

Preface

As the parents of children with cancer, we remember the daunting task of sifting through all the resources of the Internet and feeling overwhelmed.

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.

Please note that some of the information either on the Internet or in printed materials can be misleading, out of date, or not accurate. Each child and diagnosis is unique in its own way. If you have any questions we suggest that you speak to your child's doctor.

Our Story

Since 2003, Circle of Care has supported the non-medical needs of children with cancer and their families. Founded by families whose own children battled cancer and survived, we strive to be there for you. Circle of Care is 100% volunteer; all funds raised go directly to fulfill our mission of supporting children with cancer. Our programs and support services are offered to patients and families receiving care at Smilow Cancer Hospital at Yale New Haven Hospital, Connecticut Children's Medical Center, and Maria Ferari Children's Hospital as well as to other Connecticut children being treated in specialized cancer centers elsewhere.

Circle of Care has evolved from a single program to a total of seven programs today and is a hands-on, immediate and compelling support structure for families with cancer. Through the generosity of individual and corporate donors, we offer loaner laptops for use in-hospital; day of diagnosis care bags filled with essentials; a carefully-researched childhood cancer resource directory; hospital and treatment center volunteers; dream room makeovers; telephone peer support; and emergency funds for families with critical financial needs. We invite you to learn more about us and how we can help your family at www.thecircleofcare.org.

We always welcome your feedback and 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
Founders

