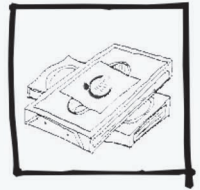
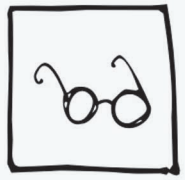
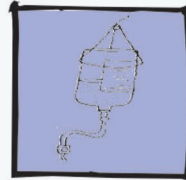


The Purple Pages



a resource for families with cancer



*"Circle of Care provides the
kind of care to newly diagnosed
families that only another parent
who has been through this
experience can give."*

www.thecircleofcare.org

Preface

As the parents of children with cancer we remember the daunting task of weeding through all the resources of the Internet and feeling overwhelmed and sometimes scared about what we might stumble upon.

This book is a compilation of the many wonderful resources available to families of children with cancer on the Internet, in print and video. We have sorted them into chapters to make it easier for you to find the information you need. Each one has been researched and reviewed to make your search even easier. We have also included a listing of Connecticut support groups for you and your families.

We always welcome your feedback and we will update this directory to keep on top of all the newest resources. If you would like to receive the updated editions – please contact us for your free copy.

Liz, Pam & Dawn

Circle of Care
for families with cancer

P.O. Box 32, Wilton CT 06897
(203) 663-6893

info@thecircleofcare.org
www.thecircleofcare.org

Acknowledgements

This book would not have been possible with out the guidance and support of Dr. Joseph McNamara, all the wonderful Nurses, Doctors and Social Workers at Yale New Haven Children's Hospital and Connecticut Children's Medical Center.

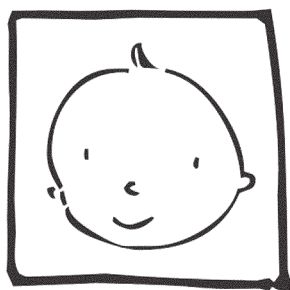
We would also like to thank our tireless researchers and fact checkers, Sarah Patterson and Lally Jurcik, contributors Ellen Belitsky and Dana McCreesh.

The Pitney Bowes Literacy & Education Fund has generously provided the funding for this book.

Table of Contents



| | |
|---|-------|
| PEDIATRIC HEALTHCARE & CANCER ORGANIZATIONS | 6-10 |
| TREATMENT CENTERS | 12-13 |
| BONE MARROW & STEM CELL TRANSPLANTATION | 14 |
| ORGANIZATIONS OFFERING ALTERNATIVE THERAPIES..... | 16 |
| RESOURCES FOR PARENTS, KIDS & TEENS | 18-25 |
| SUPPORT GROUPS | 26-27 |
| FINANCIAL HELP | 30-32 |
| INSURANCE HELP | 33-34 |
| DRUG REIMBURSEMENT | 35 |
| FREE AIR SERVICES | 36 |
| SCHOOL RELATED ISSUES | 38-40 |
| CAMPS | 42-43 |
| WISH FULFILLMENT ORGANIZATIONS | 45 |
| WIGS & ACCESSORIES..... | 46 |
| CIRCLE OF CARE SUGGESTED READING | 48-52 |
| VIDEOS..... | 53 |
| LIFE AFTER CANCER | 54 |



**Pediatric Healthcare
and
Cancer Organizations**

American Cancer Society

1599 Clifton Road
Atlanta, GA 30329-4251
(800) 227-(ACS)-2345

www.cancer.org

Has a national network of employees and volunteers who implement research, education, and patient service programs. Although programs differ according to state, some widely available programs are patient-to-patient visitation, transportation to appointments, housing near treatment centers, equipment and supplies, support groups, literature on a large variety of topics, summer camps for children with cancer, and research and educational programs.

The American Academy of Pediatrics National Headquarters

141 Northwest Point Boulevard
Elk Grove Village, IL 60007-1098
Tel: (847) 434-4000
Fax: (847) 434-8000

www.aap.org

AAP is a member-based organization of pediatricians dedicated to the health, safety, and well-being of infants, children, adolescents, and young adults. The web site provides guidelines for pediatric cancer centers, related oncology links, and general information about childhood health.

American Pediatric Surgical Association (APSA)

60 Revere Drive, Suite 500
Northbrook, IL 60062
Tel: (847) 480-9576
Fax: (847) 480-9282

[Email: eapsa@eapsa.org](mailto:eapsa@eapsa.org)

www.eapsa.org

The APSA is a surgical specialty organization composed of individuals who have dedicated themselves to the care of the pediatric surgical patient. The web site has a search feature to find a qualified pediatric surgeon (who is also a member of APSA) in your area.

American Society of Pediatric Hematology/Oncology (ASPH/O)

Tel: (847) 375-4716

[Email: info@aspho.org](mailto:info@aspho.org)

www.aspho.org

ASPH/O is a professional society of pediatric hematologists/oncologists who study and treat childhood cancer and blood diseases. The web site serves patients and families by providing a source of current peer-reviewed scientific and clinical research and links to find related information on the Internet.

Association of Pediatric Oncology Nurses

4700 W. Lake Avenue
Glenview, IL 60025-1485
Tel: (847) 375-4724
Fax: (877) 734-8755

[Email: info@apon.org](mailto:info@apon.org)

www.apon.org

APON is the professional organization for pediatric oncology nurses and other pediatric hematology/oncology health care professionals. Its members are dedicated to promoting optimal nursing care for children and adolescents with cancer and their families.

Brain Tumor Foundation for Children, Inc. (BTFC)

1835 Savoy Drive
Suite 200
Atlanta, GA 30341
Tel: (770) 458-5554

www.btfcgainc.org

BTFC provides information and emotional support to families of children with brain tumors, promotes public education and awareness of the disease, and raises funds to support research for a cure and for improvement in the treatment and the quality of life of children with brain tumors.

Childhood Brain Tumor Foundation **20312 Watkins Meadow Drive**

Germantown, MD 20876

Tel: (301) 515-2900 or (877) 217-4166

www.childhoodbraintumor.org

The mission of the CBTF is to raise funds for scientific research, heighten public awareness, and improve prognosis and quality of life for children who are affected. The web site contains articles and newsletters about childhood brain tumors and information on the organization and its services.

Children's Brain Tumor Foundation **274 Madison Avenue**

Suite 1301

New York, New York 10016

Tel: (212) 448-9494 or (866) 228-HOPE

Fax: (212) 448-1022

www.cbtf.org

CBTF provides: a free Resource Guide for Parents of Children With Brain or Spinal Cord Tumors; support services for families and survivors of childhood brain tumors; a Parent-to-Parent network pairing experienced parents with parents of newly diagnosed children; co-sponsorship of conferences and seminars for families, survivors, and health care professionals.

The Children's Cause **1010 Wayne Avenue, Suite 770**

Silver Spring, MD 20910

Tel : (301) 562-2765

Fax: (301) 565-9670

www.childrenscause.org

The Children's Cause is dedicated to accelerating the discovery of and access to innovative, safer, and more effective treatments for childhood cancer through education and advocacy. The web site provides information about FDA guidelines, NCI cancer policies, medical privacy issues, current clinical trials, and key resources.

Children's Leukemia Research Association (CLRA)

585 Stewart Avenue, Suite 18

Garden City, NY 11530

Tel: (516) 222-1944 (may call collect)

Fax: (516) 222-0457

Email: clra@childrensleukemia.org

www.childrensleukemia.org

CLRA is a nonprofit organization dedicated to raising funds to support efforts toward finding the causes and cures for leukemia, CLRA provides financial aid for treatment, medications, and lab fees for leukemia patients, public and professional education, and research grants to medical professionals.

Children's Oncology Group (COG)

P.O. Box 60012

Arcadia, CA 91066-6012

Email: coginfo@childrensoncologygroup.org

www.childrensoncologygroup.org

COG is an NCI-supported clinical trials cooperative group devoted exclusively to childhood and adolescent cancer research. COG develops and coordinates cancer clinical trials. Their web site provides information about how to locate a treatment center offering clinical trials for children with cancer.

Candlelighters Childhood Cancer Foundation

P.O. Box 498

Kensington, MD 20895-0498

(800) 366-2223

www.candlelighters.org

Founded in 1970, Candlelighters has more than 43,000 members worldwide. Some of the free services provided by Candlelighters are a Toll-free information hotline, a quarterly newsletter, and various handbooks to help families of children with cancer, local support group chapters, and national advocacy.

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 having difficulty gaining access to appropriate education, medical care, healthcare cost coverage, and/or meaningful employment. Services include medical library searches, a second opinion program, and help resolving problems with insurance or discrimination.

Childhood Leukemia Foundation

1608 Route 88 West, Suite 203
Brick, NJ 08724
Tel: (888) CLF-7109
Fax: (732) 840-5818

Email: info@clf4kids.com
www.clf4kids.com

The Childhood Leukemia Foundation is a national non-profit organization founded for the purpose of "nurturing the spirit within" children living with cancer. CLF works to foster a better quality of life for children with cancer by bringing fun and joyful experiences, and returning a sense of normalcy to their challenging lives.

National Cancer Institute (NCI)

NCI Public Inquiries Office
Suite 3036A
6116 Executive Boulevard, MSC8322
Bethesda, MD 20892-8322
Tel: (800) 422-6237 (800-4-CANCER)

www.nci.nih.gov

Provides a nationwide telephone service for people with cancer, their families and friends, and the professionals who treat them. Also available is live, on-line assistance through their web site. The NCI answers questions and sends out informational booklets on a variety of cancer-related topics.

Leukemia & Lymphoma Society

Connecticut Chapter
300 Research Parkway
Meriden, CT
(203) 379-0445
Information Resource Center:
(800) 955-4572 (9am to 6pm EST)
www.lls.org

Fairfield County Chapter
25 Third Street
Stamford, CT 06905
(203) 967-8326

www.lls.org

This organization funds research, sponsors a national program in education for the public and the medical community and publishes a large number of booklets on cancer-related topics. It also has an Information Resource Center, available by phone or via their web site, staffed by social workers, nurses and health educators who provide current, accurate, disease-related information. Financial assistance is available to families (up to \$500/year for outpatients).

National Children's Cancer Society (NCCS)

1015 Locust, Suite 600
St. Louis, MO 63101
Tel: (314) 241-1600
Toll-free: (800) 532-6459
Program Services Fax : (314) 241-6949
www.children-cancer.com

NCCS is a non-profit national organization that helps children with cancer (newborn to age 18) and their families by providing support for their medical and emotional needs. The organization provides needs-based financial assistance, advocacy, support services, education about childhood cancer, wellness education, and emotional support.

