

Neuroblastoma Educational Resources

This Interactive resource listing is an evolving list of resources for parents of children with neuroblastoma and other forms of pediatric cancer. If there is a resource you have found to be helpful that is not listed here or if you have further information about (or corrections to) any of the following organizations, please send the information to info@cncfhope.org and place Resources in the subject line.

Service Organizations

American Cancer Society
1599 Clifton Road NE.
Atlanta, GA 30329-4251
(800) ACS-2345
<http://www.cancer.org>

Its programs include patient-to-patient visitations, transportation to appointments, and housing near treatment centers, equipment and supplies, support groups, educational literature, and summer camps for children with cancer.

Canadian Cancer Society
565 w. 10th Avenue
Vancouver, BC Canada V5Z 4J4
(604) 872-4400
<http://www.bc.cancer.ca>
e-mail cancerinfo@bc.cancer.org
Provides same services as the US Cancer Society

Candlelighters Childhood Cancer Foundation
1040 Connecticut Ave. Suite 205
Kensington, MD 20895
(800) 366-CCCF
Fax: (301) 718-2686
<http://www.candlelighters.org>
email: staff@candlelighters.org
Founded in 1970, Candlelighters has more than 40,000 members worldwide. Free of charge, it provides yearly biography and resource guides, quarterly newsletters, youth newsletters, and various handbooks to help families of children with cancer.

Candlelighters Childhood Cancer Foundation (National Office)
1300 Yonge St, Suite 405
Toronto, Ontario M4T 1X3
(800) 363-1062 (Canada Only)
(416) 489-6440
<http://www.candlelighters.ca>
email: info@childhoodcancer.ca
Provides the same service as US Candlelighters.

Ronald McDonald House Coordinator
C/o Gorlin Communications Inc.
111 E Wacker Drive
Chicago, IL 60601
(312) 729-4000

Informational Organizations

The Academy for Guided Imagery
10780 Santa Monica Blvd. Suite 290
Los Angeles, CA 90025
(800) 726-2070
<http://www.academyforguidedimagery.com>
email: info@acadgi.com

This organization can assist in locating a professional in your area to help your child learn visualization.

The American Society of Clinical Hypnosis
140 N. Bloomingdale Rd
Bloomingdale, IL 60108
630-980-4740
<http://www.asch.net>
email: info@asch.net

A membership organization for doctors, psychologists, and dentists who use hypnosis in their practices. For referral to a local member, send a request with self-addressed stamped envelope.

Childhood Cancer Guides
P.O. Box 31397
Bellingham, WA 98228
www.childhoodcancerguides.org

Childhood Cancer Ombudsman Program
P.O. Box 595
Burgess, VA 22432
Fax: (804) 580-2502
Email: gpmonaco@rivnet.net

This free service helps children with cancer and their families who are experiencing difficulties gain access to appropriate education, medical care, healthcare cost coverage, and meaningful employment. Services include medical searches, a second opinion program, and help resolving insurance or discrimination problems.

The Disability Rights Education and Defense Fund
2212 Sixth Street
Berkeley, CA 94710
(800) 466-4232
<http://www.dredf.org>
email: info@dredf.org

Answers questions about Americans with Disabilities Act, explains how to file a complaint, and provides dispute resolution.

The Institute for Families of Blind Children
Attention Nancy
P.O. Box 54700 MS# 111
Los Angeles, CA 90054-0700
(323) 660-4649
<http://www.instituteforfamilies.org>
email: info@instituteforfamilies.org

Job Accommodation Network
West Virginia University
918 Chestnut Ridge Rd, Suite 1
P.O. Box 6080
Morgantown, WV 26516
(800) ADA-WORK
<http://jan.wvu.edu>
email: jan@jan.wvu.edu

Provides information about on-the-job accommodations for persons with disabilities.

National Cancer Institute (NCI)
Cancer Information Service
6116 Executive Blvd Rm 3036A
Bethesda, MD 20892-8322
(800) 4-CANCER
Fax (301) 231-6941
CANCERFAXE (301) 402-5874
<http://www.cancer.org>
e-mail: cancergovstaff@mail.nih.gov

Provides a nationwide telephone service for people with cancer, their families, friends and professionals who treat them. It provides answers and sends out informational booklets on a variety of cancer-related topics.