Circle of Care

for families of children with cancer

PO Box Wilton CT 06897

203-663-6893

info@thecircleofcare.org

www.thecircleofcare.org

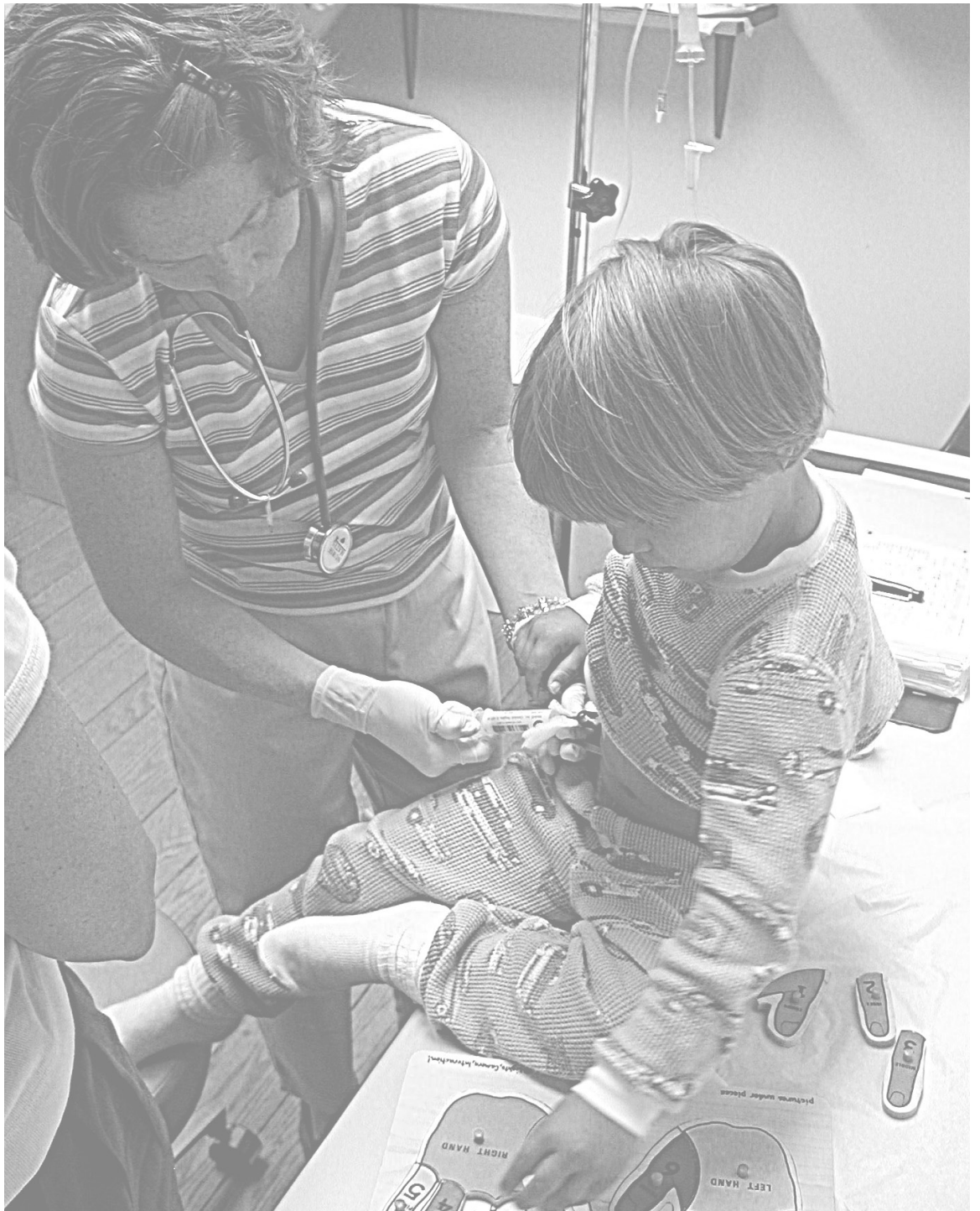
Acknowledgements

This book would not have been possible without the guidance and support of Dr. Joseph McNamara and all the wonderful nurses, doctors and social workers at Smilow Cancer Hospital and Connecticut Children's Medical Center, Maria Ferari Children's Hospital

We would also like to thank our tireless researcher and fact checker, Ryan Boyer

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PEDIATRIC HEALTHCARE AND CANCER ORGANIZATIONS

American Cancer Society

Southern New England Region

38 Richards Ave

Norwalk, CT 06854

Tel: (203) 563-1500

Fax: (203) 563-0738

www.cancer.org

The American Cancer Society is a national network of employees and volunteers that implements research, and offers educational and patient service programs. Although they differ according to state, the network offers many widely available programs. Some of these programs include patient-to-patient visitation, transportation to appointments, housing near treatment centers, equipment and supplies, support groups, and summer camps for children with cancer.

American Childhood Cancer Organization (ACCO)

P.O. Box 498

Kensington, MD 20895-0498

Tel: (855) 858-2226, or (301) 962-3520

Fax: (301) 962-3521

www.acco.org

ACCO was founded by families to support families of children and adolescents with cancer. They help shape policy, research, and programs on a national level. Some free resources they provide include a toll-free info hotline, a quarterly newsletter, and various informational handbooks.

APSA's Complete Parent & Family Resource Center from the Surgical Assn.

111 Deer Lake Road, Suite 100

Deerfield, IL 60015

Tel: (847) 480-9576

Fax: (847) 480-9282

Email: eapsa@eapsa.org

www.pediatricsurgeryMD.org

APSA is a surgical specialty organization composed of individuals who are dedicated to the care of pediatric surgical patients. Their website offers a range of online tools. These include a unique search engine to help visitors find a qualified pediatric surgeon and a member of APSA nearest you, as well as a current list of resources for parents and "cool" websites for kids.

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

4700 W. Lake Avenue

Glenview, IL 60025-1485

Tel: (847) 375-4716

Email: info@aspho.org

www.aspho.org

ASPHO is a society of professional pediatric hematologists/oncologists who study and treat childhood cancer and blood diseases. It is currently the only society dedicated solely to the professional development and interests of subspecialists in pediatric hematology/oncology. Their primary goals are to further communication amongst the researcher community, to further the dissemination of recent empirical findings and current studies, as well as provide caregivers with the most updated knowledge in their field. Its website provides patients and families a source of current peer-reviewed scientific and clinical information.

Children’s Brain Tumor Foundation (CBTF)

274 Madison Avenue, Suite 1004
New York, New York 10016
Tel: (866) 228-HOPE (228-4673)

Email: info@cbtf.org

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 those of newly diagnosed children, and co-sponsorship of conferences and seminars for families, survivors, and healthcare professionals.

