone or office interview. If you are bedridden and a telephone appointment is not possible, you may request a home or hospital visit. If you schedule an office appointment, find out which office is closest to you. In addition, be certain to ask which documents, such as a birth certificate or Social Security card, will be necessary for your appointment.

To qualify for Supplemental Security Income (SSI):

If you are disabled and have financial needs you may be eligible if you meet the specific requirements for SSI. For further information regarding requirements, call

your Social Security office at (800) 772-1213 to get a copy of the pamphlet *What You Need to Know When You Get Supplemental Security Income* (pamphlet #05-11011), published by the Social Security Administration.

To apply for Supplemental Security Income (SSI):

You may begin the process by contacting SSI by telephone (800) 772-1213, Monday – Friday to schedule a telephone or office appointment. If you are bedridden and a telephone appointment is not possible, you can request a home or hospital visit. If you schedule an office appointment, find out which office is closest to your home.

Be certain to ask which documents, such as a birth certificate or Social Security card, that you will need for your appointment.

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UNITED STATES DEPARTMENT OF VETERANS AFFAIRS

If you are a veteran and disabled, contact the Compensation and Pension Service Department to learn if you are entitled to support. The Department administers a variety of benefits and services for veterans, their dependents and survivors, including, but not limited to: service-connected compensation, DIC, non-service connected pension, burial & accrued benefits, guardianship and public contact services. For information please contact the U.S. Department of Veterans Affairs at (800) 827-1000 or www.vba.va.gov.

GENERAL INSURANCE ORGANIZATIONS

THE CENTER FOR PATIENT PARTNERSHIPS

975 Bascom Mall, Suite 4311
Madison, WI 53706
Phone: (608) 265-6267
E-mail: cpp@law.wisc.edu
Web: www.law.wisc.edu/patient_advocacy/functions/advocacy.html

The Center for Patient Partnerships helps patients and families get information about diagnosis and treatment options, insurance coverage and billing issues, employment and disability questions and conflicts. They help patients make their own decisions through careful, informed deliberation, and they help them advocate for the care they need with providers, payers, and others. There are no charges for their services and no geographic limits to their service area.

COMMUNICATING FOR AGRICULTURE AND THE SELF-EMPLOYED

112 East Lincoln
Fergus Falls, MN 56538
Phone: (800) 432-3276
(218) 739-3241
Fax: (218) 739-3832
Web: www.selfemployedcountry.org

Communicating for Agriculture and the Self-Employed publishes a book entitled *Comprehensive Health Insurance for High Risk Individuals*, which lists and describes the different high-risk insurance plans that are available in each state, i.e. the Major Risk Medical Insurance Program (MR. MIP) in California. These programs accept people with preexisting conditions who have documentation that they've been denied coverage or offered higher rates than those of the local high risk plan. Patients are advised to begin the application process as soon as possible, as there are often long waiting lists; interim coverage is sometimes available through an associated provider.

AMERICA'S HEALTH INSURANCE PLANS

601 Pennsylvania Avenue NW
South Building, Suite 500
Washington, D.C. 20004-1204
Phone: (202) 778-3200
Fax: (202) 331-7487
Web: www.ahip.org

The Health Insurance Association of America conducts surveys to determine the reasonable and customary health insurance fees for different areas.



**INSURANCE INFORMATION
INSTITUTE**

110 William Street
New York, NY 10038
Phone: (800) 331-9146
(212) 346-5500
E-mail: john@iii.org
Web: www.iii.org

The Insurance Information Institute information line offers aid to consumers in locating appropriate insurance and can answer questions about insurance issues and complaint procedures.

**MEDICAL INSURANCE CLAIMS,
INC.**

170 Kinnelon Road, Suite 10
Kinnelon, NJ 07405
Phone: (800) 355-2662
(973) 492-2828
Fax: (973) 492-9068
E-mail: info@micinsurance.com
Web: www.miconline.com

The Medical Insurance Claims, Inc. submits and follows up on medical bills to ensure maximum reimbursements. MIC produces a weekly column, *Understanding Your Health Insurance*.

**NATIONAL COALITION FOR
CANCER SURVIVORSHIP**

1010 Wayne Avenue, Suite 770
Silver Spring, MD 20910
Phone: (877) 622-7937
(301) 565-9127
Fax: (301) 565-9670
E-mail: info@canceradvocacy.org
Web: www.canceradvocacy.org

The National Coalition for Cancer Survivorship specializes in patient advocacy and assistance with regard to employment issues, job discrimination and insurance concerns. The staff will provide assistance to cancer survivors in locating cancer services and support organizations. For additional services offered by NCCS, see Sections 2 and 6.

**PATIENT ADVOCATE
FOUNDATION**

700 Thimble Shoals Boulevard, Suite 200
Newport News, VA 23606
Phone: (800) 532-5274
Fax: (757) 873-8999
E-mail: help@patientadvocate.org
Web: www.patientadvocate.org

The Patient Advocate Foundation serves as an active liaison between the patient and their insurer, employer and/or creditors to resolve insurance, job discrimination and/or debt crisis matters relative to their diagnosis through case managers, doctors and attorneys.

STATE HEALTH INSURANCE ASSISTANCE PROGRAMS provide free help with questions you may have concerning health care costs. Contact the State Health Insurance Assistance Program in your state for help with Medicare. You can visit the website at: www.shiptalk.org.

See the following page for a list of contact information by state.



STATE HEALTH INSURANCE ASSISTANCE PROGRAMS

Alabama

Phone: (800) 243-5463
(334) 242-5743
TDD: (334) 242-8895

Alaska

Phone: (800) 478-6065
(907) 269-3680
TDD: (907) 405-5437

Arizona

Phone: (800) 432-4040
(602) 542-6595
TDD: (602) 542-6366

Arkansas

Phone: (800) 224-6330
(501) 371-2782

California

Phone: (800) 434-0222
(916) 419-7541
TDD: (800) 735-2929

Colorado

Phone: (800) 696-7213
(303) 894-7552
TDD: (303) 894-7880

Connecticut

Phone: (800) 994-9422
(860) 424-5245
TDD: (860) 842-5424

Delaware

Phone: (800) 336-9500
(302) 739-6266

District of Columbia

Phone: (202) 739-0668
TDD: (202) 973-1079

Florida

Phone: (800) 963-5337
(850) 414-2060
TDD: (850) 414-2001

Georgia

Phone: (800) 669-8387
(404) 657-5334

Guam

Phone: (671) 735-7382
TDD: (671) 734-7415

Hawaii

Phone: (808) 586-7299
(888) 875-9229

Idaho

Phone: (800) 247-4422
(208) 334-4352
TDD: (800) 377-3529

Illinois

Phone: (800) 548-9034
(217) 785-9021
TDD: (217) 524-4872

Indiana

Phone: (800) 452-4800
(317) 233-3475

Iowa

Phone: (800) 351-4664
(515) 281-5705
TDD: (800) 735-2942

Kansas

Phone: (800) 860-5260
(316) 337-7386
TDD: (877) 253-3151

Kentucky

Phone: (877) 293-7447
TDD: (888) 642-1137

Louisiana

Phone: (800) 259-5301
(225) 342-5301

Maine

Phone: (877) 353-3771
(207) 621-0087
TDD: (207) 287-9234

Maryland

Phone: (800) 243-3425
(410) 767-1100
TDD: (800) 735-2258

Massachusetts

Phone: (800) 882-2003
TDD: (800) 243-4636

Michigan

Phone: (800) 803-7174
(517) 886-1242

Minnesota

Phone: (800) 333-2433
TDD: (800) 627-3529

Mississippi

Phone: (800) 948-3090
(601) 359-4929

Missouri

Phone: (800) 390-3330
(573) 817-8320

Montana

Phone: (800) 551-3191
(406) 444-7870

Nebraska

Phone: (800) 234-7119
(402) 471-2201
TDD: (800) 833-7352

Nevada

Phone: (800) 307-4444
(702) 486-3478

New Hampshire

Phone: (800) 852-3388
(603) 225-9000
TDD: (603) 225-9000

New Jersey

Phone: (800) 792-8820
TDD: (800) 992-0165

New Mexico

Phone: (800) 432-2080
(505) 476-4799

New York

Phone: (800) 342-9871

North Carolina

Phone: (800) 443-9354
(919) 807-6900
TDD: (800) 735-2962

North Dakota

Phone: (888) 575-6611
(701) 328-2440
TDD: (800) 366-6888

Ohio

Phone: (800) 686-1578
(614) 644-3458
TDD: (614) 644-3745

Oklahoma

Phone: (800) 763-2828
(405) 521-6628

Oregon

Phone: (800) 772-4134
(503) 378-2014
TDD: (800) 735-2900

Pennsylvania

Phone: (800) 783-7067
(717) 783-8975

**STATE HEALTH
INSURANCE
ASSISTANCE
PROGRAMS
(continued)**

Puerto Rico

Phone: (877) 725-4300
(787) 721-6121

Rhode Island

Phone: (401) 462-4444

South Carolina

Phone: (800) 868-9095
(803) 734-9900

South Dakota

Phone: (800) 536-8197
(605) 733-3656

Tennessee

Phone: (877) 801-0044
TDD: (615) 532-3893

Texas

Phone: (800) 252-9240
TDD: (800) 735-2989

Utah

Phone: (800) 541-7735
(801) 538-3910

Vermont

Phone: (800) 642-5119
(802) 748-5182

Virgin Islands

Phone: (340) 772-7368

Virginia

Phone: (800) 552-3402
(804) 662-9333
TDD: (800) 552-3402

Washington

Phone: (800) 562-6900
(360) 725-7073
TDD: (360) 586-0241

West Virginia

Phone: (877) 987-4463
(304) 558-3317

Wisconsin

Phone: (800) 242-1060
TDD: (888) 701-1255

Wyoming

Phone: (800) 856-4398
(307) 777-6807

QUICK INSURANCE FACTS

Here are a few definitions of common insurance terms:

PRIVATE INSURERS are companies such as Blue Cross and Blue Shield, Aetna, Cigna, etc. that contract with employers or individuals to provide insurance benefits.

