



Directory of Online Resources

This Directory is an evolving list of resources for parents of children with cancer. We need your input to add to it and make it as helpful as possible to NB parents! 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, please send the information to info@cncfhope.org. Be sure to check with your hospital social worker for *local* resources, especially with regard to lodging.

Advocacy

[Childhood Cancer Ombudsman Program](#)

<http://www.childhoodbraintumor.org/ombuds.html>

Provides complaint investigation and resolution for families of children with cancer and adult survivors of childhood cancer. A service of the [Childhood Brain Tumor Foundation](#).

<http://www.childhoodbraintumor.org/services.html>

Fax: (804) 580-2502

[Children's Cause for Cancer Advocacy](#)

<http://www.childrenscause.org>

Advocacy and education for safer and effective treatments for childhood cancer.

[National Coalition for Cancer Survivorship](#)

<http://www.mcmcllc.com>

Oldest survivor-led cancer advocacy organization in the country.

[Patient Advocacy Coalition](#)

<http://medicalreporter.health.org/tmr0497/PAC.HTM>

Helps resolve insurance coverage issues.

[Patient Advocate Foundation](#)

<http://www.patientadvocate.org>

Safeguards patients through effective mediation to assure access to care, maintenance of employment, and preservation of their financial stability. (800) 532-5274; fax: (757) 873-8999

Bone Marrow Transplant Information and Fundraising

[BMT Infonet](#)

<http://www.bmtinfonet.org>

Information and emotional support to patients and survivors of transplant.

[The Bone Marrow Foundation](#)

<http://www.bonemarrow.org>

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

[Cord Blood Donor Foundation \(CBDF\)](#)

<http://www.cordblooddonor.org>

Provides educational and public awareness and promotes further research into use of umbilical cord blood stem cells from live birth for the treatment of disease.

[Cryobanks International](#)

<http://www.cryo-intl.com>

For-profit organization for collection, processing and banking of umbilical cord blood stem cells.

[National Foundation for Transplants \(NFT\)](#)

<http://www.transplants.org>

Helps patients fundraise for transplant expenses.

[National Marrow Donor Program](#)

<http://www.marrow.org>

Donor registry and information about donor blood and marrow transplants.

[National Transplant Assistance Fund and Catastrophic Injury Program](#)

<http://www.transplantfund.org>

Helps patients fundraise for transplant expenses.

800-642-8399

[ViaCord - Cord Blood Banking and Research](#)

<http://www.viacord.com>

For-profit umbilical cord blood banking and information.

Caregivers – Advocacy and Support

[CancerCare](#)

<http://www.cancercare.org>

Support for cancer patients and their families. Financial assistance, information and referrals, community and professional education, counseling, and practical help.

[CaringBridge](#)

<http://www.caringbridge.org/>

Free website service for keeping friends and family informed during treatment.

[CarePages](#)

<http://www.carepages.com/>

Free website service for keeping friends and family informed during treatment.

[Family Caregiver Alliance](#)

<http://www.caregiver.org/caregiver/jsp/home.jsp>

A public voice for caregivers; programs include information, education, services, research, and advocacy guidance for how caregivers can affect public policy.

[Lotsa Helping Hands](#)

<http://www.nfca.lotsahelpinghands.com>

A volunteer coordination service for friends, family, colleagues, and neighbors to assist loved ones in need. It's an easy-to-use, private group calendar, specifically designed for organizing helpers.

info@lotsahelpinghands.com

[National Alliance for Caregiving](#)

<http://www.caregiving.org>

Supports family caregivers and professionals who help them; increases public awareness of issues facing family caregivers.

[National Family Caregivers Assoc](#)

<http://www.nfcacares.org/>

Support and advocacy for caregivers of loved ones with a chronic illness or disability.

[Never-Ending Squirrel Tale](#)

Practical tips, encouragement, humor, sharing, for the parents of kids with cancer—just like sitting around the clinic, only more stories!