Childhood Leukemia Foundation (CLF)

807 Mantoloking Road, Suite 203
Brick, New Jersey 08723
Tel: (888) CLF-7109 or (732) 920-8860

Email: info@clf4kids.com

www.clf4kids.com

The Childhood Leukemia Foundation is a national nonprofit organization founded to “nurture the spirit within” children living with cancer. CLF works to foster a better quality of life for children with cancer by creating fun and joyful experiences, and giving a sense of normalcy despite their challenging circumstance.

Childhood Brain Tumor Foundation

20312 Watkins Meadow Drive
Germantown, MD 20876
Tel: (301) 515-2900

Toll-Free: (877) 217-4166

Email: cbtf@childhoodbraintumor.org

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 by cancer. The website contains articles and newsletters about childhood brain tumors, as well as information on the organization and its services.

Children’s Leukemia Research Association, Inc. (CLRA)

244 5th Avenue, Suite 2969
New York, NY 10001
Tel: (212) 491-1200

Email: info@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, as well as public and professional education, and research grants to medical professionals.

PEDIATRIC HEALTHCARE AND CANCER ORGANIZATIONS

Curesearch for Children's Cancer

4600 East West Highway, Suite 600

Bethesda, MD 20814-3457

Tel: (800) 458-6223

Fax: (301) 718-0047

Email: info@curesearch.org

www.curesearch.org

CureSearch unites the Children's Oncology Group (COG) and the National Childhood Cancer Foundation (NCCF) through a shared mission to cure and prevent childhood and adolescent cancer. Their website has a disease-specific resource directory and a wealth of links for general information, insurance assistance, emotional support, and family programs. Visitors may also sign up for Childhood Cancerline—a free monthly E-newsletter, providing information on new treatments and psychosocial support.

Children's Oncology Group (COG)

222 East Huntington Drive

Suite 100

Monrovia, CA 91016

Tel: (626) 447-0064

Fax: (626) 445-4334

Email: info@CureSearch.org

www.ChildrensOncologyGroup.org

General questions, contact at

HelpDesk@childrensoncologygroup.org

Membership questions, contact at

Membershipinfo@childrensoncologygroup.org

Children's Oncology Group (COG) is an NCI-supported clinical trials cooperative group devoted exclusively to childhood and adolescent cancer research. Their website provides information about how to locate

a treatment center offering clinical trials for children with cancer and info about the long term effects of cancer treatment.

Leukemia & Lymphoma Society

Connecticut Chapter

372 Danbury Road, Suite 200

Wilton, CT 06897

Tel: (203) 665-1400

Toll-free: (888) 282-9465

Fax: (203) 665-1401

Information Resource Center:

Time: M-F 9am - 9pm

(800) 955-4572

Email: infocenter@lls.org

www.lls.org

This organization funds research, sponsors a national education programs 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 online chat, which is staffed by social workers, nurses and health educators who provide current, accurate information. Financial assistance is also available to families through this organization.

National Cancer Institute (NCI)

BG 9609 MSC 9760

9609 Medical Center Drive

Bethesda, MD 20892-9760

Tel: (800) 422-6237 M-F 8AM - 8PM EST

www.cancer.gov

NCI provides a nationwide telephone service for people with cancer, their families, friends, and the professionals who treat them. Live online assistance is also available through their

PEDIATRIC HEALTHCARE AND CANCER ORGANIZATIONS

website. NCI answers questions, sends out informational booklets on a variety of topics related to cancer, and coordinates research projects for cancer control. One such service is the Physician Data Query (PDQ). This is NCI's online list of accurate and recent information related to cancer, and is designed for patients and health professionals.

National Children's Cancer Society (N.C.C.S.)

One South Memorial Drive, Suite 800
St. Louis, MO 63102
Tel: (314) 241-1600
Fax: (314) 241-1996

www.thenccs.org

NCCS is a nonprofit national organization that helps improve the quality of life for children with cancer and their families by providing financial aid and in-kind assistance, advocacy, support services, and education about childhood cancer and wellness.