FOR-FEE-SERVICE health insurance plans allow the holder to make almost all health care decisions independently. The plan holder pays for a service, then submits the claim to the insurance company. If the service is covered in the policy, a reimbursement is mailed.

HEALTH MAINTENANCE ORGANIZATIONS (HMO) deliver medical services through physicians and other providers who contract with or are employed by the insurer. Only networked providers are covered.

POINT OF SERVICE (POS) plans often known as open-ended HMOs or PPOs permit enrollees to chose providers outside of the plan, yet encourage the use of network providers.

PREFERRED PROVIDER ORGANIZATIONS (PPO) authorize a group of medical care providers who furnish services at lower-than-usual fees in exchange for prompt payment and a pre-determined number of patients. Enrollees may select any physician they like, however if the physician is not on the PPO list, the co-pay will be higher.

FEDERAL AND STATE INSURANCE coverage includes both Medicare (insurance for the elderly) and Medicaid (insurance for low-income individuals and the disabled).

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SCHOLARSHIP INFORMATION

American Council on Education

Web: www.acenet.edu

A guide to education legislation in Washington and local education news and events.

Andre Sobel River of Life Foundation

Web: www.andreriveroflife.org

This organization honors young cancer survivors and enables them to fulfill a cherished desire by providing cash awards to be used in any way the recipient chooses.

Cancer Survivors' Fund

P.O. Box 792

Missouri City, TX 77459

Phone: (281) 437-7142

Fax: (281) 437-9568

E-mail: csf@cancersurvivorsfund.org

Web: www.cancersurvivorsfund.org

Cancer Survivors' Fund provides scholarships for young cancer survivors who are enrolled in or accepted for enrollment in an accredited undergraduate school.

College is Possible

Web: www.collegeispossible.org

In partnership with the American Council on Education, this website offers details on applying, choosing and financing college.

FinAid—The SmartStudent Guide to Financial Aid

Web: www.finaid.org/otheraid/cancer.phtml

A searchable database of scholarships and a general information guide to financial aid.

The George Bartol Memorial Scholarship Fund

Web: www.vba.va.gov

This scholarship was established to aid children who have lost a biological parent to brain cancer or children who have a biological parent battling brain cancer. Children of Vietnam Veterans who have not been awarded VA Chapter 35 benefits are strongly encouraged to apply. For an application, please e-mail Heather Bartol at heather.bartol@vba.va.gov.

George Washington University Heath Resource Center

2121 K Street NW, Suite 220

Washington, D.C. 20037

Phone: (202) 973-0904

Web: www.heath.gwu.edu

A national clearinghouse for post-secondary education options for individuals with intellectual disabilities.

Pacific West Cancer Fund

320 Andover Park East, Suite 275

Seattle, WA 98188

Stephanie Cunningham, Donald Traver (fund administrator)

There is no website, but the financial office at any college or university should be able to provide this scholarship information.

National Dissemination Center for Children with Disabilities

P.O. Box 1492

Washington, D.C. 20013

Phone: (202) 884-8441

Web: www.nichcy.org

This website contains information on each state's vocational and educational programs as well as federal government contact information.

Patient Advocate Foundation

700 Thimble Shoals Boulevard, Suite 200
Newport News, VA 23606

Phone: (800) 532-5274

Web: www.patientadvocate.org

This site has criteria and a downloadable application for an annual \$5,000 scholarship for cancer survivors.

Pediatric Brain Tumor Foundation

302 Ridgefield Court
Asheville, NC 28806

Phone: (800) 253-6530

E-mail: familysupport@pbtfus.org

Web: www.pbtfus.org

The foundation offers scholarships for brain tumor survivors.

The SAMFund

P.O. Box 35705

Brighton, MA 02135

E-mail: info@thesamfund.org

Web: www.thesamfund.org

The SAMFund distributes grants and scholarships in an effort to enable survivors to pursue their educational or professional goals.

Scholarship Resource Network Express

Web: www.srnexpress.com

Free scholarship search.

Tim & Tom Gullikson Foundation

8000 Sears Tower

Chicago, IL 60606

Phone: (888) 485-5457

Web: www.gulliksonfoundation.org

This scholarship is for educational programs, including vocational rehabilitation programs. It is open to brain tumor patients/survivors and/or children of brain

tumor patients/survivors. The application is online and also available by calling the foundation.

The Ulman Cancer Fund for Young Adults

4725 Dorsey Hall Drive, Suite A

Ellicott City, MD 21042

Phone: (888) 393-3863

Web: www.ulmanfund.org

This site has downloadable applications for two \$1,000 scholarships.

Specific Scholarships

American Cancer Society

Phone: (888) 227-2345

Web: www.cancer.org

The ACS offers college scholarships to survivors in many states. When using the website, go to “Resources” and enter your zip code for details about scholarships in your state.

American Speech-Language-Hearing Foundation (Leslie Isenberg Fund for Student with Disability)

10801 Rockville Pike

Rockville, MD 20852

Phone: (301) 897-5700

Web: www.free-4u.com/leslie_isenberg_fund_for_student_with_disability.htm

This is a \$2,000 scholarship to a full-time graduate student with a disability who is enrolled in a communications sciences disorders program.



The Ashley Foundation, Inc.

22 S. Market Street, Suite 17
Fredrick, MD 21701
Phone: (301) 694-6414
Web: www.theashleyfoundation.org

The criteria and application are available at this site. The scholarship is for Maryland residents.

Cancer Federation, Inc.

P.O. Box 1298
Banning, CA 92220
Web: www.cancerfed.com

Scholarships are for biology majors interested in research. The scholarships are available at several colleges and universities.

Brain Tumor Foundation for Children, Inc.

1835 Savoy Drive, Suite 200
Atlanta, GA 30341
Phone: (770) 458-5554
Web: www.braintumorkids.org

This program provides financial assistance and scholarships for survivors of pediatric brain tumor or spinal cord tumors. Applicants must be Georgia residents.

Central Arkansas Radiation Therapy Institute (CARTI)

Web: www.carti.com

The Dennis Jungmeyer CARTI Kids Scholarship is for pediatric patients treated at CARTI.

Jay's World

Web: www.jaysworld.org

Jay's World offers a scholarship to a young adult who is cured of cancer, in remission, or able to attend college while undergoing treatment, and is a resident of New York State.

Stephen T. Marchello Scholarship Foundation

1170 E. Long Place
Centennial, CO 80122
Phone: (303) 886-5018
Web: www.stmfoundation.org

The Stephen T. Marchello Scholarship Foundation provides scholarships for post-secondary education to Colorado high school survivors of childhood cancer.

SuperSibs!

1566 W. Algonquin Road, Suite 224
Hoffman Estates, IL 60195
Phone: (866) 444-7427
Web: www.supersibs.org

This site has criteria and application for two \$5,000 scholarships to be given to siblings of childhood cancer survivors.

Section 8

International Organizations and Centers

Much of the following list was obtained from the International Union Against Cancer (UICC), which unites 275 member organizations in 85 countries in the global fight against cancer. On the UICC website, you can find the locations of hospitality houses throughout the world, learn about global efforts to promote education and prevention, and view the listings of more than 200 international cancer organizations. **To learn more, visit www.uicc.org.**

INTERNATIONAL

International Brain Tumour Alliance

P.O. Box 244, Tadworth, Surrey KT20 5WQ, United Kingdom

Phone: 44-0-1737-813872

Fax: 44-0-1737-812712

E-mail: kathy@theibta.org

Web: www.theibta.org

The International Brain Tumour Alliance is a worldwide coalition of brain tumor support, advocacy and information groups that seeks to achieve a wider public understanding of the challenges faced by those affected by brain tumors. The IBTA's work includes advocacy for access to new treatments, assistance in the establishment of new brain tumor groups worldwide where they do not yet exist, and collaboration with other groups and individuals in the brain tumor community.



ARGENTINA

Liga Argentina de Lucha Contra el Cáncer (LALCEC)

Aráoz 2380 C1425DGJ Buenos Aires
Phone: 011 4832 4800
E-mail: info@lalcec.org.ar
Web: www.lalcec.org.ar

Sociedad Latinoamericana y del Caribe de Oncología Médica (SLACOM)

Av. Córdoba 2415, 5° Piso, C1120AAG
Buenos Aires
Phone: 54 11 4961 0981
Fax: 54 11 4964 0504
E-mail: secretaria@slacom.org
Web: www.slacom.org

AUSTRALIA

Brain Tumour Australia

P.O. Box 47
Kotara NSW 2289
E-mail: secretary@bta.org.au
Web: www.bta.org.au

Cancer Council ACT

5 Richmond Avenue, Fairbairn ACT 2609
Phone: 02 6257 9999
Fax: 02 6257 5055
E-mail: reception@actcancer.org
Web: www.actcancer.org

Cancer Council Australia

GPO Box 4708, Sydney NSW 2001
Level 5, Medical Foundation Building
92-94 Parramatta Road
Camperdown NSW 2050
Phone: 02 9036 3100
Toll-free from anywhere in Australia:
13 11 20
Fax: 02 9036 3101
E-mail: info@cancer.org.au
Web: www.cancer.org.au

Cancer Council New South Wales

153 Dowling Street
Woolloomooloo, NSW 2011
PO Box 572
Kings Cross NSW 1340
Phone: 61 2 9334 1900
Fax: 61 2 9358 1452
E-mail: info.metro@nswcc.org.au
Web: www.cancercouncil.com.au

Cancer Council Northern Territory

Casi House Unit 2 & 3
25 Vanderlin Drive
Wanguri, P.O. Box 42719 Casuarina
Phone: 08 8927 4888
Fax: 08 8927 4990
E-mail: admin@cancernt.org.au
Web: www.cancercouncilnt.com.au

Cancer Council South Australia

202 Greenhill Road
Eastwood SA 5063
Phone: 08 8291 4111
Fax: 08 8291 4122
E-mail: tcc@cancersa.org.au
Web: www.cancersa.org.au