[Share the Care](#)

<http://www.sharethecare.org/>

A grassroots organization dedicated to preventing "caregiver burnout by promoting and educating people about the benefits of group caregiving using the SHARE THE CARE™ model."

(646) 467-8097

Email: info@sharethecare.org

[Strength for Caring](#)

<http://www.strengthforcaring.com/>

An online resource and community for family caregivers that helps family caregivers take care of their loved ones and themselves.

866-466-3458

[The Wellness Community](#)

<http://www.thewellnesscommunity.org/>

Connect with others who know what you're going through as a cancer patient or a caregiver.

Children as Patients – Support

[Chai Lifeline](#)

<http://www.chailifeline.org/index.php>

Chai Lifeline is a not for profit organization dedicated to helping children suffering from serious illness as well as their family members. We offer a comprehensive range of services to address the multiple needs of patients, parents, and siblings.

Chemo Buddy Club

<http://www.chemobuddyclub.com/>

Unique gifts and gift baskets for the cancer/chemo patient, information, and encouragement.

Children's Miracle Network

<http://www.childrensmiraclenetwork.org/>

Improves the lives of children by raising funds for children's hospitals across North America.

801.278.8900

The Hole in the Wall Gang Camps

<http://www.holeinthewallgang.org/about/mission.asp>

Provides children with cancer and other serious illnesses and conditions a high quality camping experience.

Believe In Tomorrow Children's Foundation

<http://www.believetomorrow.org/>

Provides hospital and retreat housing services to critically ill children and their families .

[Songs of Love Foundation](#)

Provides personalized songs to chronically or terminally ill children and young adults.

[Chemo Angels](#)

Brightens the lives of cancer patients while they are going through this challenging time.

[Make A Child Smile Organization](#) (MACS)

Provides emotional support to children with chronic or life-threatening illnesses and their families.

[HopeKids](#)

<http://www.hopekids.org/index.aspx>

[Hugs & Hope Club for Sick Kids](#)

A ministry of encouragement for children battling critical illness.

[Post Pals](#)

Cards for ill children.

Children's Cancer Camps**[ACOR list of camps](#)**

<http://www.acor.org/ped-onc/cfissues/camps.html>

[Children's Oncology Camping Association](#)

<http://www.coca-intl.org/>

currently has 65 member camps in the US

<http://www.cancerindex.org/ccw/guide2s.htm>

Clinical Trial Information**[Clinicaltrials.gov](#)**

<http://clinicaltrials.gov/>

Search database of thousands of clinical trials, provided by the US National Institutes of Health (NIH), through its National Library of Medicine (NLM).

[National Cancer Institute](#)

<http://www.cancer.gov/clinicaltrials>

Search NCI's list of 5,000+ clinical trials, find recent clinical trial results, learn what clinical trials are, how they work, why they're useful, patient care costs, and more.

Drugs and Supplements**[BC Cancer Agency - BCCA Cancer Drug Manual](#)**

www.bccancer.bc.ca/HPI/DrugDatabase/DrugIndexPro/default.htm

A fairly comprehensive database on oncology drugs—health professional summaries give information on indications, pharmacokinetics, dosing, and side effects.

[Mayo Clinic Drugs and Supplements](#)

<http://www.mayoclinic.com/health/drug-information/DrugHerbIndex>

[Memorial Sloan-Kettering: Herbs, Botanicals, and other Products](#)

<http://www.mskcc.org/mskcc/html/11570.cfm>

[National Center for Complementary and Alternative Medicine](#)

<http://nccam.nih.gov/>

Financial Resources – Private & Nonprofit**[American Cancer Society](#)** (ACS)

<http://www.cancer.org>

Through local offices has some assistance available for expenses such as transportation, home care equipment, wigs, and babysitting; scholarships for cancer survivors.

[CancerCare](#)

<http://www.cancercare.org>

Support for cancer patients and their families. Financial assistance, information and referrals, community and professional education, counseling, and practical help.