CANCERFAX provides treatment guidelines, with data prognosis, staging, and histologic classifications.

Cure Search

1010 Wayne Avenue Suite 770
Silver Spring, MD 91066-3776
(800) 458-6223

<http://www.curesearch.org>

email: info@curesearch.org

Supports pediatric cancer treatment and research in more than 115 hospitals in North America and Australia. The newsletter, Childhood Cancer line, provides information on new treatments and psychological support.

National Information Center for Children and Youth with Disabilities (NICHCY)

1825 Connecticut Ave NW Suite 700
Washington, DC 20013
(800) 695-0285

<http://www.nichcy.org>

email: nichcy@aed.org

A clearinghouse that provides free pamphlets and information on disabilities and the rights of disabled children and their parents.

National Coalition for Cancer Survivorship

1010 Wayne Ave Suite 770
Silver Spring, MD 20910
(301) 650-9127 or (888) 650-9127
Fax (310) 565-9670

<http://www.canceradvocacy.org>

email: info@canceradvocacy.org

Organization that addresses the needs of long-term cancer survivors and advocates for changes in healthcare to maximize survivors' access to optimal treatment and support. The coalition has an extensive publications list.

PDQ (Physician Data Query)

(800) 4-CANCER

<http://www.cancernet.nci.nih.gov>

PDQ is the National Cancer Institute's computerized listing of accurate and up-to-date information for patients and health professionals about cancer treatments, research studies, clinical trials, organizations, and doctors.

Starbright Foundation

5757 Wilshire Blvd, Suite M100
Los Angeles, CA 90036
(310) 479-1212

Fax: (310) 479-1235

<http://www.starbright.org>

email: info@starbright.org

Co-chaired by Steven Spielberg and Gen. Norman Schwarzkopf, Starbright Foundation is best known for its online network of interactive, virtual-reality playgrounds where seriously ill, hospitalized children across the county meet, talk and play to help cope with the pain, stress and anxiety of treatment. For teens who are ill, "Videos will Attitude" offer guidance from peers who have "been there". The videos are free to families and come with a parent guide.

Emotional Support Organizations

Association of the Care of Children's Health (ACCH)

7910 Woodmont Avenue, Suite 300
Bethesda, MD 20814
(609) 224-1742

A nonprofit, multidisciplinary organization of health professionals and parents that promotes psychological health of children and their parents. It sponsors conferences, provides advocacy resources, and publishes journals, newsletters, and booklets.

Cancer Care, Inc
275 Seventh Ave Floor 22
New York, NY 10001
(212) 712-8400
<http://www.cancercare.org>
email: info@cancercare.org

A national, nonprofit organization that provides referrals, one-on-one counseling, specialized support groups, and educational programs.

Cancer Cured Kids
PO Box 189
Old Westbury, NY 11568
(800) CCK-7525
(516) 484-8160
Fax (516) 484-8160 (Call First)

An organization dedicated to the quality of life of kids who have survived cancer, it supplies information about educational and psychosocial needs.

Center for Attitudinal Healing
33 Buchanan Drive
Sausalito, CA 94965
(415) 331-6161
Fax (415) 331-4545
<http://healingcenter.org>

A nonprofit nonsectarian group that sponsors local and national workshops for children with catastrophic or life-threatening diseases and their siblings. It promotes the use of the arts in a loving, supportive program to help children ages six to sixteen share their feelings about their situation. It has published several excellent books.

Chai Lifeline/Camp Simcha
International Office
151 West 30th Street
New York, NY 10001
(212) 465-1300
<http://www.chailifeline.org>
email: ingo@chailifeline.org

A national nonprofit Jewish organization that provides support service programs to children and their families in crisis, including medical referrals, support groups, visit to hospitalized and housebound children, financial aid, transportation, a kosher camp for kids with cancer, and more.

ChemoCare
231 North Avenue West
Westfield, NJ 07090
(800) 55-CHEMO (outside New Jersey)
(908) 233-1103 (within New Hersey)
Fax (908) 233-0228

Provides on-to-one emotional support to cancer patients and their families under-going chemotherapy, radiation, and/or surgery, from trained and certified volunteers who have undergone the treatment themselves.