Hope Street Kids

1600 Duke Street, Suite 500,

Alexandria, VA 22314

Tel: (703) 836-4412

Fax: (703) 836-4413

Toll-free: 800-227-2732

Email: info@hopestreetkids.org

www.hopestreetkids.org

Hope Street Kids is a children's initiative of the Cancer Research and Prevention Foundation. The mission of Hope Street Kids is to eliminate childhood cancer through advocacy, education, and research and to support children with cancer and their families during and after treatment. Hope Street Kids assists both public and private research efforts through fundraising and provides leadership in advocating new research studies. The organization also translates the latest scientific breakthroughs into effective treatment and prevention strategies to improve the quality of life for all children.

Neuroblastoma Children's Cancer Society

P.O. Box 957672

Hoffman Estates, IL 60195

Toll-free: (800) 532-5162

Fax: (847) 490-0705

Email: info@neuroblastomacancer.org

www.neuroblastomacancer.org

The Neuroblastoma Children's Cancer Society is a group made up of volunteers, many of whom have children or relatives who are victims or survivors of this disease. This organization is an advocate for the children who suffer from neuroblastoma and is dedicated to serving as a support center for their families. The primary focus of the organization is to raise money to assist local research in neuroblastoma cancer, and to raise national awareness to focus additional research and funding until a cure can be found.

National Childhood Cancer Foundation

440 E. Huntington Drive

P.O. Box 60012

Arcadia, CA 91066-6012

Tel: (800) 458-6223

www.nccf.org

Supports pediatric cancer treatment and research at over 235 hospitals in North America. Their free newsletter, Childhood Cancerline, provides information on new treatments and psychosocial support.

National Dissemination Center for Children with Disabilities

P.O. Box 1492

Washington, DC 20013

Tel: (800) 695-0285

Fax: (202) 884-8441

Email: nichcy@aed.org

www.nichcy.org

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

National Organization for Rare Disorders (NORD)

55 Kenosia Avenue

P.O.Box 1968

Danbury, CT 06813-1968

Tel: (203) 744-0100

Toll-free: (800) 999-6673 (voicemail only)

Fax: (203) 798-2291

Email: orphan@rarediseases.org

www.rarediseases.org

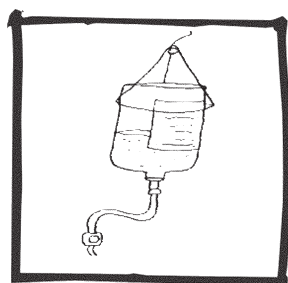
The National Organization for Rare Disorders (NORD) is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and service.

PDQ (Physician Data Query)

Tel: (800) 422-6237 (800-4-CANCER)

www.cancer.gov/cancerinformation/pdq

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, and clinical trials. The web site offers on-line live help.



Treatment Centers

TREATMENT CENTERS

Connecticut Children's Medical Center

282 Washington Street
Hartford, CT 06106
(860) 545-9000

www.ccmckids.org

The Division of Hematology/Oncology provides comprehensive care for pediatric patients with hematologic or oncologic problems. They provide diagnosis and management services for children with anemias, neutropenias, thrombocytopenias, coagulation disorders, leukemias, and all solid tumors.

Dana Farber Cancer Institute/ Boston Children's Hospital

44 Binney Street
Boston, MA 02115
(866) 408-3324

www.dana-farber.org

For more than 50 years, Dana-Farber and Children's Hospital Boston have worked together to provide the best care available for children with cancer. Patients are treated in one of the following programs: Brain Tumor (Stop & Shop Family Pediatric Brain Tumor Clinic) Cancer Survivor Program (Perini Clinic) Histiocytosis, Hodgkin's Lymphoma, Leukemi, Non-Hodgkin's Lymphoma, Solid Tumor Program.

Dana-Farber Cancer Institute/Children's Hospital Boston's Pediatric Stem Cell Transplantation Program is internationally recognized as a preeminent pediatric center for the transplantation of hematologic stem cells. The program remains at the forefront of medical transplantation research and technology. Being one of the first Pediatric Oncology programs established in the 1970s, Dana-Farber/Children's rapidly established a transplant program, which is one of the most experienced, sophisticated, and accomplished multidisciplinary childhood transplant centers in the world. Each year, the program evaluates and/or treats between 65-75 children with a variety of diseases.

The Johns Hopkins Childrens Center

600 North Wolfe Street
Baltimore, MD 21287
Tel: (410) 955-5000
Toll-free: (800) 455-6467
Fax: (410) 955-9850

www.hopkinsmedicine.org/academics/pediatrics

Consistently ranked as one of the top three children's hospitals in the nation by U.S. News and World Report, The Johns Hopkins Childrens Center offers one of the most comprehensive pediatric medical programs in the country.

St. Jude Children's Research Hospital

332 N. Lauderdale
Memphis, TN 38105
Tel: (901) 495-3300

www.stjude.org

St. Jude Children's Research Hospital, located in Memphis, Tennessee, is one of the world's premier centers for research and treatment of catastrophic diseases in children, primarily pediatric cancers. All patients accepted for treatment at St. Jude must be referred by their physicians and are treated without regard to the family's ability to pay.

The University of Texas M.D. Anderson Cancer Center

1515 Holcombe Blvd.
Houston, TX 77030
Tel: (713) 792-6161
Toll-free: (800) 392-1611

www.mdanderson.org/care_centers/childandadol/

Cutting-edge research and treatments at M. D. Anderson have helped thousands of children survive cancer with the best possible outcomes and quality of life. The Child & Adolescent Center is a nationally designated comprehensive cancer facility, one of only three dozen in the nation.

Memorial Sloan Kettering

1275 York Avenue
New York, NY 10021
(212) 639-2000

www.mskcc.org

MSK hospital has treated more children with cancer than any other institution in the world. Their unique multidisciplinary approach offers children with cancer and other potentially lethal blood disorders the best opportunity for accurate diagnosis and the most effective treatment available. Their website is filled with disease information as well as links for frequently asked questions for parents and children.

Yale New Haven Children's Hospital

20 York Street
New Haven, CT 06510
(203) 688-4242

www.YNHH.org

The goals of the Section of Hematology Oncology are to provide outstanding patient care, education for residents and fellows, and innovative research. Pediatric Oncology is a major component of the Yale Comprehensive Cancer Center. A multidisciplinary team of physicians in pediatrics, laboratory medicine, surgery, neurosurgery, orthopedics, pathology, therapeutic radiology, and diagnostic radiology, as well as nurses and social workers are closely integrated with the Section of Hematology/Oncology to optimize the coordinated delivery of clinical care.

Texas Children's Cancer Center

6621 Fannin St., CC 1410.00
Houston, TX 77030-2399
Tel: (832) 822-4200

Toll-free: (800) cancer9

Fax: (832) 825

www.txccc.org

Texas Children's Cancer Center, world renowned for its work in pediatric cancer and hematology disorders, offers innovative therapies for all forms of childhood cancer and blood disorders.

Children's Hospital of Philadelphia

34th Street & Civic Center Boulevard
Philadelphia, PA 19104-4399
Tel: (215) 590-1000

www.chop.edu

The Children's Hospital of Philadelphia is one of the leading pediatric hospitals and research facilities in the world. Our 150 years of innovation and service to our patients, their families and our community reflect an ongoing commitment to exceptional patient care, training new generations of pediatric healthcare providers and pioneering significant research initiatives.

In an exclusive survey, Child Magazine has ranked The Children's Hospital of Philadelphia the best pediatric hospital in the United States for the third consecutive time. In its comprehensive 2005 survey, the magazine also rated Children's Hospital's Cardiac Center and neonatology, oncology and orthopaedics divisions #1 in the nation and emergency medicine #4.



BMT InfoNet

(Blood & Marrow Transplant
Information Network)
2900 Skokie Valley Road, Suite B
Highland Park, IL 60035
Tel: (847) 433-3313
Toll-free: (888) 597-7674
Fax: (847) 433-4599

Email: help@bmtinfolnet.org

www.bmtinfolnet.org

Since 1990, BMT InfoNet has provided support to more than 100,000 transplant patients and their loved ones. Its services include a quarterly newsletter, a searchable Transplant Center database, a resource directory, a drug database, book recommendations, a patient support network, and help with insurance difficulties.

Bone Marrow Foundation

337 East 88th Street, Suite 1B
New York, NY 10128
Tel: (212) 838-3029
Toll-free: (800) 365-1336

www.bonemarrow.org

Provides financial assistance, education and support to those facing bone marrow transplants.

National Bone Marrow Transplant Link

20411 W. Twelve Mile Road, Suite 108
Southfield, MI 48076
Tel: (800) 546-5268 (800-LINK-BMT)
or (248) 358-1886

www.nbmtlink.org

Provides hot line, peer support, library, clearinghouse, and suggestions for financial assistance.

National Marrow Donor Program (NMDP)

3001 Broadway Street, NE, Suite 500
Minneapolis, MN 55413
Patient Advocacy: (888) 999-6743
Business Line: (800) 627-7692
(800-MARROW)

www.marrow.org

The NMDP has the world's largest computerized listing of potential bone marrow donors – 4,500,000 in 2002. The NMDP has cooperative search arrangements with many other registries worldwide. They also provide patient advocacy and assistance and information on transplant centers in the U.S.

National Transplant Assistance Fund

3475 West Chester Pike, Suite 230
Newtown Square PA 19073
Tel: (800) 642-8399
Fax: (610) 353-1616

www.transplantfund.org

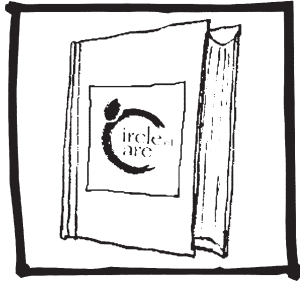
Provides fundraising assistance and donor awareness material to transplant and catastrophic injury patients nationwide.

New England Marrow Donor Program

209 Farmington Avenue
Farmington, CT 06032-1957
Tel: (860) 678-2865
Toll-free: (800) 676-4545

www.bloodct.org/marrow.htm

The New England Marrow Donor Program (NEMDP), established in 1987, is the National Marrow Donor Program (NMDP) donor center for Connecticut, Maine, Massachusetts, New Hampshire, and Vermont.



Organizations Offering Alternative Therapies

ORGANIZATIONS OFFERING ALTERNATIVE THERAPIES

Academy For Guided Imagery

30765 Pacific Coast Highway #369

Malibu, CA 90265

Tel: (800) 726-2070

www.interactiveimagery.com

This organization trains health professionals to use interactive guided imagery with their patients and clients. Self care books and tapes on guided imagery are available for sale. They can assist with locating a professional in your area to help your child learn visualization.

American Institute for Cancer Research Nutrition hotline

(800) 843-8114

www.aicr.org

Provides information on different nutritional regimens and potential health benefits.

University of Texas Center for Alternative Medicine Research

www.sph.uth.tmc.edu/utcam/

Provides extensive information on specific complementary and alternative therapies, with detailed scientific summaries of study results.

Quackwatch

www.quackwatch.com

Provides information on claims of complementary and alternative therapies that are unproven. Proven to be ineffective or proven to be unsafe.