Cancer Council Tasmania

184 Collins Street
Hobart TAS 7000
Phone: 03 6233 2030
Fax: 03 6233 2123
E-mail: infotas@cancertas.org.au
Web: www.cancertas.org.au

Cancer Council Victoria

1 Rathdowne Street
Carlton, Victoria 3053
Phone: 61 3 9635 5000
Fax: 61 3 9635 5270
E-mail: enquiries@cancervic.org.au
Web: www.cancervic.org.au

Cancer Council Western Australia

46 Ventnor Avenue, West Perth 6005,
Western Australia
Phone: 61 8 9212 4333
Fax: 61 8 9212 4334
Web: www.cancerwa.asn.au



National Cancer Control Initiative

E-mail: lan.Kemp@health.gov.au
Web: www.ncci.org.au

Peter MacCallum Cancer Institute

St Andrews Place, East Melbourne
Victoria 3002
Phone: 61 3 9656 1111
Fax: 61 3 9656 1400
Web: www.petermac.org

Queensland Cancer Fund

553 Gregory Terrace, Fortitude Valley
Queensland 4006
Phone: 61 7 3258 2200
Fax: 61 7 3257 1306
E-mail: qldcf@qldcancer.com.au
Web: www.qldcancer.com.au

**Walter and Eliza Hall Institute of
Medical Research**

1G Royal Parade, Parkville
Victoria 3050
Phone: 61 3 9345 2555
Fax: 61 3 9347 0852
E-mail: information@wehi.edu.au
Web: www.wehi.edu.au

BELGIUM

Belgian Federation Against Cancer

Chaussée de Louvain 479,
1030 Bruxelles
Phone: 02 736 99 99
E-mail: info@cancer.be
Web: www.cancer.be

**European Organisation for Research
and Treatment of Cancer (EORTC)**

Avenue Mounierlaan 83/11, Brussel 1200
Bruxelles
Phone: 32 2 774 1611
Fax: 32 2 772 6333
E-mail: nicole.heine@eortc.be
Web: www.eortc.be

**European Society of Therapeutic
Radiology and Oncology (ESTRO)**

Avenue E. Mounierlaan 83, 1200 Bruxelles
Phone: 32 2 775 9340
Fax: 32 2 779 5494
E-mail: info@Estro.be
Web: www.estro.be

Oncologic Centre Antwerp (OCA)

Lange Gasthuisstraat 35/37, 2000
Antwerpen
Phone: 03 223 5360
Fax: 03 223 5359
E-mail: louis.denis@skynet.be
Web: www.wijook.be/ocasite

Werkgroep Hersentumoren

Gasstraat 5, B-2950 Kapellen
Phone: 32 0 495 303 511
E-Mail: info@wg-hersentumoren.be
Web: www.wg-hersentumoren.be

BRAZIL

Fundação Oncocentro de São Paulo

R. Oscar Freire, 2396 São Paulo-SP – CEP:
05409-012
Phone: (11) 3089-8755
Fax: (11) 3089-8756
E-mail: dsg@fosp.saude.sp.gov.br
Web: www.fosp.saude.sp.gov.br

Instituto Nacional do Câncer (INCA)

Praça Cruz Vermelha, 23 - Centro
20230-130 - Rio de Janeiro - RJ
Phone: 55(21) 2506-6103
Fax: 55(21) 2242-2366
Web: www.inca.gov.br

**Instituto Brasileiro de Controle do
Câncer**

Av. Alcântara Machado, 2576, São Paulo
Phone: (11) 6099-3999
E-mail: rh@ibcc.org.br
Web: www.ibcc.org.br



**Sociedade Brasileira de
Cancerologia**
R Pará 197 Pituba 41837-070 Salvador, BA
Phone: (071) 3240-4868
Fax: (071) 3248-9134
Web: www.sbcancer.org.br

CANADA

British Columbia Cancer Agency
200 - 601 W. Broadway
Vancouver, BC, V5Z 4C2
Phone: (604) 877-6040
Fax: (604) 877-6161
Web: www.bccancer.bc.ca

**Canadian Association of Radiation
Oncology**
600 West 10th Avenue,
Vancouver, BC, V5Z 4E6
Phone: (604) 877-6193
Fax: (604) 877-6193
E-mail: SBroadbe@caro-acro.ca
Web: www.caro-acro.ca

Canadian Cancer Society
10 Avenue Alcorn, Bureau 200
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Phone: 47 22 86 66 00
Fax: 47 22 86 66 10
E-mail: servicetorget@kreftforeningen.no
Web: www.kreftforeningen.no

PANAMA

Asociación Nacional Contra el Cáncer

Ave. Chile y Calle 40 Apartado 7358
Zona 5 Panamá, República de Panamá
Phone: (507) 225-2512
Fax: (507) 225-5366
Web: www.panamatravel.com/ancec/mainanc.htm

PERU

Instituto de Enfermedades Neoplásicas

Av. Angamos Este 2520
Surquillo Lima
Phone: 710-6900
E-mail: postmaster@inen.sld.pe
Web: www.inen.sld.pe

Liga Peruana de Lucha Contra el Cáncer

Jr. Cahuide 955, Jesús María, Lima 11
Phone: 471-7101 / 471-3376
Fax: 470-4182
E-mail: lpcc@post.cosapidata.com.pe
Web: www.terra.com.pe/ligacancer

Oncosalud SAC

Av. Guardia Civil 571 San Borja, Lima
Phone: 224-2474
Fax: 224-2483
E-mail: contactos@oncosalud.com.pe
Web: www.oncosalud.com.pe

PHILIPPINES

Philippine Cancer Society

310 San Rafael Street
San Miguel, Manila 1005
Phone: (632) 733-3485
Fax: (632) 734-2128
Web: www.philcancer.com

POLAND

International Hereditary Cancer Centre

ul. Polabska 4
70-115 Szczecin
Phone: (48-91) 466 15 33
Fax: (48-91) 466 15 53
E-mail: lubinski@sci.pam.szczecin.pl
Web: www.hereditarycancer.net

PORTUGAL

Instituto Português de Oncologia de Francisco Gentil

Web: www.ipolisboa.min-saude.pt

Liga Portuguesa Contra o Cancro

Av. Columbano Bordalo Pinheiro
n° 57-3°F, 1070-061 Lisboa
Phone: 21-7221810
Fax: 21-7268059
E-mail: info@ligacontracancro.pt
Web: www.ligacontracancro.pt

SERBIA AND MONTENEGRO

Serbian Society for the Fight Against Cancer

Pasterova 14 Street, Belgrade
Phone: 011-656-386
Fax: 011-656-386
E-mail: serbca@ncrc.ac.yu
Web: www.serbiancancer.org

SINGAPORE

National Cancer Centre

11 Hospital Drive
Singapore 169610
Phone: 65 6236 9424
Fax: 65 6536 5501
E-mail: coporate@nccs.com.sg
Web: www.nccs.com.sg

Singapore Cancer Society

Block 22 Boon Keng Road #01-11
Singapore 330022
Phone: 6396 6241
Fax: 6396 6243
E-mail: enquiry@singaporecancer
society.org.sg
Web: www.singaporecancer
society.org.sg

SLOVAKIA

Slovak League Against Cancer

Spitalska 21, Bratislava 81232
Phone: 421-2-529-65148
E-mail: lpr@ipr.sk
Web: www.ipr.sk

SLOVENIA

Institute of Oncology Ljubljana

Zaloska cesta 2
SI - 1000 Ljubljana
Phone: 386-1-5879-110
Fax: 386-1-5879-400
E-mail: info@onko-i.si
Web: www.onko-i.si/en

SOUTH AFRICA

Cancer Association of South Africa

P.O. Box 2121 Bedfordview, Johannesburg
2008, Gauteng South Africa
Phone: 0800-22-66-22
27-(0)11-616-7662
Fax: 27-(0)11-622-3424
E-mail: info@cansa.org.za
Web: www.cansa.org.za

SPAIN

Asociación Española Contra el Cáncer

C/ Amador de los Ríos, 5, 28010 Madrid
Phone: 91-319-41-38
Fax: 91-319-09-66
Web: www.todocancer.com/esp

Institut Català d'Oncologia

Unitat d'Atenció al Client
Av. Gran via s/n km 2,7
08907 L'Hospitalet de Llobregat
Phone: 93-260-77-80
Fax: 93-260-77-27
E-mail: ico@ico.scs.es
Web: www.iconcologia.net

SWEDEN

Swedish Cancer Society

David Bagares gata 5, 101 55 Stockholm
Phone: 08-677-10-00
E-mail: info@cancerfonden.se
Web: www.cancerfonden.se

SWITZERLAND

Krebsliga Schweiz

Effingerstrasse 40, Postfach 8219, 3001 Bern
Phone: 0844 85 00 00
Fax: 033 773 65 40
E-mail: info@swisscancer.ch
Web: www.swisscancer.ch

Swiss Institute for Experimental Cancer Research

Ch. des Boveresses 155
Case postale CH - 1066 Epalinges
Phone: 41 (0)21 692 58 58
Fax: 41 (0)21 652 69 33
E-mail: Claudine.Ravussin@isrec.ch
Web: www.isrec.ch



SYRIA

Syrian Cancer Society

Aleppo
P.O. Box 16542
Phone: 963 (21) 2644246
Fax: 963 (21) 26499150
E-mail: scts@scts-sy.org
Web: www.scts-sy.org/en

TAIWAN

Hope Society for Cancer Treatment

Phone: (02)8772-1386
Fax: (02)8772-1349
E-mail: hope@ecancer.org.tw
Web: www.ecancer.org.tw/ehope

John Tung Foundation

Phone: (02)2776-6133
Fax: (02)2752-2455
Web: www.jtf.org.tw

THAILAND

National Cancer Institute of Thailand

268/1 Rama 6 Rd. Radjatewe
Bangkok 10400
Phone: 66 (2) 354-7025
Fax: 66 (2) 354-7028 -35
Web: www.nci.go.th