Child Life Council
11821 Parklawn Drive, Suite 310
Rockville, MD 20852
(301) 881-7090
Fax: (301) 881-7092
<http://www.childlife.org>
email: clcadmin@childlife.org

Promotes the well-being of children and families in healthcare settings by supporting the development and practice of the child life professionals with training conferences, publications, and information.

Coping Magazine
PO Box 682268
Franklin, TN 37068
(615) 790-2400
Fax: (615) 794-0179

A bimonthly publication devoted to people whose lives have been touched by cancer.

Famous Phone Friends
9101 Sawyer Street
Los Angeles, CA 90035
(310) 204-5683
<http://famousfonefriends.org>
email: info@famousfonefriends.org

Links children who are confined to the hospital or home due to injury or illness with entertainers and athletes by telephone. Obtain a referral from a physician nurse, hospital volunteer, or treatment center social worker.

Friends Network
PO Box 4545
Santa Barbara, CA 93140
Attention: Kevon Neal

A national nonprofit organization the distributes the FunLetter, full-color activities newsletter, to children with cancer

National Children's Cancer Society
One South Memorial Drive, Suite 800
St. Louis, MO 63102
(314) 241-1600
Fax: (314) 241-1996

<http://www.children-cancer.com>
email: pbeck@children-cancer.org

Advocates for children affected by childhood cancer and their families by providing financial assistance, education, and emotional support.

Parents Caring and Sharing
c/o Chumie Bodek
109 Rutledge Street
Brooklyn, NY 11211

(718) 596-1542 pr 596-9002 (call during business hours, Eastern time)

Provides outreach, a support network, and newsletter for Jewish Orthodox Families with children with cancer. Holds monthly meetings and links families of children with similar diseases.

Songs of Love Foundation
PO Box 750809
Forest Hills, NY 11375
(800) 960-SONG (7664)

<http://www.sonsoflove.org>
info@songoflove.org

A nonprofit organization that has a volunteer group of more than 200 artists who produce personalized musical portraits for children and teens with chronic or life-threatening diseases.

Bone Marrow and Stem Cell Transplantation

Additional resources for bone marrow or stem cell transplant families are listed at <http://www.mbtnews.org/>

The Barbara DeBoer Foundation
2069 S Busse Road
Mount Prospect, IL 60056
(800) 8995-8478 or
(847) 981-0130

<http://www.deboefoundation.cor>

Helps to identify and utilize resources in your community to raise necessary funds for transplants.

BMT Family Support Network
PO Box 845
Avon, CT 06001
(800) 826-9376

Provides information, resources, and telephone links to families involved in bone marrow transplants. Also serves grieving families.

Children's Organ Transplant Association
2501 Cota Drive
Bloomington, IN 47403
(800) 366-2682
<http://www.cota.org>
Email: cota@cota.org
Provides fund raising help.

National Bone Marrow Transplant Link
29209 Northwestern Highway #624
Southfield, MI 48034
(800) LINK-BMT or (810) 932-8483
Operates a hot-line, and provides peer support, a library, clearinghouse, and suggestions for financial assistance.

National Marrow Donor Program (NMDP)
3001 Broadway Street, NE, Suite 100
Minneapolis, MN 55413
Donor Information: (800) MARROW-2
Patient Search Information: (888) 999-6743
Corporate Recruitment Programs: (800) 526-7809
Fax: (612) 627-8195
<http://www.marrow.org>
Email: patientinfo@nmdp.org
The NMDP has developed the world's largest computerized listing of potential marrow donors.

The National Transplant Assistance Fund
150N Radnor Chester Road, Suite F-120
Radnor, PA 19087
(800) 642-8399 or (610) 535-6106
<http://www.ntafund.org>
Provides fundraising assistance and donor awareness material to transplant patients nationwide.

Financial Assistance

Cancer Fund of America
2901 Breezewood Lane
Knoxville, TN 37921
(800) 578-5284
Fax (615) 938-2968
<http://www.cfoa.org>
Helps defray cancer-related expenses not covered by insurance.

The Sparrow Foundation
1155 N 130th, Suite 310
Seattle, WA 98104
(206) 745-5403
Provides help with fundraising for any medical needs.