American Society of Clinical Hypnosis

140 N. Bloomingdale Rd.

Bloomington, IL 60108-1017

Tel: (630) 980-4740

Fax: (630) 351-8490

Email: info@asch.net

www.asch.net

A membership organization for doctors, psychologists, and dentists who use hypnosis in their practices. Their web site provides a locator for member practitioners.

National Center for Complementary and Alternative Medicine (NCCAM)

P.O. Box 7923

Gaithersburg, MD 20898

Toll-free: 888-644-6226

Tel: (301) 519-3153

Fax: (866) 464-3616

Email: info@nccam.nih.gov

www.nccam.nih.gov

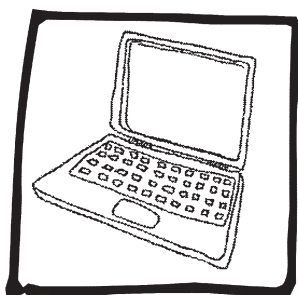
NCCAM is dedicated to exploring complementary and alternative healing practices, training complementary and alternative medicine (CAM) researchers, and disseminating information to the public and professionals.

Oncolink

www.oncolink.upenn.edu

Provides information and video segments on specific complementary and alternative therapies, how to discuss the topic with your doctor, how to choose a reliable provider.





Resources for Parents, Kids & Teens

RESOURCES FOR PARENTS

Cancer Guide

www.cancerguide.org

Created by Steve Dunn, a cancer survivor, this web site is very welcoming and empathetic and offers information on a variety of topics: pros & cons of researching your cancer, cancer fundamentals, recommended books, understanding clinical trials (includes a glossary), researching technical literature, accessing medical databases (including MedLine), bone marrow transplants, rare cancers, alternative therapies.

CancerCare, Inc.

275 Seventh Avenue

New York, NY 10001

Tel: (800) 813-4673 (800) 813-HOPE)

www.cancercare.org

CancerCare is a national non-profit organization whose mission is to provide free professional help to people with all cancers through counseling, education, information and referral and direct financial assistance.

CancerCare of CT (Main Office)

120 East Avenue

Norwalk, CT 06851-5703

Tel: (203) 854-9911 or

(800) 813-HOPE (4673)

Email: ctinfo@cancercare.org

CancerCare of Connecticut provides free professional help to people with all cancers and their families in the state of Connecticut through counseling, education, information and referral and direct financial assistance.

CaringBridge

4607 Beacon Hill, Suite 200

Eagan, MN 55122-2702

Tel: (651) 452-7940

www.caringbridge.com

This nonprofit organization can help you set up a free web site that you can update with your child's condition. This can help alleviate high phone bills and keep extended family members updated.

Curesearch

Headquarters Office

4600 East West Highway, #600

Bethesda, MD 20814-3457

(800) 458-6223

A leader in the search to cure childhood cancer one child at a time. Website offers information to parents and families related to specific cancer type, treatment stage, as well as tips on navigating the healthcare system and how to get support.

The Center For Hope

590 Post Road

Darien, CT 06820

(203) 655-4693

www.centerforhope.org

The Center for Hope helps adults and children living with a life-threatening illness or grieving a death and coping with the related trauma. It offers professional counseling, support groups and educational programs, in an atmosphere of hope and renewal. A place for kids and their families to then come to have someone to talk to, to meet other kids going through a similar thing, to get help with all the tough stuff that comes when someone is very ill or you are grieving. Support groups are offered on an on-going basis for parents and siblings of children with cancer.

Children's Cancer Web

www.cancerindex.org/ccw/index.htm

With hundreds of thousands (probably millions) of cancer-related pages on the Internet finding appropriate information about childhood cancer can be a real challenge. The aim of "Children's Cancer Web" is to make it easier to find more specific childhood cancer information quickly. Links are sorted into categories (by disease-type, and other topics), and where possible annotation is provided to give the reader a brief description of each site/organization.

Coping Magazine

P.O. Box 682268

Franklin, TN 37068

Tel: (615) 790-2400

www.copingmag.com

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

Home Care Guide

www.hmc.psu.edu/pedsonco.

Homeguide

A very helpful web site for those caring for young persons with cancer at home.

The Hugs and Hope Club for Sick Kids

www.hugsandhope.org

The Hugs and Hope Club for Sick Kids is a ministry devoted to encouraging children battling critical illness and their families. The goal of the organization is to share God's love and provide friendship and support to families of sick children who live within the United States through the following projects and programs:

- *Mailing cheery cards (a.k.a. "happy mail")*
- *Providing balloon bouquets to hospitalized children*
- *Granting children's wishes*
- *Sending Birthday Party Boxes*
- *Providing Christmas gifts through our Elf Project*
- *Assigning a personal "parent pal" who cheers, encourages, and supports the family in crisis.*

Oncologyparents.org

www.oncologyparents.org

This Site was started in 1998 by parents for parents of children with all types of Cancer.

The goal of the site is to help make things a bit easier for other parents, by posting helpful information. The site includes Parents Pages, Kids Pages, links to hospitals, organizations, research and treatments, an "Ask the Doc" section, and a Chat Room.

Make A Child Smile Organization

(MACS)

P.O. Box 16262

Plantation, FL 33318

www.makeachildsmile.org

The mission of MACS is to provide emotional and financial support to families whose children suffer from chronic or life-threatening illnesses and also give those who visit the MACS web site the opportunity to show support by sending mail to the children. Each month, new children are featured. A picture and biography describing the child and information about their family is published on the site. Hundreds of 'net surfers, schools, service organizations, girls/boys scouts and church groups use the MACS site as a philanthropic project where they can send cards, letters and small gifts to the featured children and their siblings.

Never-Ending Squirrel Tales

www.squirreltales.com

Practical tips and encouragement for the parents of kids with cancer. World famous guest book.

Ronald McDonald House Charities (RMHC)

One Kroc Drive

Oak Brook, Illinois 60523

Tel: (630) 623-7048 (charity information and donations)

Fax: (630) 623-7488

www.rmhc.org

RMHC provides information about local Ronald McDonald Houses on a national and international basis. The Houses provide lodging for families of seriously ill children being treated away from home. The web site has a feature that locates RMHC chapters and a Ronald McDonald House in a specific area.

Ronald McDonald House

501 George Street
New Haven, CT
(203) 777-5683

The Ronald McDonald House provides a comfortable, supportive alternative for these families. It serves as a temporary residence near the medical facility where family members can sleep, eat, relax and find support from other families in similar situations. In return, families are asked to make a donation ranging from \$5 to \$20 per day; if that isn't possible, their stay is free.

RxList

500 3rd Street
Suite 530
San Francisco, CA 94107
Email: info@rxlist.com

www.rxlist.com

Information on specific medications.

Time For Life Resource Center

80 South Main Street
West Hartford, CT 06107
Tel: (860) 521-3707
Fax: (860) 521-1128

Monday – Friday, 9:00am – 5:00pm (EST)

Email: info@timeforlife.org

www.timeforlife.org

Serving communities in the Connecticut and Massachusetts areas, Time For Life serves children with cancer and their families from the point of diagnosis, through treatment, and on to survival. Free community programs offered include art therapy, “Cooking with Cancer” classes, a body-image program for girls, and programs for moms and dads of cancer kids. They also offer a free summer program (5-day stay) on Martha’s Vineyard for the benefit of the whole family.

Songs of Love Foundation

P.O. Box 750809,
Forest Hills, NY 11375
Toll-free Tel: 1-800-960-SONG(7664)
Fax: (718) 441-7372

Email: Info@SongsOfLove.org
www.songslovelove.org

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

STARBRIGHT Foundation

1850 Sawtelle Blvd., Suite 450
Los Angeles, CA 90025
Tel: (310) 479-1212 or (800) 315-2580
Fax: (310) 479-1235

www.starbright.org

The STARBRIGHT Foundation is dedicated to the development of projects that empower seriously ill children to combat the medical and emotional challenges they face on a daily basis. STARBRIGHT projects address the core issues that accompany illness – the pain, fear, loneliness, and depression that can be as damaging as the sickness itself.

Supersibs!

1566 W Algonquin Road, Suite 224
Hoffman Estates, IL 60195
Tel: (866)444-SIBS (7427)

www.supersibs.org

SuperSibs! helps children redefine the “cancer sibling” experience - by providing needed support services and by helping to draw out the greater and important lessons that may benefit these children later in their own lives. A pediatric cancer diagnosis affects EVERYONE in the family. Siblings need to know, especially during the fight against cancer, that they are special and important people, too, and that there is an organization to provide support for their unique needs.

Circle of Care for Families with Cancer

P.O. Box 32
Wilton, CT
(203) 663-6893
(800) 887-6801

www.thecircleofcare.org
info@thecircleofcare.org

This organization supports children with cancer and their families from the time of diagnosis to recovery and beyond. It was founded by local families whose children have battled and survived cancer. This website contains information about their resources and programs including Lifeline, a parent to parent support program. Check out the section called The Purple Pages with links to essential resources on the Internet, in print and video.

Yale New Haven Children's Hospital

20 York Street
New Haven CT 068
(203) 688



www.ynhh.org
<http://www.ynhh.org/pediatrics/cancer/parents.html>

Pediatric Cancer Services – Frequently asked questions

In addition to the child, cancer affects parents, siblings, grandparents and an entire circle of friends. This section answers common questions family and friends may have and shares the experiences of other families whose children have been treated at Yale-New Haven Children's Hospital.



RESOURCES FOR KIDS

Brave Kids

1510 11th Street
Suite 203
Santa Monica, CA 90401
Tel: (800) 568-1008
Fax: (310) 395-5402

Email: info@bravekids.org
www.bravekids.org

The mission of Brave Kids is to help children with chronic, life-threatening illnesses or disabilities. For adults, the site includes message boards, a directory of health care resources, and recent and accurate medical info. There is a special section of the web site called Club Brave Kids, designed just for children dealing with cancer. It includes, message boards (for both cancer patients and their siblings), weekly polls, news about other Brave Kids, medical info just for kids and teens, and games.

CancerSourceKids.com

40 Tall Pine Drive
Sudbury, MA 01776
Email: info@cancersource.com
www.cancersourcekids.com

A web site where kids can learn about cancer and have fun with games and art, with sections for kids 6-12, teens 13-18, and parents.

Band-aids and Blackboards

www.lehman.cuny.edu/faculty/jfleitas/bandaides/

Joan Fleitas, Assistant Professor of Nursing at Fairfield University, provides this site, designed to offer the child's perspective on what growing up with a serious medical condition. The site supports kids, teenagers and adults on dealing with their medical and emotional issues and going back to school. Kids are advised on dealing with teasing, what to expect in the classroom and how to get back to life. A great site for kids, teens and parents of kids with medical challenges.

Soaringwords, Inc.