TUNISIA

Association Tunisienne de Lutte contre le Cancer

Boulevard du 9 Avril 1938
1006 Tunis
Tel: 216 71 561 184
Fax: 216 71 573 642
E-mail: stelfair@planet.tn
Web: www.atcc.org.tn

TURKEY

Turkish Association for Cancer Research and Control

Ataç 1. Sokak No: 21/1
06410 Yenisehir/Ankara
Phone: 312-431 2950 or 312-431 2951
Fax: 312-431 3958
E-mail: info@turkkanser.org.tr
Web: www.turkcancer.org

UNITED KINGDOM

Action Cancer

1 Marlborough Park, Belfast BT9 6XS
Phone: 028 9080 3344
Fax: 028 9080 3356
E-mail: info@actioncancer.org
Web: www.actioncancer.org

Brain Tumour UK

P.O. Box 27108
Edinburgh, EH10 7WS
Phone: 0845 4500 386
E-mail: enquiries@braintumouruk.org.uk
Web: www.braintumouruk.org.uk

British Association for Cancer Research

BACR Secretariat
c/o The Institute of Cancer Research
McElwain Laboratories
Cotswold Road
Sutton
Surrey SM2 5NG
Phone: 44 (0) 20 8722 4208
Fax: 44 (0) 20 8770 1395
E-mail: bacr@icr.ac.uk
Web: www.bacr.org.uk

Cancer Research UK

61 Lincoln's Inn Fields
London, WC2A 3PX
Phone: 020 7121 6699
Fax: 020 7269 3100
Web: www.cancerresearchuk.org



Cancer Backup

3 Bath Place, Rivington Street
London EC2A 3JR
Phone: 0808 800 1234
(0) 20 7696 9003
Fax: (0) 20 7696 9002
Web: www.cancerbackup.org

Cochrane Cancer Network

Web: www.canet.org

The Institute of Cancer Research

123 Old Brompton Road,
London SW7 3RP
Phone: 44 (0) 20 7352 8133
Fax: 44 (0) 20 7370 5261
Web: www.icr.ac.uk

Lymphoma Coalition

E-mail: info@lymphomacoalition.org
Web: www.lymphomacoalition.org

Macmillian Cancer Support

89 Albert Embankment, London SE1 7UQ
Phone: 020 8563 9800
Web: www.macmillan.org.uk

The Paterson Institute for Cancer Research

Wilmslow Road, Withington
Manchester M20 4BX
Phone: 0161 446 3156
Fax: 0161 446 3109
E-mail: inquiries@picr.man.ac.uk
Web: www.paterson.man.ac.uk

World Cancer Research Fund (WCRF)

19 Harley Street, London W1G9QJ
Phone: 020 7343 4200
Fax: 020 7343 4201
E-mail: wcrf@wcrf.org
Web: www.wcrf-uk.org

URUGUAY

Comisión Honoraria de Lucha contra el Cáncer

Brandzen 1961 Piso 12
Phone: 598 2 402 0809
598 2 402 0809
Fax: 598 2 402 0810
Web: www.urucan.org.uy

VENEZUELA

Sociedad Anticancerosa de Venezuela

Canonigos a Esperanza, No. 43
San Jose 1010 Caracas
Phone: 58 2 561 9622
Web: www.sociedadanticancerosa.org

VIETNAM

National Cancer Institute

43- Quan Su Street - Hanoi
Phone: 84 4 825 2143
84 4 825 7697
Fax: 84 4 825 3757
E-mail: bvk@nci.org.vn
Web: www.nci.org.vn



**Rehabilitation
Organizations and
Resources**

Nationwide Rehabilitation
Organizations

State Vocational
Rehabilitation Agencies

Section 9

Rehabilitation Organizations and Resources

NATIONWIDE REHABILITATION ORGANIZATIONS

ABLEDATA

8630 Fenton Street, Suite 930
Silver Spring, MD 20910
Phone: (800) 227-0216
Fax: (301) 608-8958
E-mail: abledata@orcmacro.com
Web: www.abledata.com

Abledata provides information about and descriptions of more than 20,000 products for people with physical, sensory, or cognitive disabilities. Information Specialists are available to help provide specific information about a particular device, type of device, and manufacturers and distributors of assistive technology.

AMERICAN PHYSICAL THERAPY ASSOCIATION

1111 North Fairfax Street
Alexandria, VA 22314-1488
Phone: (800) 999-2782
(703) 684-2782
TDD: (703) 683-6748
Fax: (703) 684-7343
E-mail: svcctr@apta.org
Web: www.apta.org

The American Physical Therapy Association can direct patients to the local chapters in their state, which can then give out a list of physical therapists in the area. Patients can also look under “Physical Therapists” in the phone book to find local physical therapy programs.

COMMISSION ON ACCREDITATION OF REHABILITATION FACILITIES

4891 East Grant Road
Tucson, AZ 85712
Phone: (888) 281-6531
(520) 325-1044
Fax: (520) 318-1129
Web: www.carf.org

This is a national organization that maintains the accreditation standards for rehabilitation facilities. It performs external audits on the quality of services for programs such as those related to pain, brain and spinal cord injury, and outpatient medical rehabilitation.



**INDEPENDENT LIVING
RESEARCH UTILIZATION**

2323 South Shepard, Suite 1000
Houston, TX 77019
Phone: (713) 520-0232 (Voice/TDD)
Fax: (713) 520-5785
E-mail: ilru@ilru.org
Web: www.ilru.org

The Independent Living Research Utilization is a national organization that provides information, training, research and technical assistance in independent living. They also publish a newsletter called *Insights*.

**LEARNING SERVICES
CORPORATION**

10 Speen Street, 4th Floor
Framingham, MA 01701
Phone: (888) 419-9955 ext. 12
Web: www.learningservices.com

The Learning Services Corporation specializes in brain injury rehabilitation. There are 10 locations nationwide, and they publish a quarterly newsletter on neuro-rehabilitation called *re-Learning Times*.

REHABTOOL.COM

P.O. Box 572190
Houston, TX 77257
Phone: (281) 531-6106
Fax: (281) 531-6406
E-mail: info@rehabtool.com
Web: www.rehabtool.com

Rehabtool.com is an online resource that helps children and adults with disabilities increase their independence and productivity through the use of assistive technology. Their website provides information about assistive and adaptive technology products, communication devices, computer access equipment, speech synthesis and voice recognition software.

**STATE VOCATIONAL
REHABILITATION AGENCIES**

assist individuals with disabilities.

Services include:

- Career Opportunities
- Education
- Independent Living
- Vocational Training

You can find a complete list online at www.ssa.gov/work/ServiceProviders/rehabproviders.html.

STATE VOCATIONAL REHABILITATION AGENCIES

Alabama

Phone: (334) 281-8780
(800) 441-7607

Alaska

Phone: (907) 465-2814
(800) 478-2815

American Samoa

Phone: (684) 699-1371

Arizona

Phone: (602) 542-3332
(800) 563-1221

Arkansas

Phone: (501) 296-1600
(800) 330-0632

California

Phone: (916) 263-8981

Colorado

Phone: (303) 866-4150
(866) 870-4595

**Commonwealth of
Mariana Islands**

Phone: (670) 664-6448

Connecticut

Phone: (800) 842-1508

Delaware

Phone: (302) 761-8275

District of Columbia

Phone: (202) 442-8663

Florida

Phone: (850) 488-6210
(800) 451-4327



STATE VOCATIONAL REHABILITATION AGENCIES (continued)

Georgia

Phone: (404) 657-3000

Guam

Phone: (671) 475-4200

Hawaii

Phone: (808) 692-7721

Idaho

Phone: (208) 334-3390

Illinois

Phone: (800) 843-6154

Indiana

Phone: (317) 232-1262

Iowa

Phone: (515) 281-4211
(800) 532-1486

Kansas

Phone: (785) 296-3959

Kentucky

Phone: (502) 564-4440

Louisiana

Phone: (504) 925-4131
(800) 737-2958

Maine

Phone: (207) 624-5950
(800) 698-4440

Maryland

Phone: (410) 554-9388
(888) 554-0334

Massachusetts

Phone: (617) 204-3600
(800) 245-6543

Michigan

Phone: (517) 373-4026
(800) 605-6722

Minnesota

Phone: (651) 296-9981
(800) 328-9095

Mississippi

Phone: (601) 853-5100
(800) 443-1000

Missouri

Phone: (573) 751-3251
(877) 222-8963

Montana

Phone: (406) 444-2590
(877) 296-1197

Nebraska

Phone: (402) 471-3644
(800) 742-7594

Nevada

Phone: (775) 684-4070

New Hampshire

Phone: (603) 271-3471
(800) 299-1647

New Jersey

Phone: (609) 292-5987

New Mexico

Phone: (800) 224-7005
(505) 954-8500

New York

Phone: (800) 222-5627

North Carolina

Phone: (919) 855-3500

North Dakota

Phone: (701) 328-8950
(800) 755-2745

Ohio

Phone: (614) 438-1200
(800) 282-4536

Oklahoma

Phone: (405) 951-3400
(800) 845-8476

Oregon

Phone: (503) 945-5880

Pennsylvania

Phone: (717) 787-6176
(800) 622-2842

Puerto Rico

Phone: (787) 727-0610

Rhode Island

Phone: (401) 421-7005

South Carolina

Phone: (803) 896-6500

South Dakota

Phone: (605) 773-3195

Tennessee

Phone: (615) 313-4891

Texas

Phone: (800) 628-5115

Utah

Phone: (801) 538-7530
(800) 473-7530

Vermont

Phone: (800) 361-1239

Virginia

Phone: (800) 552-5019
(804) 662-7000

Virgin Islands

Phone: (340) 774-0930
Ext. 4190

Washington

Phone: (800) 637-5627
(360) 438-8000

West Virginia

Phone: (304) 766-4601
(800) 642-8207

Wisconsin

Phone: (608) 243-5600
(800) 442-3477

Wyoming

Phone: (307) 777-7389

Section 10

Additional Support Resources



BEREAVEMENT SUPPORT

THE COMPASSIONATE FRIENDS, INC.