Free Air Services

Air Care Alliance
(800) 296-1217

<http://www.angelflightfla.org/aircareall.org/acahome.html>

ACA is a nationwide association of humanitarian flying organizations

Corporate Angel Network, Inc. (CAN)
Westchester County Airport, Building 1
White Plains, NY 10604
(914) 328-1313
Fax (800) 328-4226

www.coprangelnetwork.org

Email: info@coprangelnetwork.org

A nationwide, nonprofit program designed to give patients with cancer the use of available seats on corporate aircraft to get to and from recognized cancer treatment centers. Patients must be able to walk and travel without life-support systems or medical attention. A child may be accompanied by up to two adults. This service will also fly donors. There is not cost or financial need requirements.

DreamLine, Inc.
Contact: Bob Iverson
1701 N. Clybourn
Chicago, IL 60614
(312) 202-9000
Fax: (312) 202-0188

<http://bobiverson.com/dreamline.htm>

Provides free airline travel for children with serious illnesses needing transportation for emergency medical treatment or vacation.

Mission Air Transportation Network
Proctor & Gamble Building
4711 Young Street
North York, ON Canada M2N 6K8
(416) 222-6335
Fax: (416) 222-6930

An organization that provides free air transport to Canadians in financial need who must travel from their own communities to recognized facilities for medical care.

National Patient Air Transport Hotline
24-hour hotline: (800) 296-1217

Specialists refer callers to the most appropriate, cost-effective charitable or commercial services, including volunteer pilot organizations and airline transport programs.

Wish Fulfillment Organizations

In addition to the large organizations listed below, there are many smaller and local organizations that grant wishes to seriously ill children. A comprehensive list of wish fulfillment organizations can be found on the Web at <http://www.patientcenters.com/childcancer/>.

Children's Wish Foundation International
8615 Roswell Road
Atlanta, GA 30350
(770) 393-WISH
(800) 323-WISH
Fax (404) 393-0683

<http://www.childrenswish.org>

Email: wish@childrenswish.org

Fulfills wishes of terminally ill children in the US and Europe.

The Children's Wish Foundation of Canada
95 Bayly Street, Suite 404
Ajax, Ontario
Canada L1S 7K8
(905) 426-5656
Fax: (905) 426-4111

Its goal is to provide a once-in-a-lifetime experience for children ages three to eighteen with high risk, life-threatening diseases. There are chapters throughout Canada. Parents can call for the location of the chapter nearest to them.

The Dream Factory, Inc.
1218 South Thirst Street
Louisville, KY 40203
(800) 456-7556
Fax: (502) 584-0023
<http://www.dreamfactoryinc.com>
Email: info@dreamfactoryinc.com

Grants wishes of children ages three to thirteen who are seriously or chronically ill. There are chapters in 30 states.

Make A Wish Foundation of America
4742 N 24th Street, Suite 400
Phoenix, AZ 85016
(602) 279-WISH or (800) 722-WISH
Fax: (602) 279-0855
<http://www.wish.org>

Grants wishes to children under the age of eighteen with life-threatening illnesses. US and International chapters and affiliates exist.

The Starlight Foundation
International Headquarters
12424 Wilshire Boulevard, Suite 1050
Los Angeles, CA 90025
(310) 207-5558

Fulfills wishes for seriously ill children ages four to eighteen. There are chapters in the United States, Canada, Australia, and the United Kingdom.

Sunshine Foundation Headquarters
1041 Mill Creek Drive
Feasterville, PA 19053
(215) 396-4770
<http://www.sunshinefoundation.org>
Email: philly@sunshinefoundation.org

Grants wishes to chronically or terminally ill children ages three to twenty-one. It has not geographic boundaries.

Bereavement Support

The Centering Corporation
7230 Maple Street
Omaha, NE 68134
(402) 553-1200
<http://www.centering.org>
Email: Danni@centeringcorp.com

Publishes a free catalog which contains an extensive listing of books, cards, and audio and videotapes on death and grieving.

Children's Hospice International
2202 Mt. Vernon Avenue, Suite 3c
Alexandria, VA 22301
(703) 684-0330
(800) 24-CHILD

The Compassionate Friends National Office

PO Box 3696

Oak Brook, IL 60522-3696

(630) 990-0010

Fax: (630) 990-0246

<http://www.compassionatefriends.org>

A self-help organization that offers understanding and friendship to bereaved families through support meetings at local chapters and telephone support (they match persons with similar losses). It publishes a newsletter for parents and one for siblings, and offers a Resource Catalog with comprehensive list of books, audio, and video materials on adult and sibling grief.

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