505 Eighth Avenue, Suite 404
New York, NY 10018
Tel: (212) 290-7627
Fax: (212) 290-0072

Email: heal@soaringwords.org
www.soaringwords.org

Soaringwords uses the power of the Internet to help children and their families cope with catastrophic events and illness. Soaringwords.org is not medical or clinical in nature. It is inspirational and fosters care, empathy, hope and understanding as kids connect with other kids and parents connect with other parents. The web site includes content from many acknowledged leaders in counseling, mind-body wellness, religion and healing.

Kids Cancer Network

www.kidscancernetwork.org/
In 1992, young cancer survivor Kenon Neal founded Kids Cancer Network to provide "a dose of hope™" for kids and their families isolated by the rigors of childhood cancer treatment.. He developed a "Fun Letter", an eight page activities letter for children with cancer, including games to play, pictures to color and ideas to share. There are six issues that come out a year. Parts of a sample issue can be downloaded from this site.

Just For Kids Page on The Midwest Children's Brain Tumor Center

Midwest Children's Brain Tumor Center
Advocate Lutheran General Children's Hospital
www.advocatehealth.com/lgch/services/cancer/brainumor/kids.html
Two kids, Christopher and Jessica, talk about things that go on during treatment. There are pages on explaining symptoms, visiting the doctor, radiographic tests and treatments.

American Brain Tumor Kids Page

www.abta.org/kids/home.htm

This is a new site under construction that shows promise. There are three current sections- brain tumor information, facts and figures and Alex's journey video clips. The BT information page has a series of questions and answers for kids (learning section). The activity page has crossword puzzles, word searches, and word scrambles that are related to brain tumors. One can also view parts of a video called Alex's Journey, about a boy who is diagnosed with a brain tumor (the entire video can be obtained free of charge through ABTA-ordering instructions on the page). Parts include: The introduction with Jack Hanna and his daughter (a brain tumor survivor). The technician talks about MRI's. The doctor talks about surgery. Alex talks with another child (a very good segment about cancer/hair and other stuff) Alex goes home.

Blood Count Information for Kids with Cancer

www.coninfo.nursing.uiowa.edu/sites/pedspain/bcounts/index.htm

University of Iowa site that uses cartoon type characters to explain blood counts to kids.



RESOURCES FOR TEENS

CancerSourceKids.com

40 Tall Pine Drive
Sudbury, MA 01776

Email: info@cancersource.com

www.cancersourcekids.com

A web site where kids can learn about cancer and have fun with games and art, with sections for kids 6-12, teens 13-18, and parents.

Cancer Kids

Email: webmaster@cancerkids.org

www.cancerkids.org

Cancer Kids is a web-based organization which began in 1997 with one simple goal: to help children with cancer tell their stories to the world. This goal is accomplished by providing links to the personal web pages of children who are battling cancer, through the "Stories" section of our web site. Unfortunately, for some children the battle with cancer doesn't end in the word "remission" or "cure". In one sense, these brave little warriors have lost their battle with the cancer monster. Yet in another sense, they have actually been granted the ultimate victory by being given angel wings. Cancer Kids is honored to pay tribute to these children through the Cancer Kids "Wall of Memory".

Planet Cancer

3710 Cedar St., Box 11
Austin, TX 78705

Tel: (512) 452-9010

Fax: (512) 451-3110

Email: headquarters@planetcancer.org

www.planetcancer.org

Web site for young adults dealing with cancer. Includes real world advice, discussion boards, and recommendations for books, music and films.

Teens Living with Cancer

Melissa's Living Legacy Foundation

245 Citation Dr.

Henrietta, NY 14467

Tel: (585) 334-0858

Fax: (585) 334-0858

Email: info@teenslivingwithcancer.org

www.teenslivingwithcancer.org

Includes cancer facts, tips on dealing with friends and family, and discussion boards.

The Ulman Cancer Fund for Young Adults

PMB #505

4725 Dorsey Hall Dr. Suite A

Ellicott City, MD 21042

Toll-free: (888) 393-FUND

Tel: (410) 964-0202


Email: info@ulmanfund.org

www.ulmanfund.org

The Ulman Cancer Fund For Young Adults was founded to provide support programs, education, and resources, free of charge, to benefit young adults, their families and friends, who are affected by cancer, and to promote awareness and prevention of cancer.

Look Good, Feel Better for Teens

www.lookgoodfeelbetter.org/index_6.00.html

A free public service program  provides useful information and tips for teens (boys and girls ages 13-17) dealing with the appearance and sociological side-effects related to cancer and its treatment.

Review 11/11/01

2bMe

www.2bMe.org

A site for teens with cancer. Very fun – teenage appropriate site with great graphics. Biggest problem is that it loads slowly but has some great tips.

Band-aids and Blackboards-

Teen Section

**[www.lehman.cuny.edu/faculty/
jfleitas/bandaides/](http://www.lehman.cuny.edu/faculty/jfleitas/bandaides/)**

Joan Fleitas, Assistant Professor of Nursing at Fairfield University, provides this site, designed to offer the child's perspective on what growing up with a serious medical condition. The site supports kids, teenagers and adults on dealing with their medical and emotional issues and going back to school. Kids are advised on dealing with teasing, what to expect in the classroom and how to get back to life. There are many wonderful Thoughts and stories from teens with medical problems (not necessarily cancer).

PatchWorx

www.patchworx.org

A safe, secure, moderated, online community for teens who are seriously ill or disabled, with games, puzzles, and more. Make friends with common interests, and interact with Patches, the mascot.



Oncology Family Night... Laugh, Learn & Listen

Oncology family night is open to parents and family members who have a child diagnosed with cancer and for cancer patients and their siblings (6-12). Participants have the opportunity to laugh, learn and listen in a supportive environment.

For: All family members

When: 2nd Thursday of each month 6 - 7:30 pm.

Where: CCMC Hematology/Oncology Unit clinic 2-J

Facilitators: Mary Lalberte, LCSW, Oncology Social Worker
Stephanie Knight, RN Certified Pediatric Oncology Nurse
Christine Tatuem, Medical Oncology Social Worker

Please call to register: (860) 545-9620 Mary Lalberte

Support Group for Families and Siblings

The Center for Hope and the Leukemia & Lymphoma Society offer Family Support Groups for parents with a child who has cancer and for children who have a sibling with cancer.

For: Parents, grandparents or nannies of a child with cancer and the child's siblings.

When: The third Thursday of every month the groups run concurrently 6:15 - 7:15 pm.

Where: The Center for Hope, Darien, CT

Facilitators: Center for Hope Counselors Lauren Riorden, PhD and Angela Rosolen, MSN

Please call to register: (203) 655-4693

Forum for Parents to receive Education & Support

Features guest speakers on issues such as follow-up care, concerns about lasting effects of treatment, and diagnostic tests for hormonal studies or learning disabilities.

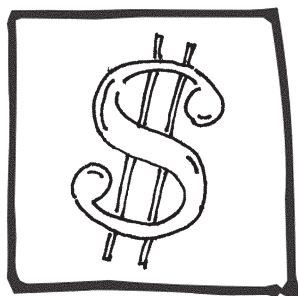
- For:** Parent of a child with cancer
- When:** 4 times a year – call for next session
- Where:** Yale New Haven Children's Hospital Rm CH201 (located on the right at the top of the stairs from the atrium)
282 Washington Street, Hartford, CT.
- Facilitators:** Connie Nicolosi, LCSW Oncology Social Worker
Carolyn Demsky, MSN Oncology Nurse
- Please call to register:** (203) 688-7519

Support Group for Teens

- For:** Teens with cancer
- When:** First Thursday of the month 6 - 8 pm.
- Where:** CCMC Hematology/oncology clinic 2J
282 Washington Street, Hartford, CT
- Facilitators:** Lynn Nochisaki RN, Oncology Nurse
Christine Tatum, Medical Child Life Specialist
- Please call to register:** (203) 688-7519



NOTES



Financial Help

FINANCIAL HELP

Cancer Fund of America

2901 Breezewood Lane
Knoxville, TN 37921
Tel: (865) 938-5281
Toll-free: (800) 578-5284 or
(800) 441-1664

www.cfoa.org

Helps defray cancer-related expenses not covered by insurance.

Children's Leukemia Research Association (CLRA)

585 Stewart Avenue, Suite 18
Garden City, NY 11530
Tel: (516) 222-1944 (may call collect)
Fax: (516) 222-0457

Email: clra@childrensleukemia.org

www.childrensleukemia.org

CLRA is a nonprofit organization dedicated to raising funds to support efforts toward finding the causes and cures for leukemia. CLRA provides financial aid for treatment, medications, and lab fees for leukemia patients, public and professional education, and research grants to medical professionals.

Consumer Credit Counseling Foundation

Toll free: (877) 426-6363
Email: info@4-creditcounseling.com
www.4-creditcounseling.com

A national, nonprofit consumer credit counseling agency that provides 24-hour Toll-free credit counseling over the telephone. Provides help with budget, payments, and debt collection.

Social Security Administration

Toll-free: (800) 772-1213
www.ssa.gov
Agency to contact for receiving disability income for your child

National Children's Cancer Society (NCCS)

1015 Locust, Suite 600
St. Louis, MO 63101
Tel: (314) 241-1600
Toll-free: (800) 532-6459
Program Services Fax : (314) 241-6949
www.children-cancer.com

NCCS is a non-profit national organization that helps children with cancer (newborn to age 18) and their families by providing support for their medical and emotional needs. The organization provides needs-based financial assistance, advocacy, support services, education about childhood cancer, wellness education, and emotional support.

CancerCare of CT (Main Office)

120 East Avenue
Norwalk, CT 06851-5703
Tel: (203) 854-9911 or
(800) 813-HOPE (4673)

Email: ctinfo@cancercare.org

CancerCare of Connecticut provides free professional help to people with all cancers and their families in the state of Connecticut through counseling, education, information and referral and direct financial assistance.

Sparrow Clubs USA (National Office)

906 NE Greenwood Ave, Suite#2
Bend, OR 97701
Tel: (541) 312-8630
Toll-free: (800) 469-8542
Fax: (541) 312-8632

Email: terri@sparrowclubs.org
www.sparrow-fdn.org

Promotes youth compassion by establishing and supporting Sparrow Clubs to help those local children in medical crises. Provides a grant for the ill child that local children/schoolmates friends earn by doing community service or fund raising.

Friends of Karen, Inc.

Westchester Office

P.O.Box 190

118 Titicus Road

Purdys, NY 10578

Tel: (914) 277-4547

Long Island Office

21 Perry Street

Port Jefferson, NY 11777

Tel: (631) 473-1768

Dedicated to providing emotional, financial and advocacy support to children with life-threatening illnesses and their families. They have served children throughout the New York metropolitan area including Fairfield County, CT for more than twenty-five years.