P.O. Box 3696
Oak Brook, IL 60522-3696
Phone: (877) 969-0010
(630) 990-0010
Fax: (630) 990-0246
E-mail: nationaloffice@compassionatefriends.org
Web: www.compassionatefriends.org

The Compassionate Friends is a mutual assistance organization of support groups for bereaved parents and siblings. This non-profit organization publishes numerous pamphlets for grieving parents and siblings (several of them available in Spanish), as well as a listing of numerous related books that are for sale. Two newsletters are published—one for parents and one for siblings—for which there is a subscription fee. There are hundreds of chapters located across the United States.

HOSPICE FOUNDATION OF AMERICA

1621 Connecticut Avenue NW, Suite 300
Washington, D.C. 20009
Phone: (800) 854-3402
Fax: (202) 638-5312
E-mail: info@hospicefoundation.org
Web: www.hospicefoundation.org

The Hospice Foundation of America has teleconferences and publications on grief bereavement. For additional information regarding other services, see Section 3, page 21.

GRIEF NET

P.O. Box 3272
Ann Arbor, MI 48106-3272
E-mail: cendra@griefnet.org
Web: www.griefnet.org

Grief Net is a collection of resources concerning loss and grief. Resources include information on mailing lists and discussion groups, an online library, and information about support groups. The site is sponsored by Rivendell Resources, a non-profit foundation.

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WELLSPOUSE ASSOCIATION

63 West Main Street, Suite H
Freehold, NJ 07728
Phone: (800) 838-0879
(732) 577-8899
Fax: (732) 577-8644
E-mail: info@wellspouse.org
Web: www.wellspouse.org

The Wellspouse Association is a non-profit national self-help organization serving the “well spouse” of the chronically ill. Members help each other develop coping and survival skills through local support groups (including bereavement), letter and telephone networks, and personal outreach. The foundation publishes a bimonthly newsletter called *Mainstay* and holds West and East Coast regional conferences for spouses.

FASHION, COSMETICS AND PLASTIC SURGERY

ABOUT FACE

123 Edward Street, Suite 1003
Toronto, ON Canada M5G 1E2
Phone: (800) 665-3223
Fax: (416) 597-8494
E-mail: info@aboutfaceinternational.org
Web: www.aboutfaceinternational.org

About Face is an international organization providing information, programs and services to help patients with facial differences and their loved ones.

AMERICAN SOCIETY OF PLASTIC SURGEONS

444 E. Algonquin Road
Arlington Heights, IL 60005
Phone: (888) 475-2784
Web: www.plasticsurgery.org

Contact the American Society of Plastic Surgeons to receive the names of five licensed surgeons located near you. ASOPS is also able to verify that a particular surgeon is licensed.

LET'S FACE IT

University of Michigan
School of Dentistry/Dentistry Library
1011 N. University
Ann Arbor, MI 48109
Phone: (360) 676-7325
E-mail: faceit@umich.edu
Web: www.dent.umich.edu/faceit/

Let's Face It provides information and support resources for people with facial difference and their families. A 50-page resource guide is published annually and is available for \$3.

LOOK GOOD, FEEL BETTER

The Cosmetic, Toiletry and Fragrance Association
1101 17th Street NW, Suite 300
Washington, D.C. 20036
Phone: (800) 395-5665
(800) 227-2345
Web: www.lookgoodfeelbetter.org

The Look Good, Feel Better program offers educational materials and free makeovers for women undergoing cancer treatment. Resources are also available for men and teens.

NATIONAL ALOPECIA AREATA FOUNDATION

P.O. Box 150760
San Rafael, CA 94915-0760
Phone: (415) 472-3780
Fax: (415) 472-5343
E-mail: info@naaf.org
Web: www.alopeciaareata.com

Information is provided about hair loss, current research and treatment, insurance and coping. This group also publishes a newsletter, sponsors an annual international conference and coordinates a network of support groups nationwide.

SOFT OPTIONS

6345 Galletta Drive
Newark, CA 94560
Phone: (510) 300-5885
E-mail: info@wearsoftoptions.com
Web: www.wearsoftoptions.com

The group offers fashionable, absorbent, soft headwear for women and men experiencing hair loss due to cancer treatments.

TENDER LOVING CARE

c/o American Cancer Society
1599 Clifton Road NE
Atlanta, GA 30329-4251
Phone: (800) 227-2345
(800) 850-9445
TDD: (800) 228-4327
Fax: (800) 279-2018
E-mail: customerservice@tlccatalog.org
Web: www.cancer.org

Tender Loving Care prints a free catalog/magazine for female cancer patients. It includes a wide selection of headwear for women experiencing hair loss (often at prices below retail), as well as medical information and articles on cancer-related topics. TLC is a program of the American Cancer Society.

PAIN MANAGEMENT

AMERICAN CHRONIC PAIN ASSOCIATION, INC.

P.O. Box 850
Rocklin, CA 95677
Phone: (800) 533-3231
Fax: (916) 632-3208
E-mail: acpa@pacbell.net
Web: www.theacpa.org

This group offers support and information for people in chronic pain.

AMERICAN PAIN FOUNDATION

201 North Charles Street, Suite 710
Baltimore, MD 21201-4111
Phone: (888) 615-7246
E-mail: info@painfoundation.org
Web: www.painfoundation.org

The American Pain Foundation serves people with extreme pain through the latest research information, advocacy groups and support groups.

AMERICAN PAIN SOCIETY

4700 West Lake Avenue
Glenview, IL 60025
Phone: (847) 375-4715
Fax: (877) 734-8758
E-mail: info@ampainsoc.org
Web: www.ampainsoc.org

The American Pain Society is a multidisciplinary organization of basic and clinical scientists, practicing clinicians, policy analysts, and others. The mission of the APS is to advance pain-related research, education treatment and professional practice.

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MICHIGAN BACK AND NECK PAIN PROGRAM

Michigan Head, Pain and Neurological Institute
3120 Professional Drive
Ann Arbor, MI 48104
Phone: (734) 677-6000
Fax: (734) 677-2422
Web: www.pain.org

The Michigan Head, Pain and Neurological Institute offers comprehensive services for the evaluation and treatment of chronic and acute back and neck pain problems. The system is nationally accredited by the Joint Commission of Accreditation of Health Care Organizations and the Commission of Accreditation of Rehabilitation Facilities, and delivers successful outcomes for referred patients.

NATIONAL CHRONIC PAIN OUTREACH ASSOCIATION

P.O. Box 274
Millboro, VA 24460
Phone: (540) 862-9437
Fax: (540) 862-9485
Web: www.chronicpain.org
E-mail: ncpoa@cfw.com

The National Chronic Pain Outreach Association is an information and referral service for patients dealing with chronic pain due to cancer. It offers numerous educational materials, support groups, health professional referrals, and a newsletter.

NATIONAL HEADACHE FOUNDATION

820 North Orleans, Suite 217
Chicago, IL 60610
Phone: (888) 643-5552
E-mail: info@headaches.org
Web: www.headaches.org

The National Headache Foundation provides the headache sufferer with knowledge and support to deal with the pain. It offers a nationwide network of support groups, a newsletter, educational publications and more.

LONG-TERM CARE

Alabama

Phone: (800) 243-5463
(334) 242-5743

Alaska

Phone: (800) 730-6393
(907) 334-4480

America Samoa

Phone: (800) 999-4454

Arizona

Phone: (800) 432-4040
(602) 542-6454

Arkansas

Phone: (501) 682-8952

California

Phone: (800) 231-4024
(916) 419-7510

Colorado

Phone: (800) 288-1376 ext 217
(303) 722-0300

Connecticut

Phone: (860) 424-5200

Delaware

Phone: (302) 255-9390

District of Columbia

Phone: (202) 434-2140

Florida

Phone: (888) 831-0404

Georgia

Phone: (888) 454-5826

Guam

Phone: (671) 735-7382 ext 5

Hawaii

Phone: (808) 586-0100

Idaho

Phone: (877) 471-2777
(208) 334-3833

Illinois

Phone: (800) 252-8966
(217) 785-3143

Indiana

Phone: (800) 622-4484

Iowa

Phone: (515) 725-3327

Kansas

Phone: (877) 662-8362
(785) 296-3017

Kentucky

Phone: (800) 372-2973
(502) 564-5497
ext. 3438

Louisiana

Phone: (800) 259-4990
(225) 342-7100

Maine

Phone: (800) 499-0229
(207) 621-1079

Maryland

Phone: (800) 243-3425
(410) 767-1091

Massachusetts

Phone: (800) 882-2003
(617) 727-7750

Michigan

Phone: (517) 335-0148

Minnesota

Phone: (651) 431-2500

Mississippi

Phone: (899) 948-3090
(601) 359-4927

Missouri

Phone: (800) 309-3282
(573) 526-0727

Montana

Phone: (800) 332-2272
(406) 444-7785

Nebraska

Phone: (800) 942-7830
(402) 471-2307

Nevada

Phone: (775) 688-2964
ext. 249

New Hampshire

Phone: (800) 442-5640
(603) 271-4704

New Jersey

Phone: (877) 582-6995
(609) 943-4026

New Mexico

Phone: (505) 476-4799

New York

Phone: (800) 342-9871
(518) 474-7329

North Carolina

Phone: (919) 733-8395

North Dakota

Phone: (800) 451-8693

North Mariana Islands

Phone: (800) 999-4454

Ohio

Phone: (800) 266-4346
(614) 644-7922

Oklahoma

Phone: (405) 521-6734

Oregon

Phone: (503) 378-6533

Pennsylvania

Phone: (717) 783-7096

Puerto Rico

Phone: (787) 725-1515

Rhode Islands

Phone: (401) 785-3340

South Carolina

Phone: (803) 734-9898

South Dakota

Phone: (605) 773-3656

Tennessee

Phone: (615) 741-2056

Texas

Phone: (800) 242-2412
(512) 438-4356

Utah

Phone: (801) 538-3910

Vermont

Phone: (802) 863-5620

Virginia

Phone: (804) 565-1600

Virgin Islands

Phone: (787) 725-1515

Washington

Phone: (800) 422-1384
(800) 562-6028

West Virginia

Phone: (304) 558-3317

Wisconsin

Phone: (800) 815-0015

Wyoming

Phone: (307) 322-5553

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PHARMACEUTICAL ASSISTANCE PROGRAMS