[Cancer Fund of America](#)

<http://www.cfoa.org/>

Free products, such as nutritional supplements, candy, small toys, and miscellaneous items, [application](#)

<http://www.cfoa.org/downloads/APPLICATION.pdf>

[Children's Cancer Fund of America](#)

<http://www.cfoa.org/>

For cancer related expenses not covered by insurance. Average grant \$50.00.

[Disabled Children's Relief Fund](#) (DCRF)

<http://www.dcrf.com/>

Provides disabled children with assistance to obtain wheelchairs, orthopedic braces, walkers, lifts, hearing aids, eyeglasses, medical equipment, physical therapy, and surgery.

[First Hand Foundation](#)

<http://www.cerner.com/firsthand/>

Helps families of children with health problems address the financial aspects of their child's healthcare.

[Jessica's Hope Chest](#)

<http://www.4jhc.org/index.html>

Assists families with critically ill children and helps with costs of necessities not covered by private medical insurance and/or government medical assistance programs.

[National Children's Cancer Society](#) (NCCS)

<http://www.nationalchildrenscancersociety.com>

Some financial assistance for travel, meals, lodging, medical expenses not covered by insurance for families with need: [application](#)

<http://www.nationalchildrenscancersociety.com/NetCommunity/admin/NetCommunity/Document.Doc?&id=22>

[The Partnership for Prescription Assistance](#)

<https://www.pparx.org/Intro.php>

Help for qualifying patients who lack prescription coverage to get needed medicines free or at reduced cost.

1-888-4PPA-NOW (1-888-477-2669)

[Partnership for Prescription Assistance for Kids](#)

<http://kids.pparx.org/>

Financial Resources – Government

[Medicaid](#) (called “Medical Assistance” in some states)

<http://www.cms.hhs.gov/MedicaidGenInfo/>

For disabled children (and adults) who qualify; apply through your county. Eligibility varies by state. Jointly funded by federal and state. Pays medical expenses, travel, lodging, meals, and drugs -- works as a secondary insurance (paying co-pays, deductibles, other) after your primary insurance is billed.

[State Children's Health Insurance Program \(SCHIP\)](#)

<http://www.insurekidsnow.gov/>

A Federal-State partnership that offers low-cost or free health insurance coverage to uninsured infants, children, and teens.

See information for each [state](#)

<http://www.insurekidsnow.gov/states.asp>

1-877-543-7669 (1-877-KIDS-NOW)

[Supplemental Security Income \(SSI\)](#)

<http://www.ssa.gov/d&s1.htm>

Information about [SSI for under 18](#)

<http://www.ssa.gov/applyfordisability/child.htm>

& [for over 18](#) <http://www.ssa.gov/applyfordisability/adult.htm>

Note: High-risk and recurrent neuroblastoma are listed as disability indications (but other factors are considered for determination). Benefits are retroactive to DATE OF APPLICATION not date of diagnosis, so it is important to apply immediately after diagnosis for maximum benefit. See the SSA's disability evaluation for childhood cancers in the [Blue Book](#)

<http://www.ssa.gov/disability/professionals/bluebook/113.00-NeoplasticDiseases-Malignant-Childhood.htm#113.21Neuroblastoma>

SSI monthly payments are for those with disability, very low income, and minimal resources. For child over 18, the family's income and resources are not included even if the child lives at home. In most states, once disability is approved (with or without SSI payments) the child is automatically eligible for Medicaid (also called Medical Assistance), which serves as a primary or secondary insurance.

Health Insurance

healthinsuranceinfo.net

<http://healthinsuranceinfo.net/>

What Cancer Survivors Need to Know About Health Insurance

http://www.canceradvocacy.org/resources/pubs/pdf/Health%20Insurance_Book.pdf

Insure Kids Now!

www.insurekidsnow.gov

A Federal-State partnership that offers low-cost or free health insurance coverage to uninsured children of low-wage, working parents.

[Managing Care, Managing Claims \(MCMC\)](#)

<http://www.mcmcllc.com>

Offers customized managed care, medical bill review, and integrated service programs.