Friends of Karen's Family Support Program provides comprehensive family case management to children with catastrophic and life-threatening illnesses and their families. Our social workers access and coordinate all available public and private resources and/or provide referrals to these resources. Where need remains, Friends of Karen provides direct financial assistance for medical care and other illness-related expenses, including - but not limited to - transportation to medical treatment including parking, meals for parents while a child is inpatient, home care needs, child care for siblings when parents have to be with their hospitalized child, health insurance and basic living expenses that become unmanageable due to lost wages as a result of the high cost of medical care

Genus Credit Management/American Financial Solutions

Toll-free: (800) 570-3341

www.genus.org

Nonprofit credit counseling agency that offers free debt management and educational programs to help financially distressed families.

Leukemia & Lymphoma Society

Connecticut Chapter

300 Research Parkway

Meriden, CT

Tel: (203) 379-0445

Information Resource Center:

(800) 955-4572 (9am to 6pm EST)

www.lls.org

Fairfield County Chapter

25 Third Street

Stamford, CT 06905

Tel: (203) 967-8326

www.lls.org

This organization provides financial assistance to families (up to \$500/year for outpatients), funds research, sponsors a national program in education for the public and the medical community and publishes a large number of booklets on cancer-related topics. It also has an Information Resource Center, available by phone or via their web site, staffed by social workers, nurses and health educators who provide current, accurate, disease-related information.

Paying the Bills

101 Tremont Street, Suite 812

Boston, MA 2108

Tel: (617) 574-9493

Fax: (617) 574-9608

Email: Info@neserve.org

www.neserve.org

Services: Written by parents who have children with special needs. Offers numerous tips for families on financing health care for children with special needs. Authors have tapped their own experiences, as well as those of other families and professionals, in order to share information and techniques for getting payment for children's health care. Booklet is available for purchase through the mail or from the website. \$10.00

Danny Fund

PO Box 271
 Pelham, NY 10803
 Tel: (914) 843-8553
 Fax: (914) 738-6140

Email: thedannyfund@aol.com

Services: Provides financial, emotional and advocacy support for children with a catastrophic illness or injury.

Children's Cancer Association

7524 SW Macadam, Suite B
 Portland, OR 97219
 Tel: (503) 244-3141
 Fax: (503) 892-1922

www.childrenscancerassociation.org

We're here to help. The Children's Cancer Association (CCA) is a 501 (c)(3) nonprofit organization that was established in loving memory of five-year-old Alexandra Ellis who courageously fought cancer for two and half years before she died on May 7, 1995. In the year of Alexandra's death, CCA was born. Since then, CCA has worked to offer award-winning programs, along with information, advocacy and support that help enrich the quality of life for seriously ill children and their families.

National Children's Cancer Society (NCCS)

1015 Locust, Suite 600
 St. Louis, MO 63101
 Tel: (800) 532-6459, (314) 241-1600
 Fax: (314) 241-1996

Email: eharriss@children-cancer.org
www.children-cancer.com

Services: Helps children with cancer and their families by providing financial and fundraising assistance related to medical treatment such as lodging and travel. Provides advocacy support interceding on behalf of children with bills, home care needs, insurance companies, hospitals, and other agencies to negotiate reasonable financial solutions for a child's care. Support services and education about childhood cancer and nutrition is available as well.



Insure Kids Now!

Toll-free: (877) 543-7669 (877-KIDS NOW)

www.insurekidsnow.gov

The US Department of Health and Human Services began the Insure Kids Now! Program to link the nation's uninsured children with free or low-cost health insurance.

The National Association of Insurance Commissioners (NAIC)

2301 McGee, Suite 800

Kansas City, MO 64108-2662

Tel: (816) 842-3600

www.naic.org

An organization of insurance regulators from the 50 States, the District of Columbia, and the four US territories.

Patient Advocacy Coalition, Inc.

777 East Girard Ave., Suite 250

Englewood, CO 80110

Tel: (303) 744-7667

www.patientadvocacy.net

Helps resolve insurance reimbursement problems. Has a comprehensive list of State Insurance Commissioners Offices on their web site.

Patient Advocate Foundation

700 Thimble Shoals Blvd, Suite 200

Newport News, VA 23606

Tel: (800) 532-5274

Fax: (757) 873-8999

[Email: info@patientadvocate.org](mailto:info@patientadvocate.org)

www.patientadvocate.org

Provides publications, help with insurance problems, referrals to attorneys.

State of Connecticut Insurance

Department Consumer Affairs Division

PO Box 816

Hartford, CT 06142

Tel: (860) 297-3900

www.state.ct.us/cid

Childhood Cancer Ombudsman Program

P.O. Box 595

Burgess, VA 22432

Fax: (804) 580-2502

[Email: gpmonaco@rivnet.net](mailto:gpmonaco@rivnet.net)

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

Candlelighter's Childhood Cancer Foundation

PO Box 498

Kensington, MD 20895-0498

Tel: (800) 366-2223 or (301) 962-3520

Fax: (301) 962-3521

[Email: staff@candlelighters.org](mailto:staff@candlelighters.org)

www.candlelighters.org

Services: Organization formed by parents of young cancer patients. An important goal of the organization is to help families cope with the emotional stresses of their experiences. Can give information on camps for children with cancer. Has an ombudsman program to assist families and survivors with problems in education, employment, insurance, welfare or military enlistment. National pediatric cancer foundation provides information, local support groups and specialized information to families and caregivers of children with cancer.

Centers for Medicare and Medicaid Services

7500 Security Blvd.

Baltimore, MD 21244-1850

Tel: (877) 267-2323 or (410) 786-3000

www.cms.hhs.gov

Services: Provides information on Medicare and Medicare hospice benefits.

Health Insurance Info net

1275 York Avenue
New York, NY 10021
Tel: (212) 639-2000

www.healthinsuranceinfo.net

Services: Organization distributes "A Consumer Guide for Getting and Keeping Health Insurance" for each state. Guides are available at the web site and are periodically updated. News You Can Use - Article "Discount Plans - Know What They Are Before You Buy."

Health Insurance Association of America

1201 F Street, NW Ste. 500
Washington, DC 20004-1204
Tel: (202) 824-1600
Fax: (202) 824-1722

Email: webmaster@aahp.org

www.hiaa.org

Services: Offers assistance to people with a history of cancer in locating health insurance. Publications available.

HUSKY Plan

P. O. Box 280747
East Hartford, CT 06108
Tel: (877) 284-8759

www.huskyhealth.com

The HUSKY Plan is designed to help all children who don't have health insurance. It includes services under the traditional Medicaid program (now known as HUSKY Part A). It also provides brand-new health services for children in higher-income families (called HUSKY Part B). There's also HUSKY Plus—a new coverage option for children who have intensive physical or behavioral health needs. HUSKY gives a special boost to Connecticut's working families. Many parents don't have health coverage for children through work. With HUSKY, your children are covered. Even families with high incomes can get most HUSKY services at a group rate. HUSKY is funded by the state and federal governments, and administered by the Department of Social Services.

Outlook: Life Beyond Childhood Cancer

UW-Madison School of Nursing, K6/277
600 Highland Ave.

Madison, WI 53792-2455

Tel: (608) 262-5523

Email: jaamond@facstaff.wisc.edu

www.outlook-life.org

Services: Outlook is an interactive web based information system designed to address the needs of survivors of childhood cancer and their families. Provides information on managing late-term side effects like infertility. Offers information on financial resources, insurance issues, emotional support and chat rooms.

Children's Health Insurance Program

Family Voices

2340 Alamo SE, Suite 102

Albuquerque, NM 87106

Tel: (505) 872-4774 or (888) 835-5669

Fax: (505) 872-4780

Email: kidshealth@familyvoices.org

www.familyvoices.org

Services: Provides resources, tips, brochures and a newsletter, offering advocacy for children's health care needs.

First Hand Foundation

2800 Rockcreek Parkway

Kansas City, MO 64117

www.firsthandfoundation.org

Services: Members of Children's Health Matters are committed to ensuring that children have health coverage and access to quality medical care through advocating on the state level for Medicaid agencies and state legislatures and by raising community awareness about Medicaid and the State Children's Health Insurance Program (SCHIP). First Hand is a philanthropic, nonprofit foundation established to help children with health problems address financial situations and their healthcare.



Pharmaceutical Research and Manufacturers of America (PhRMA)

1100 15th Street, NW
Washington, DC 20005
Tel: (202) 835-3400
Fax: (202) 835-3414

www.helpingpatients.org

Lists companies that provide prescription medicines free of charge to physicians whose patients might not otherwise have access to necessary medicines. In 2002, PhRMA members provided free prescription medicines to more than 5.5 million patients in the United States.

Centers for Medicare & Medicaid Services –

Prescription Drug and Other Assistance Programs (Medicare)
7500 Security Boulevard
Baltimore, MD 21244-1850
Tel: (877) 267-2323

www.medicare.gov

The Prescription Drug and Other Assistance Programs section of the Medicare.gov web site provides information on public and private programs that offer discounted or free medication, programs that provide assistance with other health care costs, and Medicare health plans that include prescription coverage.

NeedyMeds

www.needymeds.com

Many drug manufacturers have what's called Patient Assistance Programs. These programs are designed to help those who can't afford their medicines obtain them at no cost or low cost. This web site contains the latest, most complete, and most accurate information on patient assistance programs available. The site has a searchable database for both "drugs" and "programs". This organization provides information and referral only, not medicines.

RxHope

254 Mountain Avenue
Building B, Suite 200
Hackettstown, NJ 07840
Tel: (908) 850-8004
Fax: (908) 850-8269

Email: customerservice@RxHope.com

www.rxhope.com

Resource for prescription assistance programs.



FREE AIR SERVICES

Mercy Medical Airlift

The National Patient Travel Center
4620 Haygood Road, Suite 1
Virginia Beach, VA 23455
Tel: (757) 318-9175

Patient Helpline: (800) 296-1217

www.patienttravel.org

Provides free transportation to medical treatment (travel distance 1,000 miles or less) for people who cannot afford public transportation or who cannot tolerate it for health reasons.

Corporate Angel Network, Inc.

(CAN) Westchester County Airport

One Loop Road
White Plains, NY 10604-1215
Tel: (866) 328-1313 or (914) 328-1313

www.corpangelnetwork.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 no cost or financial need requirements.

Air Care Alliance

1515 East 71st Street, Suite 312
Tulsa, OK 74136
Tel: (333) 260-9707

www.aircareall.org

A nationwide association of humanitarian flying organizations that provide flights for healthcare, compassion, and community service.

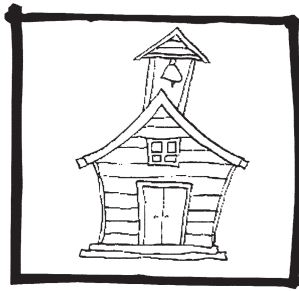
Miracle Flights for Kids

2756 N. Green Valley Parkway,
#115 Green Valley, NV 89014-2120
Tel: (702) 261-0494

www.miracleflights.org

An organization that purchases commercial airline tickets, utilizes private aircraft, and combines resources from individual donors to provide free transportation to medical treatment centers all across America.