Canadian Pharmacy Online

Phone: (800) 226-3784
Web: www.canadadrugs.com

Commitment to Care (Temodar Assistance)

Phone: (800) 521-7157
Web: www.temodar.com

Genentech Patient Access Programs

Phone: (800) 232-2717
Web: www.gene.com
www.spoonline.com

Medicare Rights Center

Phone: (212) 869-3850
Web: www.medicarerights.org

Medicine Bridge

Phone: (877) 667-6337
Web: www.medicinebridge.com

The Medicine Program

Web: www.themedicineprogram.com

Needy Meds

Phone: (215) 625-9609
Web: www.needymeds.com

Partnership for Prescription Assistance

Phone: (888) 477-2669
Web: www.pparx.org

Pharmacia Patients in Need

Phone: (800) 242-7014
Web: www.patientsinneed.com

Rx Assist

Phone: (401) 729-3284
Web: www.rxassist.org

RxHope

Phone: (908) 713-7600
Web: www.rxhope.com

PHARMACEUTICAL COMPANIES

Allos Therapeutics

Phone: (303) 426-6262
Web: www.allos.com

Astra Zeneca

Phone: (800) 424-3727
Web: www.astrazeneca.com

Bristol Myers

Phone: (212) 546-4000
Web: www.bms.com

Elan Pharmaceuticals, Inc.

Phone: (800) 252-3526
Web: www.elan.com

Genentech

Phone: (800) 821-8590
Web: www.gene.com

Glaxo Wellcome, Inc.

Phone: (888) 825-5249
Web: www.gsk.com

NeoPharm

Phone: (847) 887-0800
Web: www.neopharm.com

Purdue Pharma L.P.

Phone: (877) 787-3831
Web: www.pharma.com

Schering Oncology Biotech

Phone: (800) 521-7157
Web: www.schering.com

Smithkline Beecham

Phone: (888) 825-5249
Web: www.gsk.com

Xenova

Phone: 44(0) 1753-706600
Web: www.xenova.com

PSYCHOLOGICAL COUNSELING

Cancer Support Organizations

AMERICAN PSYCHOSOCIAL ONCOLOGY SOCIETY

2365 Hunters Way
Charlottesville, VA 22911
Phone: (866) 276-7443
(434) 293-5330
Fax: (434) 977-0899
E-mail: info@apos-society.org
Web: www.apos-society.org

The American Psychosocial Oncology Society has been established for cancer patients and their caregivers to locate local referrals for counseling and support services. The referral program aims to connect patients or patient advocacy organizations to psychiatrists, psychologists, nurses and social workers skilled in the management of cancer-related distress.

CANCER CARE INC. COUNSELING LINE

Phone: (800) 813-4673

This support line is staffed 24 hours with professionals trained to help cancer patients and family members with psychological, financial, and bereavement counseling.

THE WELLNESS COMMUNITY

919 18th Street NW, Suite 54
Washington, D.C. 20006
Phone: (888) 793-9355
(202) 659-9709
Fax: (202) 659-9301
E-mail: help@thewellnesscommunity.org
Web: www.wellness-community.org

The Wellness Community is designed to assist people in their recovery from cancer through education and support across the country. Its staff helps teach

stress management, nutrition, pain control, relaxation and other techniques through many workshops. WC also offers grief counseling.

Psychological Organizations

THE NEUROPSYCHOLOGY CENTRAL WEBSITE

E-mail: jbrowndyke@neuropsychologycentral.com
Web: www.neuropsychologycentral.com

This site can help you find a variety of helpful information concerning research, pediatric medicine, neuromedicine, imaging and more.

SEX AND SEXUALITY

AMERICAN ASSOCIATION OF SEX EDUCATORS, COUNSELORS AND THERAPISTS

P.O. Box 1960
Ashland, VA 23005-1960
Phone: (804) 752-0026
Fax: (804) 752-0056
E-mail: aasect@aasect.org
Web: www.aasect.org

For names of sex therapists in your area, send inquiry and a self-addressed stamped envelope to AAECT at the above address.

AMERICAN CANCER SOCIETY

1599 Clifton Road NE
Atlanta, GA 30329-4251
Phone: (800) 227-2345
Web: www.cancer.org

The American Cancer Society offers helpful articles and publications on how to cope with changes in sexual desire and some of the physiological side effects that can occur during treatment.

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CANCER CARE, INC.

275 7th Avenue, 2nd Floor
New York, NY 10001

Phone: (800) 813-4673
(212) 712-8400

E-mail: info@cancercare.org

Web: www.cancercare.org

Cancer Care, Inc. services include psychological counseling for cancer patients and offers a Sexuality and Cancer Program. To learn about additional services from this organization, see Sections 2 or 7. Support is also available in Spanish.

STEREOTACTIC RADIOSURGERY AND RADIATION

Cyberknife

ACCURAY

1310 Chesapeake Terrace
Sunnyvale, CA 94089

Phone: (408) 716-4600

Fax: (408) 716-4601

Web: www accuray.com/cyberknife.htm

Gamma Knife

ELEKTA, INC.

Neurosurgery & Oncology Department
4775 Peachtree Industrial Boulevard
Building 300, Suite 300

Norcross, GA 30092

Phone: (770) 300-9725

Fax: (770) 448-6338

E-mail: info.america@elekta.com

Web: www.elekta.com

INTERNATIONAL RADIOSURGERY SUPPORT ASSOCIATION

3005 Hoffman Street
Harrisburg, PA 17110

Phone: (717) 260-9808

Fax: (717) 260-9809

E-mail: office@irsa.org

Web: www.irsa.org

Novalis

BRAINLAB, INC.

3 Westbrook Corporate Center
Suite 400

Westchester, IL 60154

Phone: (800) 784-7700

(708) 409-1343

Fax: (708) 409-1619

Web: www.novalis-surgery.com

General Radiation Information

AMERICAN COLLEGE OF RADIOLOGY

1891 Preston White Drive
Reston, VA 20191

Phone: (800) 227-5463

(703) 648-8900

Fax: (703) 648-2514

E-mail: info@acr.org

Web: www.acr.org

**Proton Beam Acceleration
Radiotherapy**

**LOMA LINDA UNIVERSITY
MEDICAL CENTER**

Proton Inquiries, Department of Radiation
Medicine, Room A875,
11234 Anderson Street
Loma Linda, CA 92354
Phone: (800) 776-8667
(909) 558-4288
Fax: (909) 588-4829
E-mail: referral@dominion.llumc.edu
Web: www.llu.edu/proton

X-Knife

RADIONICS, INC.

22 Terry Avenue
Burlington, MA 01803-2516
Phone: (800) 466-6814
(781) 272-1233
Fax: (781) 272-2428
E-mail: info@radionics.com
Web: www.radionics.com

FERTILITY AND PREGNANCY

FERTILE HOPE

Physical Address:

42 W. 24th Street
New York, NY 10010

Mailing Address:

P.O. Box 624
New York, NY 10014
Phone: (888) 994-4673
E-mail: info@fertilehope.org
Web: www.fertilehope.org

Founded in October 2001, Fertile Hope is a national non-profit organization dedicated to providing reproductive information, support and hope to cancer patients whose medical treatments present the risk of infertility. Fertile Hope is currently pursuing strategies in research, awareness, education, financial assistance and support.

**PREGNANT WITH CANCER
NETWORK**

P.O. Box 1243
Buffalo, NY 14220
Phone: (800) 743-4471
E-mail: info@pregnantwithcancer.org
Web: www.pregnantwithcancer.org

The Pregnant with Cancer Network is a national non-profit organization for women diagnosed with cancer while pregnant. Services include a support network and information related to pregnancy and cancer.



11

Air
Transportation

Section 11

Air Transportation

ANGEL FLIGHT AMERICA

National Office
4300 Westgrove Drive
Addison, TX 75001
Phone: (877) 621-7177
Fax: (214) 234-8459
E-mail: execdir@angelflightamerica.org
Web: www.angelflightamerica.org

Angel Flight America is a national network of seven member organizations that provides free flights to ambulatory patients in need of life-sustaining treatments at medical facilities far from home. Transport is also available for accompanying parent or family member.

CHILDREN'S FLIGHT OF HOPE, INC.

113 Edinburgh South, Suite 160
Cary, NC 27511
Phone: (919) 466-8593
Fax: (919) 460-8160
E-mail: info@childrensflightofhope.org
Web: www.childrensflightofhope.org

Children's Flight of Hope is a non-profit organization that provides free air transportation to medical facilities for children with critical medical needs.

CORPORATE ANGEL NETWORK

Westchester County Airport
One Loop Road
White Plains, NY 10604-1215
Phone: (866) 328-1313
(914) 328-1313
Fax: (914) 328-3938
E-mail: info@corpangelnetwork.org
Web: www.corpangelnetwork.org

This organization arranges free plane transportation for cancer patients and bone marrow donors going to and/or from recognized cancer treatment centers. Patient must be able to walk up the stairs of a private aircraft without assistance and require no form of medical help or life support while on board.

FLIGHTS FOR LIFE, INC.

P.O. Box 26485
Phoenix, AZ 85068
Phone: (623) 492-9213
E-mail: president@flightsforlife.org
Web: www.flightsforlife.org

Flights for Life provides round-trip transportation for individuals who must travel to and from their residence for a non-emergency medical treatment.



HOPE AIR

Proctor & Gamble Building
4711 Yonge Street, Suite 703
Toronto, ON M2N 6K8 Canada
Phone: (877) 346-4673
Fax: (416) 222.6335
E-mail: mail@hopeair.org
Web: www.hopeair.org

Hope Air is a registered charity that arranges free medical air transportation to Canadians who must travel to receive medical care unavailable in their community.