Ph: (800) 227-1464 Fax: (617) 375-7777

Patient Advocacy Coalition

<http://medicalreporter.health.org/tmr0497/PAC.HTM>

Helps resolve insurance coverage issues.

Hearing Device Assistance & Resources

The Starkey Hearing Foundation

<http://www.sotheworldmayhear.org/contactus/>

Committed to assisting deaf and hard-of-hearing persons with limited financial resources who permanently reside within the United States.

John Tracy Clinic

<http://www.johntracyclinic.org/>

Free services worldwide for parents of infants and preschool children with hearing loss.

Miracle Ear Children's Foundation

<http://www.atk.ku.edu/hearingaidfunding.htm>

Provides new or reconditioned "Miracle-Ear" hearing aids and services free of charge to families who have hearing impaired children ages 16 years or younger, with an income level that does not allow them to receive public support.

<http://www.hdhearing.com/Learning/Part3.htm>

<http://www.hdhearing.com/Learning/Part2PDF.PDF>

Hospice**Information/Medical Research about Neuroblastoma & Treatment**

CancerGuide

http://cancerguide.org/scurve_basic.html

Primer explaining survival curves and statistics used in medical literature.

Especially good essay on "The Median is not the Message" by Stephen Jay Gould

http://cancerguide.org/median_not_msg.html

PubMed

<http://www.ncbi.nlm.nih.gov/sites/entrez?db=PubMed>

MedlinePlus

<http://medlineplus.gov/>

A service of the US National Library of Medicine and the National Institutes of Health; includes descriptions of diseases, medical dictionary, encyclopedia, index of drugs and supplements.

emedicine

<http://www.emedicine.com/>

Cell Stem Cell

<http://www.cellstemcell.com/>

Nature Medicine

<http://www.nature.com/nm/index.html>

OncoLink

<http://www.oncolink.com/>

Harvard Links

<http://mcb.harvard.edu/BioLinks/Immunology.html>

AMA

<http://www.ama-assn.org/>

Online Medical Dictionaries

<http://cancerweb.ncl.ac.uk/omd/>

<http://www.nlm.nih.gov/medlineplus/mplusdictionary.html>

<http://www.medterms.com/script/main/hp.asp>

Science in the News Weekly <http://www.americanscientist.org>

Walter Reed Army Institute of Research

<http://wrair-www.army.mil/Resources/library/Library.asp>

U.S. Food and Drug Administration

<http://www.fda.gov/>

Harvard Health & Medical Information

<http://www.health.harvard.edu/>

National Library of Medicine

<http://www.nlm.nih.gov/>

Cancer Survival Toolbox

<http://www.cancersurvivaltoolbox.org/>

In Chinese, English, and Spanish

National Cancer Institute <http://www.cancer.gov/>

Rare Cancer Alliance (RCA)

<http://www.rare-cancer.org/>

Disseminates information and provides support to all pediatric and adult rare cancer patients.

Patient-Centered Guides

<http://www.patientcenters.com/>

Patient-Centered Guides are a mix of medical, practical and emotional information, grounded in Western medicine, told by people who have been there.

Lodging

ITM Hospitality Fund

<http://www.itmhospitalityfund.com/pages/512431/index.htm>

Joe's House

<http://www.joeshouse.org/>

[Ronald McDonald House Charities](#)

www.rmhc.org

Provides a "home away from home" for families of seriously ill children receiving treatment at nearby hospitals.

Support for Parents and Patients

Neuroblastoma Foundations
Pediatric Cancer Foundations

Alex's Lemonade Stand
<http://www.alexlemonade.org/>

St. Baldricks Foundation
<http://www.stbaldricks.org/#>

American Red Cross
<http://www.redcross.org/index.html>

Cure Search
<http://www.curesearch.org/>

Hope Street Kids
<http://www.hopestreetkids.org/>

Gilda's Club
<http://www.gildasclub.org/>

Advocates the importance of emotional and social support for anyone touched by cancer.