School Related Issues

CT State dept of Education

www.state.ct.us/sde

Your child may qualify for an IEP, IDEA or 504 plan as a result of their diagnosis. Refer to this website to download the IEP manual to learn more about how to advocate for your child within your local school system.

National Dissemination Center for Children with Disabilities

P.O. Box 1492

Washington, DC 20013

Tel: (800) 695-0285

Fax: (202) 884-8441

Email: nichcy@aed.org

www.nichcy.org

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

The Health Library, Main Branch

G-2B Stanford Shopping Center

Palo Alto, CA 94304

(650) 725-8400 1(800) 295-5177

(outside the 650 area code)

Fax: (650) 725-1444

Email: healthlibrary@stanfordmed.org

Contact: Howard Fuller, Librarian

www.healthlibrary.stanford.edu

Services Offered by The Health Library: Don't know what to make of a new diagnosis? Drowning in information? The Health Library is here to help you gain greater understanding of the health and medical issues that are important to you and your family, and it is free and open to the public. The Health Library has trained volunteer staff available to help you find all the information you need no matter how complex. This website contains links to

Leukemia-Lymphoma Society

Connecticut Chapter

300 Research Parkway

Meriden, CT

Tel: (203) 379-0445

Information Resource Center:

Tel: (800) 955-4572 (9am to 6pm EST)

www.lls.org

Fairfield County Chapter

25 Third Street

Stamford, CT 06905

Tel: (203) 967-8326

www.lls.org

Trish Greene Back to School Program for Children with Cancer

This program is sponsored by the Leukemia & Lymphoma Society and was developed to foster communication between healthcare professionals, parents, patients and school personnel in preparation for the return to school and other activities. Informative materials, videos and a wealth of literature are available through the Leukemia Lymphoma Society.

Ped-Onc Resource Center

www.acor.org/ped-onc/cfissues/backtoschool

Resources and information for parents of children with cancer... by parents of children with a special emphasis on school issues and other back to life help.

Cells Alive

www.cellsalive.com/toc.htm

This site is helpful for explaining about cells to older elementary and teenage students. There is a colorful slide presentation with images that may be used for classroom projects.

The Candlelighters Childhood Cancer Foundation

National Office

P.O. Box 498

Kensington, MD 20895-0498

Tel: (800) 366-CCCCF (800) 366-2223

www.candlelighters.org

Candlelighters Childhood Cancer Foundation is committed to their mission of providing support, education and advocacy for children and adolescents with cancer, survivors of childhood/adolescent cancer, their families and the professionals who care for them.

New Comprehensive Book for Parents and Teachers.

One free copy available to families of children with cancer, and one free copy for the child's teacher.

Educating the Child with Cancer, A Guide for Parents and Teachers is an essential resource for families who have faced the childhood cancer diagnosis. Written by top researchers in the field, and balanced with parent's personal experiences, this 322 page resource covers learning issues from infancy through adulthood. A good education provides hope for the future.

Children's Brain Tumor Foundation

274 Madison Avenue, Suite 1301

New York, NY 10016

Toll-free Patient Support Line:

(866) 228-HOPE

www.cbtf.org


Understanding that knowledge is critical for families and patients facing the challenge of a brain tumor, this website provides an array of information and resources to assist in accessing expert care to ensure quality of life for the child in your life with a brain or spinal cord tumor. You will find a comprehensive resource list on this site focusing on special education needs.

Outlook—Life Beyond Childhood Cancer

www.outlook-life.org

The Outlook Web Site was developed to provide an innovative and unique resource that addresses the issues of childhood cancer survivors, provides information and support to families and professionals and 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 collaborated in the development of the web based system called This project is designed, managed, and guided by survivors of childhood cancer in conjunction with a team of experts in pediatric oncology, nursing, social work, cancer information, psychology and web design and programming. Under the subsection school & job is information about long-term effects of cancer treatment on school performance and learning.

BOOKS

Educating the Child with Cancer, A Guide for Parents and Teachers is an essential resource for families who have faced the childhood cancer diagnosis. Written by top researchers in the field, and balanced with parent's personal experiences, this 322 page resource covers learning issues from infancy through adulthood. A good education provides hope for the future. *New Comprehensive Book for Parents and Teachers*, offered by Candelighters One free copy available to families of children with cancer, and  free copy for the child's teacher.

Negotiating the Special Education Maze: A Guide for Parents and Teachers. Winifred Anderson, Stephen Chitwood, and Deidre Hayden, 1997.



VIDEOS

Why, Charlie Brown, Why?

Available on a loan basis from American Cancer Society.

Making the Grade: Back to School After Cancer for Teens, and With a Little Help from my Friends: Living With Leukemia and Lymphom a distributed by the Leukemia and Lymphoma Society of America.

Leukemia-Lymphoma Society

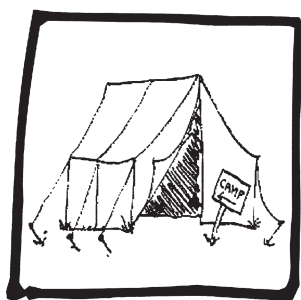
Connecticut Chapter
300 Research Parkway
Meriden, CT
Tel: (203) 379-0445
Information Resource Center:
(800) 955-4572 (9am to 6pm EST)
www.lls.org

Fairfield County Chapter
25 Third Street
Stamford, CT 06905
Tel: (203) 967-8326
www.lls.org

Starbright Videos with an Attitude

Three videos provided to families free of charge that are designed specifically for teens. **Back to school: Teens preparing for school re-entry**, **Plastic Eggs or Something!?: Cracking Hospital Life** and **What am I chopped liver?: Communicating with your doctor.**

The Starbright Foundation. Free to adolescents with illness and their families. Call 1-800-315-2580.



Camps

American Cancer Society (ACS)

Cancer Camps

Toll-free: (800) ACS-2345

www.cancer.org

In some areas, the American Cancer Society sponsors camps for children who have, or have had, cancer. These camps are equipped to handle the special needs of children undergoing treatment. Please contact your local ACS office for a camp in your area. Individual camps will have more information about specific dates for the camp sessions.

Camp Make-a-Dream

P.O. Box 1450

Missoula, MT 59806

Tel: (406) 549-5987

Email: camp@montana.com

Camp Make-A-Dream is operated by Children's Oncology Camp Foundation and is a medically supervised, cost-free camp for children (ages 6-13), teens (ages 14-18) and young adults (ages 19-25) with cancer and their siblings (ages 6-17).

Camp Sunshine

35 Acadia Road

Casco, ME 04015

Tel: (207) 655-3800

Fax: (207) 655-3825

Email: info@campsunshine.org

www.campsunshine.org

This camp is the only program in the nation whose mission is to address the impact of a life threatening illness on every member of the immediate family. Families attend one of the week-long camp sessions which includes meals, onsite medical services, counseling services, and recreational activities. While at camp, each family stays in their own family suite. Families are sponsored by an individual, civic group, corporation, or foundation, which enables them to spend a week at Camp Sunshine free of charge.

Camp Rising Sun

PO Box 1004

Meriden CT 06450

Tel: (203) 379-4762

Tina Saunders, Camp Coordinator

Camp Rising Sun is a camp sponsored by the American Cancer Society for children who have been diagnosed with cancer. Children ages 6 - 18 attend camp free of charge. Camp is staffed by volunteer counselors who give a week of their time, love and energy. We have a pediatric oncologist and three nurses on campus 24-hours a day to tend to medical needs. Camp Rising Sun started with 8 children in its first year and this past summer which marked our 19th season, 100 children enrolled for a week of fun and friendship.

Situated on the shores of Triangle Lake in the northwest hills of Connecticut, Camp Jewell YMCA offers, modern, heated cabins with fireplaces, carpeting and lounges, waterfront with sandy beach, playing fields, basketball and tennis courts, ROPES course, an infirmary, well lit amphitheater for performances, dances and ceremonies, an arts and crafts studio and a working farm. Children participate at their own level and take part in all activities under careful, qualified supervision.

Camp Simcha

151 West 30th Street

New York, NY 10001

Tel: (877) CHAI LIFE

www.chailifeline.org

A pioneer in kosher summer camping for children with cancer and other medically catastrophic illnesses, Camp Simcha—established by Chai Lifeline in 1987 and located in Glen Spey, NY—runs multiple two-week sessions for youngsters from throughout North America, Europe and Israel who have encountered serious illnesses.

Children's Oncology Camping

Association International (COCA)

Email: cocainfo@candle.org

www: [coca-intl.org](http://www.coca-intl.org)

COCA is an international assembly of people and member camps providing camping programs for children with cancer. For more information about their camps, visit the web site.

First Descents

P.O. Box 2193

Vail, CO 81658-2193

Tel: (970) 476-9400

Fax: (970) 476-0112

Email: info@firstdescents.org

www: [firstdescents.org](http://www.firstdescents.org)

First Descents is a free, seven-day kayak camp for young adults with cancer. Started by professional kayaker and Nike ACG athlete Brad Ludden, First Descents uses kayaking and other outdoor activities to help campers face challenges and overcome obstacles associated with living with cancer in a fun and supportive environment.

Joseph's Journey

P.O. Box 150453

Lakewood, CO 80215-0453

Tel: (303) 989-5710

Email: Josephsjourney@aol.com

www: [josephsjourney.org](http://www.josephsjourney.org)

Joseph's Journey is dedicated to providing wilderness experiences to children with life-threatening illnesses. Adventures include hiking, fishing, camping, hunting, climbing, and are led by experienced, qualified guides.

Hole In The Wall Gang

Matthew Cook, MSW, Camp Director

565 Ashford Center Road

Ashford, CT 06278

Tel: (860) 429-3444

Fax: (860) 429-7295

Email: ashford@holeinthewallgang.org

www: [holeinthewallgang.org](http://www.holeinthewallgang.org)

The Hole in the Wall Gang Camp, founded by Paul Newman in 1988, is a nonprofit residential summer camp, an ingeniously designed and dazzlingly equipped Wild West hideout in northeastern Connecticut, where children with cancer and other life-threatening illnesses do not have to sit on the sidelines. More than 1,000 children between the ages of seven and fifteen from across the country and abroad attend each year, free of charge.

Silver Lining Ranch

The Silver Lining Foundation

1490 Ute Avenue

Aspen, CO 81611

Tel: (970) 925-9540

Email: info@silverliningfoundation.org

www: [silverliningfoundation.org](http://www.silverliningfoundation.org)

The Benedict-Forstmann Silver Lining Ranch Program in Aspen, Colorado, is home for up to twenty children a session throughout the summer, finishing up the year with winter ski groups. Horseback riding, white water rafting, campfire picnics, and downhill skiing are the adventurous settings in which children share common medical challenges and establish lifetime friendships. A pediatric oncologist, oncology nurse, counselor and social worker are available on a 24-hour basis.