LIFELINE PILOTS

Suite 302, Byerly Terminal
Greater Peoria Regional Airport
6100 West Dirksen Parkway
Peoria, IL 61607
Phone: (800) 822-7972
(309) 697-6282
Fax: (309) 697-6541
E-mail: mail@lifelinepilots.org
Web: www.lifelinepilots.org

LifeLine Pilots is a national non-profit organization that provides free air transportation for healthcare to people in medical and financial stress.

MERCY MEDICAL AIRLIFT

Patient Assistance Center
4620 Haygood Road, Suite 1
Virginia Beach, VA 23455
Phone: (888) 675-1405
(757) 318-9175
Fax: (757) 318-9107
E-mail: mercymedicalops@erols.com
Web: www.mercymedical.org

This organization connects persons in medical and financial crisis with providers of charitable patient air transportation services. Patients must verify financial need, and physician must indicate that travel is for essential medical care.

MIRACLE FLIGHTS FOR KIDS GROUP

2756 North Green Valley Pkwy, Suite 115
Green Valley, NV 89014-2120
Phone: (800) 359-1711
(702) 261-0494
Fax: (702) 261-0497
E-mail: dbdell@miracleflights.com
Web: www.miracleflights.com

Free air medical transportation is provided to families who need medical treatment out of the state, regardless of patient's age. There is no mileage or location limit.

NORTHWOODS AIR LIFE LINE

P.O. Box 2973
Kingsford, MI 49802-2973
Phone: (800) 311-1760
Web: www.northwoodsairlifeline.org

This non-profit organization provides free flights to help people obtain medical assistance that is unavailable to them in the Upper Peninsula of Michigan. This service helps individuals who are financially distressed, unable to travel by other means, or under severe time constraints.

U.S. AIR AMBULANCE

5919 Approach Road
Sarasota, FL 34248
Phone: (800) 633-5384
Fax: (941) 926-7690
E-mail: info@usairambulance.com
Web: www.usairambulance.com

Air Ambulance America provides air transportation services for patients with cancer. Trained medical personnel are in attendance if necessary.



Section 12

Wish Fulfillment Organizations

A WISH WITH WINGS, INC.

917 West Sanford
Arlington, TX 76012
Phone: (817) 469-9474
Fax: (817) 275-6005
E-mail: wish@awishwithwings.org
Web: www.awishwithwings.org

A Wish with Wings, Inc. serves children with scarce resources and life-threatening diseases. The organization primarily serves children who were treated or who reside in Texas. They also provide assistance to others who are interested in initiating their own organization for wish fulfillment.

BELIEVE IN TOMORROW NATIONAL CHILDREN'S FOUNDATION

6601 Frederick Road
Baltimore, MD 21228
Phone: (800) 933-5470
Fax: (410) 744-1984
Web: www.believeintomorrow.org

This program, aimed at reducing the stress and anxiety in the lives of children with life-threatening illness, includes programs such as support groups, wilderness retreats, in-hospital entertainment and wish fulfillment. It also has a newsletter and other informational materials.

CHILDREN'S HOPES AND DREAMS – WISH FULFILLMENT FOUNDATION

86 Auble Road
Blairstown, NJ 07825
Phone: (973) 361-7366
Fax: (973) 361-6627
Web: www.childrenswishes.org

Children's Hopes & Dreams has been serving children with serious childhood illnesses since 1983. They are one of the oldest wish fulfillment organizations in the world, and their programs serve over 14,000 seriously ill children each year.

CHILDREN'S WISH FOUNDATION INTERNATIONAL

8615 Roswell Road
Atlanta, GA 30350-7526
Phone: (800) 323-9474
(770) 393-9474
Fax: (770) 393-0683
E-mail: contact@childrenswish.org
Web: www.childrenswish.org

The Children's Wish Foundation International fulfills wishes and provides hospital parties and educational materials to children during their hospital stays.



CROSSING THE FINISH LINE

170 West Germantown Pike, Suite C-3
East Norriton, PA 19401
Phone: (484) 674-4778
Fax: (484) 674-4785
E-mail: info@crossingthefinishline.org
Web: www.crossingthefinishline.org

Recognizing the emotional and physical demands of cancer treatment, Crossing the Finish Line offers cancer patients and their caregiver a week-long retreat, free of charge. Retreat locations include California, Delaware, New Jersey, Pennsylvania and South Carolina. Contact CTFL for additional details.

DREAM FOUNDATION

1528 Chapala Street, Suite 304
Santa Barbara, CA 93101
Phone: (805) 564-2131
Fax: (805) 564-7002
E-mail: info@dreamfoundation.org
Web: www.dreamfoundation.org

Dream Foundation is a wish-granting organization that focuses on adults. Their goal is to offer special and needed support to patients between 18 and 65.

FAIRY GODMOTHER FOUNDATION

1340 West Fullerton Avenue, Box 179
Chicago, IL 60614-2362
Phone: (773) 388-1160
E-mail: info@fairygodmother.org
Web: www.fairygodmother.org

The Fairy Godmother Foundation strives to bring joy to the lives of individuals—18 and older—in their time of greatest need by turning dreams into reality.

GIVE KIDS THE WORLD

210 South Bass Road
Kissimmee, FL 34746
Phone: (800) 995-5437
(407) 396-1114
Fax: (407) 396-1207
E-mail: dream@gktw.org
Web: www.gktw.org

This is a non-profit wish-fulfillment organization for kids with life-threatening illnesses and their families. They offer free tickets to many amusement parks, such as Walt Disney World, SeaWorld, Islands of Adventure, Universal Studios, Epcot Center and more. A letter from one's doctor is necessary at least a month prior to booking the trip. Be sure to ask about discounted airfares and hotel rates that are often available.

MAKE-A-WISH FOUNDATION OF AMERICA

National Office
3550 North Central Avenue, Suite 300
Phoenix, AZ 85012-2127
Phone: (800) 722-9474
(602) 279-9474
Fax: (602) 279-0855
E-mail: mawfa@wish.org
Web: www.wish.org

The Make-A-Wish Foundation is a national organization that grants wishes for children with terminally or life-threatening diseases who are 18 years of age or younger. It currently has over 75 chapters nationwide. For the nearest regional chapter, call the national office.

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MARTY LYONS FOUNDATION, INC.

326 West 48th Street
New York, NY 10036
Phone: (212) 977-9474
Fax: (212) 977-1752
E-mail: pamelap@martylyonsfoundation.org
Web: www.martylyonsfoundation.org

The Marty Lyons Foundation is a national organization that grants wishes of children between the ages of 3 and 17 who have life-threatening diseases or terminal illnesses. Those interested can submit applications for their wish fulfillment.

STARLIGHT STARBRIGHT CHILDREN'S FOUNDATION

5757 Wilshire Boulevard, Suite M100
Los Angeles, CA 90036
Phone: (800) 315-2580
(310) 479-1212
Fax: (310) 479-1235
E-mail: info@starlight.org
Web: www.starlight.org

Starlight Starbright's mission is to soften the hard edges of what a family experiences when a child has a serious illness. They build playrooms and teen lounges in hospitals so kids can play games, e-mail, chat with friends, and even do their homework from their hospital bed. When the kids get to go home, they keep them connected through online chat rooms and special outings for the entire family. They also provide information about illnesses and treatments on their website and through videos and games.

SUNSHINE FOUNDATION

National Headquarters
1041 Mill Creek Drive
Feasterville, PA 19053
Phone: (800) 767-1976
(215) 396-4770
Fax: (215) 396-4774
E-mail: philly@sunshinefoundation.org
Web: www.sunshinefoundation.org

The Sunshine Foundation grants wishes to terminally or chronically ill children 3-21 years of age. One program they offer is the Dream Village located in Florida. Its purpose is to provide an oasis for families to escape hospitals and needles, if only for a short time.

Section 13

Other Resources

BOOKS FOR ADULTS

35 Ways to Help a Grieving Child

This guidebook addresses how to include children in decision-making, what to expect from different ages, and how to provide safe outlets for children to express emotion. Published by The Dougy Center.

ISBN 189053403X, © 1999

100 Questions and Answers About Brain Tumors, by Virginia Stark-Vance, MD and M.L. Dubay

This is a straightforward answer guide to a variety of questions asked by patients, caregivers, families and friends. The book covers many different topics including the basics of brain tumors, causes, diagnosis, treatment and related side effects, and emotional coping strategies.

ISBN 0763723088, © 2004

The Anatomy of Hope: How People Prevail in the Face of Illness, by Jerome Groopman

An exploration into the world of Dr. Groopman's practice as he tries to answer the impossible: "Why do some people find and sustain hope during difficult circumstances, while others do not? What can we learn from those who

do, and how is their example applicable to our own lives?" The author explains the differences between real hope and false hope, essentially "delineating a biology of hope."

ISBN 0375757759, © 2005

Brain Tumors: Leaving the Garden of Eden, by Paul M. Zeltzer, M.D.

This comprehensive introductory guide for patients contains basic facts about brain tumors, from symptoms to pain treatment.

ISBN 0976017105, © 2004

Brain Tumors: Finding the Ark, by Paul M. Zeltzer, M.D.

In this companion guide book to *Brain Tumors: Leaving the Garden of Eden*, Zeltzer gives detailed information covering many aspects of brain tumors, including complementary and alternative (CAM) therapies, preventing side effects, navigation of the healthcare system, children's brain tumors, and more.

ISBN 0976017113, © 2006

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The Cancer Survivor's Guide: The Essential Handbook to Life After Cancer, by Michael Feuerstein, PhD, MPH, and Patricia Findley, DrPH, MSW

This guide introduces a self-management program for any cancer survivor. It counsels readers through a step-by-step process of how to take charge of the physical, mental, and emotional challenges that come with surviving cancer.