The Sparrow Foundation
<http://www.sparrowfoundation.org/>
Assists with fundraising for medical needs.
517.364.5680 call to verify

Kristin's Friends
Financial assistance - computers, laptops medical equipment and help with insurance-related issues for families with life-threatening illnesses.
410-239-8154

Kelly Ann Dolan Fund
www.kadmf.org
Financial assistance with rent. Provides video on family financial management.
215-643-0763

Justin Scott Foster Foundation
<http://www.jsffoundation.com/index.html>
Creates public awareness about childhood cancer, gives special awards to children in treatment and financial assistance to families are in financial crisis, funds pediatric cancer research.

Special Love, Inc.—Virginia
<http://www.speciallove.org>
Emergency funds for families participating in the camp program who are in need; college scholarships for children diagnosed with cancer.

The Candlelighters Childhood Cancer Foundation
<http://www.candlelighters.org>
Provides information, peer support, and advocacy through publications, an information clearinghouse, and a network of local support groups, and maintains a list of organizations to which eligible families may apply for financial assistance. 800-366-2223

Association Cancer Online Resources

<http://www.acor.org/>

Provides support, information, and community to everyone affected by cancer and related disorders

Cancer Kids

<http://www.cancerkids.org/>

A web-based organization that helps children with cancer tell their stories to the world.

Survivorship & Late Effects

[The Cancer Survivors Project](#)

<http://www.cancersurvivorsproject.org/index.html>

An organized, international community of long-term cancer survivors and their friends working together to improve the lives of children and adults after cancer.

[Survivor Alert](#)

Part of ongoing efforts nationally to educate adolescent and young adult cancer survivors about research showing that an early history of cancer creates a need for lifelong follow-up care, and to motivate them to take charge of their health.

[National Coalition for Cancer Survivorship](#)

Survivor-led cancer advocacy organization.

[Long Term Follow-up Guidelines](#)

Prepared by COG (Children's Oncology Group) and provides recommendations for screening and management of late effects after childhood cancer treatment.

[Long-Term Treatment Complications](#)

Prepared by Memorial Sloan-Kettering, with detailing potential late effects from specific chemotherapy agents, and other treatments.

See a brief overview at [after childhood cancer](#).

[Candlelighters](#)

Good information, including two articles published in 2006 *New England Journal of Medicine* on [results of the Childhood Cancer Survivor Study](#) and information on late effects on the drop-down menu under the "Treatment" button on the home page. Parents also can order a copy of Nancy Keene's book "Educating the Child with Cancer" from their store.

[ACOR's Ped-Onc Survivors listserv](#)

a great source of information and support

ACOR also maintains a [list of survivorship clinics](#)

Transportation

[Air Care Alliance](#)

Supports the Nationwide Community of Charitable Aviators

Maintains a [list of all free air flight services](#) for medical and other needs; updated regularly.

[American Airlines Miles for Kids in Need](#)

Provides transportation (with donated miles) for children up to the age of 23 in need of medical treatment; patient must be recommended by a social worker.

(800) 421-0600

[AMTRAK](#)

Offers a rail fare discount to passengers with disabilities. To receive the discount you must book your reservation by telephone or at a ticket counter. Discounts are not available through online booking.

[Continental Airlines](#)

Compassion (Bereavement) Fares

Corporate Angels

[Northwest Airlines KidCaresSM](#)

Donated WorldPerks® miles are used to provide free air travel for a child, accompanied by one parent or guardian, to obtain needed medical treatment.

Phone: (612) 726-4206 Fax: (612) 726-3942

[National Patient Travel Center](#)

Facilitates patient access to appropriate charitable medical air transportation resources in the United States.

1-800-296-1217

[Operation Liftoff](#)

Provides transportation for children with a life-threatening illness for treatment or dream trip

Wish Granting Organizations

List of wish granting organizations

<http://www.familyvillage.wisc.edu/general/wish-grant-orgs.html>

Make-a-Wish Foundation

<http://www.wish.org/>

Children's Dream Fund

<http://www.childrensdreamfund.org/ez/>

Helps make critically ill children's dreams come true.

Please contact info@cncfhope.org with any comments