NOTES

WISH FULFILLMENT ORGANIZATIONS

Bear Necessities Pediatric Cancer Foundation, Inc.

23 W. Hubbard Street, 3rd Floor
Chicago, IL 60610

Tel: (312) 836-BEAR (2327)

Fax: (312) 836-1284

Email: office@BearNecessities.org
www.bearnecessities.org

Bear Necessities offers a "Small Miracles" program which grants wishes for children with cancer so that they can forget their illness and enjoy being a child, if even for a moment.

Believe in Tomorrow Children's Foundation

(formerly Grant-A-Wish)

6601 Frederick Road
Baltimore, MD 21228

Tel: (410) 744-1032

www.grant-a-wish.org

A national children's charity that provides supportive services to children 17 years old and younger who are battling life-threatening illnesses.

Children's Hopes and Dreams Foundation

280 Route 46

Dover, NJ 07801

Tel: (973) 361-7366

Fax: (908) 459-9399

www.childrenswishes.org

Children's Hopes and Dreams Foundation serves over 14,000 seriously ill children each year. Fulfillment of wishes have included visits with celebrities, visits with favorite relatives, puppies, Disney World, shopping, etc.

Children's Wish Foundation International

8615 Roswell Road

Atlanta, GA 30350-7526

Tel: (800) 323-WISH or

(770) 393-WISH

www.childrenswish.org

Has fulfilled wishes of children with life-threatening illnesses in 32 countries around the globe.

Make-a-Wish Foundation of America CT Chapter

126 Monroe Turnpike

Trumbull, CT 0661

Tel: (203) 261-9044

www.wish.org

U.S. and international chapters and affiliates. This chapter grants wishes to children through out the state of Connecticut under the age of 18 with life-threatening illnesses.

Sunshine Foundation

5400 County Road

547 North

Davenport, FL 33837

Tel: (863) 424-4360

www.sunshinefoundation.org

Grants wishes to chronically or terminally ill children ages 3 to 21 across the country.

The Starlight Children's Foundation

5900 Wilshire Boulevard, Suite 2530

Los Angeles, CA 90036

Tel: (800) 274-7827 or

(323) 634-0080

www.starlight.org

Fulfills wishes for seriously ill children ages 4 to 18.



WIGS AND ACCESSORIES

Angel Locks, Inc.

P.O. Box 7116
North Arlington, NJ 07031
Toll-free: (877) 93-LOCKS
(877) 935-6257
Tel: (201) 246-7979
Fax: (201) 246-7970

www.angellocks.org

Angel Locks, Inc. is a nonprofit organization that provides quality, synthetic wigs to children with financial need who suffer from hair loss. The organization provides wigs to children up to age 18 who have hair loss due to, but not limited to, chemotherapy, leukemia, alopecia, and burns.

Locks of Love

2925 10th Avenue North
Suite 102
Lake Worth, FL 33461
Tel: (561) 963-1677
Fax: (561) 963-9914
Toll-free: 888-896-1588

[Email: carolina@locksoflove.org](mailto:carolina@locksoflove.org)

www.locksoflove.org

Locks of Love provides high quality hair pieces to financially disadvantaged children under the age of 18 suffering from long-term medical hair loss.

HipHat

108 West Adalee Street
Tampa, FL 33603
Toll-free: (877) 447-4287

[Email: info@hiphat.com](mailto:info@hiphat.com)

www.hip-hat.com

As an alternative to wigs, this company offers hats that are cool, comfortable, and fashionable.

Wigs for Kids

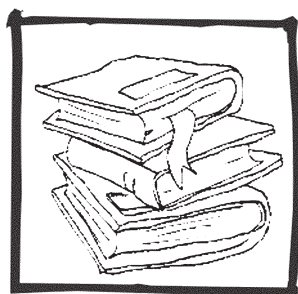
Executive Club Building
21330 Center Ridge Road,
Suite C
Rocky River, Ohio 44116
Tel: (440) 333-4433
Fax: (440) 333-0200

[Email: info@wigsforkids.org](mailto:info@wigsforkids.org)

www.wigsforkids.org

Wigs for Kids is a not-for-profit organization providing hair replacement solutions for children affected by hair loss due to chemotherapy, alopecia, burns and other medical conditions.






**Circle of Care
Suggested Reading
and
Videos**

The following publications can be found at libraries, bookstores or on the Internet. Most books are available, either new or used, at Amazon.com, BarnesandNoble.com or Chapters.Indigo.Ca. An ISBN identifying code has been included, if available, to help you find books more easily. To locate a book on websites, simply search on the ISBN—no need to type in the book's title or author. An additional source of books for children with cancer is www.cancerkids.com. and www.curesearch.org.

Childhood Leukemia Helping Your Child in the Hospital Working with Your Doctor A Parent's Guide to Solid Tumor Cancers

by Nancy Keene

Nancy Keene is a renowned  in the field of childhood cancer, a mom of a cancer survivor herself she has taken her experience and melded it with over 100 other families to produce very informative guides for families of children with cancer.

Armfuls of Time: The Psychological Experience of the Child with a Life-Threatening Illness

by Barbara M. Sourkes, PhD.

University of Pittsburgh Press, 1995.

ISBN 0822955652

Reviews the psychological effects of cancer and explains the therapeutic process.

Highly recommended.

Cancer Patient Workbook: Everything You Need to Stay Organized and Informed

by Joanne Willis and Diane Blumenson

ISBN 0789467828

Interactive guide helps cancer patients stay organized with treatment tips, laymen's explanation of medical terms and treatments, inspirational and humorous insights. Worksheets help track doctor visits, use of medication and organizations to contact.

BOOKS FOR THE PATIENT

Chemo, Crazyness & Comfort: My Book About Childhood Cancer

By Nancy Keene and Trevor Romain

Candlelighters Childhood Cancer

Foundation, 2002, 185 pages

ISBN: 0972404309

A resource book that provides practical advice for children diagnosed with cancer between 6 and 12 years of age. Warm and funny illustrations and easy-to-read text help the child (and parents) make sense of cancer. Themes address medical tests, hospitalization, and treatment, including chemotherapy, radiation, stem cell transplantation and their side effects. Offers tools and journal space to help children deal with the physical and emotional impact of both the cancer and the treatment. Ages 6-12 Order at www.candlelighters.org.

The Amazing Hannah: Look at Everything I Can Do!

by Amy Klett

Friends of Hannah Klett and Growing

Hope, 2001, 25 pages Ages 1-6

A photo story created for a preschooler with leukemia, to help her adapt to doctor visits and treatments. Using the word "tubies" to describe the central line, its function and care, this book can be read and shown to children as young as one year.

Free www.candlelighters.org or

Email info@candlelighters.org.

Some Things Change and Some Things Stay the Same

by Fred Rogers

The American Cancer Society,

Tel: (800) ACS-2345

1989, ISBN

This book reassures children with cancer that they are still children with feelings that are OK to express as their lives change. The book lets children know that some of the changes that they experience will be hard to deal with and that sometimes they will need to cry or hold a loved one's hand. They may be unable to do many of the things that they used to do, and that is all part of having cancer. However, this book shows children that they may become used to their surroundings in a hospital, with their new friends and caring doctors and nurses. Most of all, this book lets children know that they are still children with favorite things to do, and there are people who love them a lot. Ages 7-12.

Going to the Hospital

by Fred Rogers

G. P. Putnam's Sons, 1997

PBS's "Mr. Rogers" introduces children (ages 3 to 8) to hospitals.

When You Have An Operation On Your Head or Back

by Henrietta Egleston Hospital

Nursing Staff

Egleston Hospital

1405 Clifton Rd., NE,

Atlanta, GA 30322

Phone: (404) 325-6000, ext. 6156

This is a good activity book for children about to undergo an operation on their head and back. It goes through, step-by-step, everything that your child may experience in a hospital, as well as providing pictures and opportunities for your child to draw and fill in the blanks. Age 6-16.

Fuzzy and Frankie

by Susan Murray

Goetz Printing Co.

Dept. of Hematology/Oncology,

Children's National Medical Center

111 Michigan Avenue, NW,

Washington, DC 20010-2970

Tel: (202) 745-2140

1991, ISBN 91-60256

In this beautifully illustrated story, Fuzzy, a teddy bear who belongs to a sick boy, Frankie, tells you his point of view. Frankie is going to the hospital with Fuzzy, and Fuzzy realizes from the grim faces around him that something is very wrong with Frankie. Frankie must undergo a series of tests, and Fuzzy wishes that he could do something to make Frankie feel better. Frankie, however, becomes weaker, and he misses his friends. When Frankie sees his parents crying, Fuzzy explains why his parents are worried about him. Slowly he gets visitors, and he notices that the other children in the hospital were fat or had lost their hair because of their medicines. Soon, Frankie gets well again, and he is able to go home. Ages 8-11.

The C Word: Teenagers and Their Families Living with Cancer

by Elena Dorfman

New Sage Press, 1998.

ISBN 093916521X

Five teens with cancer, their families, and best friends are interviewed about the affects the disease has had on their lives. Both fears and realities concerning relationships and chemotherapy are addressed with frankness. Both patients and their loved ones should be comforted by the similarities of experiences shared. The issues addressed are on target. Students seeking information for reports and general readers are provided with an opportunity to achieve a deeper understanding of what living with serious disease is like for all concerned.

My Book for Kids with Cancer: A Child's Autobiography of Hope

by Jason Gaes

\$11.95 in hardcover

Melius & Peterson Publishing Corp.

524 Citizens Building

Aberdeen, SD 57401

1987, ISBN 0-937603-04-X

This is a very moving book written by a cancer patient, Jason Gaes, who encourages kids to have a positive attitude, and that not all kids with cancer die! He gives advice on how to get through injections, nightmares, and treatments of all sorts. He describes both how his uncle discovered Jason's 'cancer' and the entire process of cancer treatment. He gives his opinions on the different types of treatment and medicines that he took over the duration of his cancer. Also, he tells kids the positive side of having cancer and having no hair!

An expert wrote this book—a kid who has had cancer and survived. The book is appropriate for children suffering from cancer, age 7-14, and are afraid and have many difficult questions. While he does speak about the Lord and His help to get through the days, it also has a general message to which a child of any religion can relate. The book takes about 10 minutes to read.

Chemo Girl: Saving the World One Treatment at a Time

by Christina Richmond

Jones & Bartlett, 1997, 24 pages

ISBN: 0763703141

This is the fictional tale of a superhero, with cartoon-like illustrations, was written to help children cope with chemotherapy treatments. Presents a positive, non-threatening side of chemotherapy and a sense of hope. Can be read to younger children. Ages 9-12.