ISBN 9781569243329, © 2006

Chasing Daylight: How My Forthcoming Death Transformed My Life, by Eugene O'Kelly

Eugene O'Kelly was a successful CEO of a large international accounting firm. In May 2005, he was diagnosed with terminal brain cancer and was told he only had a few months to live. The author describes the steps he took to "simplify" his life and create as many memories as he could with the time he had left.

ISBN 0071471723, © 2005

Facing Forward: When Someone You Love Has Completed Cancer Treatment

This booklet, written by the National Cancer Institute, shares the common feelings and reactions many caregivers experience after treatment ends. It is available at www.cancer.gov/cancertopics/Facing-Forward-When-Someone-You-Love-Has-Completed-Cancer-Treatment (or call National Brain Tumor Foundation).

Finding the Money: A Guide to Paying Your Medical Bills, by Diane Pammenter Tolley

Diane Tolley has helped families manage the staggering costs of major medical bills for over 15 years. Through her book, she explains how to organize records, talk with creditors, and delegate responsibility for bills so that families can focus on health issues. In addition, she provides tips on how to fundraise successfully.

ISBN 0970622007, © 2001

Handbook for Mortals: Guidance For People Facing Serious Illness, by Joanne Lynn, M.D. and Joan Harrold, M.D.

An excellent resource for anyone facing the end of life. This guide provides a realistic outlook for what to expect with a terminal condition. The authors focus on pain management, artificial feeding and assisted suicide.

ISBN 0195116623, © 1999

Helping Children Understand Cancer – How to Talk to Your Children About Your Cancer Diagnosis

This fact sheet from Cancer Care offers parents ten essential tips on how to communicate with their children about their cancer diagnosis. Published by Cancer-Care, Inc.

Phone: (800) 813-4673

Web: www.cancercare.org

Helping Teens Cope with Death

Adolescence is a period of profound changes. When a teen also deals with a major loss, those developmental changes and the turmoil they create can be compounded. This practical guide explains teenagers' common grief reactions, specific challenges grieving teens face, and much more. Produced by The Dougy Center.

ISBN 1890534021, © 1999

I Had Brain Surgery, What's Your Excuse? by Suzy Becker

Suzy Becker's memoir takes the readers back to a difficult time in her life as she goes through seizures, brain surgery, and recovery. Becker manages to successfully balance humor and fear by matching humorous sketches with her writing. This personal account focuses on how Becker overcomes the initial loss of memory, humor, and other abilities.

ISBN 0761139796, © 2005

Life After Cancer Treatment

A comprehensive guide from the National Cancer Institute for survivors facing post-treatment issues, such as potential physical and emotional changes, changes in social relationships and workplace issues. This book is part of their “Facing Forward Survivor Series.” Available at www.cancer.gov/cancerinfo/life-after-treatment (or call National Brain Tumor Foundation).

LIVESTRONG: Inspirational Stories from Cancer Survivors

In this book, survivors from all walks of life talk about what “living strong” in the face of cancer means to them. Available at bookstores and the Lance Armstrong Foundation (www.laf.org). ISBN 0767921380, © 2005

Mom’s Cancer, by Brian Fies

An illustrated novel documenting the story of Fies’ mother’s battle with lung cancer that metastasized to the brain. The author focuses on the way the cancer affects both the family and the patient. ISBN 0810958406, © 2006

Navigating Through a Strange Land: A Book for Brain Tumor Patients and Their Families, by Tricia A. Roloff

Deep and meaningful, this book is “a support group between covers.” Over fifteen patients and family members share their stories, experiences and lessons learned to help with all phases of treatment and recovery. The book includes chapters by doctors and other professionals on healthy coping techniques and an extensive resource directory. ISBN 1577491084, © 2001

What About The Kids? Understanding Their Needs in Funeral Planning & Services

Suggests options for involving children and teens in memorial services and how to explain terms such as burial and cremation to children. Includes suggestions from

children and teens on what was helpful and what was not, based on their experience at funerals. Produced by The Dougy Center. ISBN 1890534048, © 1999

When Someone You Love Has Advanced Cancer: Support for Caregivers

Written by the National Cancer Institute, this booklet is for those whose loved one has been told that he or she has advanced cancer that is no longer responding to treatment. This booklet explores many of the questions and crossroads often faced by caregivers. It is available at www.cancer.gov/cancertopics/When-Someone-You-Love-Has-Advanced-Cancer (or call National Brain Tumor Foundation).

BOOKS FOR CHILDREN

My Name is Buddy – A Book for Children About Brain Tumors

The reader follows Buddy, a Golden Retriever, on his journey through a brain tumor diagnosis and treatment. This true story uses photographs and narrative to describe Buddy’s experiences before and after surgery and talks about his feelings and fears as a brain tumor patient. *My Name is Buddy* includes a CD-ROM with comedian Dom DeLuise as the voice of Buddy. Available free from NBTF.

Alex’s Journey

The story of a child with a brain tumor, for ages 8-12. Available from the American Brain Tumor Association in Chicago, IL at no charge: (800) 886-2282. © 2002

Sammy’s Mommy Has Cancer

A children’s story about family changes when a parent has cancer, for ages 2-8. By Sherry Kohlenberg, illustrated by Lauri Crow. Published by Magination Press. ISBN 0945354568, © 1993

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Where's Jess? For Children Who Have a Brother or Sister Die

Written by Marvin Johnson and Joy Johnson, this book is for small children ages 4-8 who have had a sibling die. ISBN 156123009X, © 1982

BOOKS FOR PROFESSIONALS

35 Ways to Help a Grieving Child

This guidebook addresses how to include children in decision-making, what to expect from different ages, and how to provide safe outlets for children to express emotion. Published by The Dougy Center.

ISBN 189053403X, © 1999

Children and Grief: When a Parent Dies

Written by J. William Worden, this book on bereavement integrates theory, research, and concise practical suggestions for clinicians, in addition to identifying those children most at risk and discussing models for intervention. Published by The Guilford Press.

ISBN 1572307463, © 2001

Children Who Grieve – A Manual for Conducting Support Groups

Written by Roberta Beckmann. Published by Learning Publications.

ISBN 1556910509, © 1990

The Forgotten Mourners: Guidelines for Working with Bereaved Children

Written by Susan C. Smith and Margaret Pennells, this book provides advice about what bereaved children need and how people caring for them can help. The authors raise awareness of the sensitive issues involved for bereaved children, highlighting their needs and their emotional and behavioral responses when bereavement occurs. Published by Jessica Kingsley Publishers. ISBN 1853027588, © 1999

The GLIOMAS

This nearly 800-page book is a powerful collection of research on brain cancer. Authored by Mitchel Berger and Charles B. Wilson from the University of California at San Francisco, this text covers the results of new research and clinical experiences. Available from the UCSF bookstore; (415) 476-1666.

Helping Bereaved Children – A Handbook for Practitioners

Written by Nancy Boyd Webb, this highly acclaimed book offers detailed guidelines for the helping process and the self-care needs of bereavement counselors. It contains case descriptions on how children deal with death in their own words, and first-hand reflections from therapists who work with them. Published by The Guilford Press.

ISBN 1593851642, © 2005

Healing the Bereaved Child

Written by Alan D. Wolfelt, PhD, this is a comprehensive book for caregivers of bereaved children. This 316-page book is a must-read for child counselors, hospice caregivers, funeral directors, school counselors and teachers. Published by Accelerated Development.

ISBN 1879651106, © 1996

Waving Goodbye: An Activities Manual for Children in Grief

This manual contains over 45 activities to use with children and teens in peer-to-peer grief support groups. It also suggests activities to help younger children understand the abstract concept of death and their feelings about the loss of a loved one. Available from The Dougy Center. Call (866) 775-5683.

MAGAZINES AND BROCHURES

COPING

A bimonthly magazine for those living with cancer. The magazine's primary purpose is to empower readers with the knowledge they need to cope with the many issues they confront in their daily lives. Published by Media America, Inc. Visit www.copingmag.com or call (615) 790-2400.

CURE

CURE (Cancer Updates, Research, and Education) is a magazine developed for individuals coping with cancer and blood disorders. *CURE* provides scientific information in an easy-to-understand format. It is published by physicians committed to providing quality care to their patients. Each full-color, quarterly issue of *CURE* features recent advances in diagnosis and treatment, cancer prevention, clinical trials, cancer news, support group information, and expert opinions. To order, call (800) 210-2873 or visit www.curetoday.com.

TODAY'S CAREGIVER

The first national magazine dedicated to caregivers. This organization also coordinates "Sharing Wisdom Caregivers Conferences." Visit www.caregiver.com for more information and to subscribe.

PROFESSIONAL ORGANIZATIONS

AMERICAN ASSOCIATION FOR CANCER RESEARCH (AACR)

615 Chestnut Street, 17th Floor
Philadelphia, PA 19106-4404
Phone: (866) 423-3965
(215) 440-9300
Fax: (215) 440-7228
E-mail: aacr@aacr.org
Web: www.aacr.org

AMERICAN ASSOCIATION OF NEUROLOGICAL SURGEONS (AANS)

5550 Meadowbrook Drive
Rolling Meadows, IL 60088
Phone: (888) 566-2267
(847) 378-0500
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Fairfax, VA 22031
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(703) 502-1550
Fax: (703) 502-7852
Web: www.astro.org

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E-mail: asco@asco.org
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ASSOCIATION OF ONCOLOGY SOCIAL WORK (AOSW)

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CONGRESS OF NEUROLOGICAL SURGEONS (CNS)

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INTERCULTURAL CANCER COUNCIL (ICC)

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NATIONAL ACADEMY OF NEUROPSYCHOLOGY (NAN)

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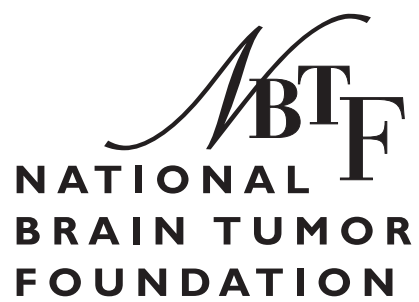
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