Henry and the White Wolf

by Tyler Karu and Tim Karu

Workman Publishing, 2000,

31 pages ISBN: 0761121358

Written and illustrated by a teenage brother and sister, this is an allegory about a sick hedgehog that is healed by the feared white wolf. Geared to help children cope with the physical discomforts and fears of prolonged medical treatment, this book can also be used with children whose parents and/or friends are ill. Included with the book is a stone for children to hold onto in hard times, a symbol, which parallels the story.

Ages 4-8

Stevie's New Blood

by Kathryn Ulberg Lilleby

Chad Chronick (Illustrator)

Oncology Nursing Press, 2000,

43 pages ISBN 1890504173

Stevie is undergoing bone marrow transplant (BMT) in the hopes that it will cure his leukemia. Anna, his sister - and donor - will learn what it is like to give her bone marrow. The story explains bone marrow and/or stem cell transplantation from a child's point of view and can be adapted for children of various ages. The book also can be adapted for the child whose parent is having a transplant or for the friend of a child undergoing BMT. Ages 6-10 Order from www.ons.org/publications/books/index.shtml.

Maddy's Book

By Lori Rasche and

Audrey Walker (Web site designer)

This is an interactive book for children whose family member must undergo treatment for cancer or leukemia. Through this Web site, a child can create his or her own customized book that can be printed out and read. To access Maddy's Book, please go to www.maddysbook.com

Teenagers Face to Face with Cancer

by Karen Gravelle and Bertram A. John
\$11.50

Julian Messner, A Division of Simon & Schuster, Inc.

Simon & Schuster Building,
Rockefeller Center

1230 Avenue of the Americas,
New York, NY 10020

1986, ISBN 0-671-54549-3

This is a book by sixteen teenagers with cancer. They describe their experiences with the disease, and how they deal with family, friends, and school while coping with their illness. These teenagers describe how they felt when they first found out they had cancer and then how they felt with various forms of treatment—ranging from chemotherapy to amputation of a limb. Each child tells you how they feel about their plans for the future and coming to terms with the fact that they might die. These children feel that their bout with cancer has left them stronger in various ways. Age: Teen

The Problem with Hair: A Story for Children Learning About Cancer

by Karen Sue Foss

Centering Corporation, 1996.

ISBN 1561230995

Story of how group of friends handles one friend's loss of hair while undergoing cancer treatment.

They Never Want to Tell You: Children Talk About Cancer

by David J. Bearison,

Harvard University Press, 1991.

ISBN 0674883705

Developmental psychologist records children's feelings about their disease.

BOOKS FOR SIBLINGS**Why Charlie Brown, Why?**

Leukemia & Lymphoma Society

Tel: (800) 955-4572

this book/video is about a child whose friend has cancer. Highly recommended for younger school age children. It is excellent for the child's school and/or other groups to view before your child returns to regular activities.

Contact Candlelighters (800) 366-2223) or the Leukemia Society (800) 955-4LSA)

When Your Brother or Sister Has Cancer

The American Cancer Society.

To obtain a free copy

call 800-227-2345 or

www.cancer.org

Oliver's Story: For "Sibs" of Kids with Cancer

By Michael Dodd

Published by Candlelighters Childhood Cancer Foundation, 2004

ISBN: 0972404341

This is a story written through the eyes of six year old Oliver and focuses on the many questions that siblings have when their brother or sister is diagnosed with cancer, and offers constructive ways on how they can provide support. Ages 4-10 Free copy, call Candlelighters National Office at (800) 366-2223 or www.candlelighters.org.

What About Me? When Brothers or Sisters Get Sick

by Alan Peterkin

Magination Press, 1992.

ISBN 0945354495

Suggestions for children coping with a sick sibling. Ages 5-8.

SCHOOL RELATED BOOKS

FOOD

Cancervive Back to School Kit.

Kit contains a "Teachers Guide for Kids with Cancer" and 2 award winning videos (Item 123).

www.cancervive.org/materials

James Bounces Back

By Debra Giugliano Trezza,

Daisy Dohanos (Illustrator)

ISBN: 0-9726425-1-X

A back to school educational book for boys diagnosed with cancer and their classmates. Ordered through the School Re-entry Program, Stony Brook University Hospital (631) 444-7720

The Trish Greene Back-to-School Program for Children with Cancer

Leukemia and Lymphoma Society

Information on how to increase communication among healthcare professionals, parents and school officials when children are ready to go back to school after being out for treatment.

To obtain: call 800-955-4572 or visit

www.lls.org

Teachers of Children with Cancer

Back To School – American Cancer Society (800) ACS-2345

Back To School: Teens - American Cancer Society (800) ASC-2345

Cancervive Teacher's Guide – (310) 203-9232

www.cancervive.org/materials

Non-Chew Cookbook

by Randy J. Wilson

Wilson Publishing, Inc. 1986

ISBN 0961629908

Recipes for non-chewable dishes.

Eating Hints for Cancer Patients

National Cancer Institute.

*Booklet covers what to eat during treatment, managing problems, special diets, and recipes. To obtain: call (800) 422-6237 or logon to: **www.nci.nih.gov***



VIDEOS

Why Charlie Brown, Why – Leukemia

This book/video is about a child whose friend has cancer. Highly recommended for younger school age children. It is excellent for the child's school and/or other groups to view before your child returns to regular activities. Contact Candlelighters (1-800-366-2223) or the Leukemia Society (1-800-955-4LSA)

I'm Still Me: A video for children with cancer and their classmates

Includes a Guide for Medical Personnel and Teachers. The primary purpose of I'm Still Me! Is to help children with leukemia and other cancers successfully reintegrate into the classroom after their diagnosis and during their treatment. The Leukemia and Lymphoma Society 1-800-955-4572 or www.lls.org.

My Hair's Falling Out My Hair's Falling Out...

Am I Still Pretty? ASIN: 0965083209 (school age)

A Childhood Cancer Education Video is a fictional, one-person performance, which tells the story, of a young girl who is diagnosed with leukemia, undergoes hospitalization and chemotherapy, and returns to school, her cancer in remission.

Plastic Eggs or Something!?: Cracking Hospital Life

As a teenager dealing with a serious illness, you probably have a lot of questions. Well, you're not alone. Other kids your age have been through this experience and are here to give you the inside scoop. In this video you'll get the straight story on everything from communicating with hospital staff to making yourself as comfortable as possible in the hospital environment. Ages 10-18. Starbright Videos Free www.starbright.org/projects/vwa/order.aspx

Communicating With Your Doctor

This video shows you how to stay actively involved in your treatment by communicating with your doctor. Listen to other teens describe their experiences and offer tips on how to have a positive impact on your healthcare experience by talking candidly with your doctor. www.starbright.org/projects/vwa/order.aspx

Operation Sneak-A-Peak (20 min).

Aquarius Healthcare.

Join puppets on a tour of a hospital. Video's aim is to help children feel more comfortable about hospital stays.

Rising to the Challenge: Youngsters Speak Their Truth with Cancer. (15 min).

Aquarius Healthcare.

Children with cancer offer their thoughts and feelings about their illnesses. Ages 10 and up.

Welcome Back (14 min)

Aquarius Healthcare.

Children talk about their fears, expectations, and experiences when they return to school. Discusses cancer and some the myths about the disease.

Aquarius Healthcare videos available at 888-420-2963 or

www.aquariusproductions.com

Back To School After Cancer

– companion to Cancervive's Teacher Guide

Order: (310) 203-9232 or

www.Cancervive.org/materials

Back To School After Cancer: For Teens

Order: (310) 203-9232

www.Cancervive.org/materials

What am I Chopped Liver?:

Cancer Cured Kids

PO Box 189
Old Westbury, NY 11568
Tel: (516) 484-8160

Organization dedicated to the quality of life of kids who have survived cancer. Cancer Cured Kids supplies information about the educational and psychosocial needs of survivors.

Long-Term Effects of Childhood Cancer Treatment

www.cancersurvivorchild.org

The design and development of the Long-Term Effects of Childhood Cancer Treatment web site was funded by a grant from the Texas Cancer Council. This site provides overviews of the essential components of physical concerns, psychosocial care, and issues of the future that a survivor and his/her family and health care provider would want to consider.

National Coalition for Cancer Survivorship (NCCS)

1010 Wayne Avenue
Suite 770
Silver Spring, MD 20910
Tel: (301) 650-9127
Fax: (301) 565-9670

Email: info@canceradvocacy.org

www.canceradvocacy.org

An organization that addresses the needs of long-term cancer survivors and advocates for change in healthcare to maximize survivor's access to optimal treatment and support. Extensive publications list.

Outlook-Life Beyond Childhood Cancer

www.outlook-life.org

It is estimated that by the year 2010, one in every 250 young adults will be a survivor of childhood cancer. This web site addresses needs and issues of long term pediatric cancer survivors.

Yale New Haven Children's Hospital

20 York Street
New Haven CT 068
203-688-2000

www.ynhh.org

The Yale New Haven Children's Hospital recently opened a HEROS clinic for survivors of childhood cancer. Thankfully, more children are surviving cancer than ever before. While survivors typically enjoy healthy, active lifestyles, they are also at increased risk for problems such as subsequent neoplasms, congestive heart failure, osteoporosis, decreased fertility, post-traumatic stress disorder and learning disabilities. A new clinic has been established at Yale for children and adults who were treated for childhood cancer over five years ago. This is a highly specialized resource seeing patients twice a month to supplement care received from the patients' primary care doctors.

For a pamphlet about the clinic, write or call (203) 688.2000 or Toll-free (888) 700 6543.



NOTES

NOTES

The Purple Pages, A Childhood Cancer Resource for Families.

Copyright © 2005 Circle of Care for families with cancer

Circle of Care for families with cancer is a 501(c)(3) tax-exempt nonprofit corporation founded with love by three mothers of children with cancer to provide support to other families walking in their shoes.

Published by

Circle of Care for families with cancer

Editor: Liz Salguero, Sarah Patterson

Cover Design: Jennifer Moore, MD

Designed & Printed by The Paper Mill, Greenwich CT

December 2005 first printed edition

The information in this book has been compiled to provide access to reliable resources for parents and families of children with cancer.

Each resource has been checked for accuracy at the time of printing. Circle of Care cannot insure the accuracy of the information over long periods of time. Check our web site for updates
www.thecircleofcare.org

Be sure to check with your doctor before making any changes to your routine and/or medical care.

Always seek the advice of a professional.



Circle of Care for those families with cancer is a 501(c)(3) tax-exempt nonprofit corporation founded by a group of families whose children have battled and survived cancer. We are dedicated to supporting children with cancer and their families by sharing our knowledge and experiences from the time of diagnosis to recovery and beyond.

Circle of Care brings community, hope and support to families with cancer.

*With Great Appreciation for
your Support & Funding*



Pitney Bowes

**LITERACY &
EDUCATION
FUND**