NCCS also has an online community (nccsonlinecommunity.ning.com) for parents, caregivers, and survivors of childhood cancer to connect and share with another via personal accounts.

National Dissemination Center for Children with Disabilities (NICHCY)

1825 Connecticut Ave. NW
Washington, DC 20009
Toll-free: (800) 695-0285
Tel: (202) 884-8200
Fax: (202) 884-8441

Email: NICHCY@fhi360.org

www.NICHCY.org

The National Dissemination Center for Children with Disabilities provides access to disability organizations, parent groups, state agencies, and other assistance resources.

National Organization for Rare Disorders (NORD)

55 Kenosia Avenue
Danbury, CT 06810
Tel: (203) 744-0100
TDD: (203) 797-9590
Voicemail Toll-free: (800) 999-6673
Fax: (203) 798-2291

www.rarediseases.org

NORD is a unique syndicate of voluntary health organizations dedicated to helping people with rare "orphan" diseases, and to assisting the organizations that serve them. They are committed to the identification, treatment, and cure of rare disorders through education, advocacy, research, and service programs.

Neuroblastoma Children's Cancer Society

P.O. Box 957672
Hoffman Estates, IL 60195
Toll free: (800) 532-5162
Fax: (847) 605-0705

Email: info@neuroblastomacancer.org

www.neuroblastomacancer.org

The Neuroblastoma Children's Cancer Society is a group of volunteers whose lives have been affected by cancer. They advocate for children who suffer from neuroblastoma and are dedicated to serving as a support center for their families. The primary focus of the organization is to raise funds to assist

local research in neuroblastoma cancer, and to raise national awareness so as to focus additional research and funding until a cure can be found.

The American Academy of Pediatrics

National Headquarters
141 Northwest Point Boulevard
Elk Grove Village, IL 60007-1098
Toll Free: (800) 433-9016
Tel: (847) 434-4000
Fax: (847) 434-8000

www.aap.org

AAP is a member-based organization of pediatricians dedicated to the health and safety of persons 0-21 years of age. The AAP website provides guidelines for pediatric cancer centers, related oncology links, and general information about childhood health.

The Children's Cause For Cancer Advocacy

750 First Street, NE 7th Floor
Washington, DC 20002
Tel : (202) 336-8374 or (202) 336-8375

www.childrenscause.org

The Children's Cause is dedicated to accelerating the discovery of and access to innovative, safe, 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.

NOTES

TREATMENT CENTERS

Children's Hospital of Philadelphia

34th Street and Civic Center Boulevard

Philadelphia, PA 19104-4399

Tel: (215) 590-1000

Physician Referral Service: (800) 879-2467

www.chop.edu

The Children's Hospital of Philadelphia is one of the leading pediatric hospitals and research facilities in the world. The institution represents over 150 years of noted innovation and quality service. Its enduring values and standards reflect an ongoing commitment to exceptional patient care, to training new generations of pediatric healthcare providers and pioneering significant research initiatives. In an exclusive survey, Child Magazine ranked The Children's Hospital of Philadelphia the best pediatric hospital in the USA for the third time consecutively. US News and World Report ranked Chop 2nd in the nation in the 2010-11 report.

Connecticut Children's Medical Center

282 Washington Street

Hartford, CT 06106

Tel: (860) 545-9000

Kidsline: (800) 243-1552

Physician Referral: (888) 543-7778

www.connecticutchildrens.org

The goal of CCMC is to provide medical care for the child and family, with sensitivity to cultural diversity. Every inpatient child has a private room, and parents are encouraged to room-in at the medical center. Families are involved in all aspects of a child's care. An understanding of the developmental and emotional needs of children guides how the staff will care for them. Child Life specialists, on staff seven days of the week, work to make the hospital experience comprehensible and, therefore, less frightening for the children. The Division of Hematology/Oncology provides comprehensive care for pediatric patients with related problems. They provide diagnosis and management services for children with anemias, neutropenias, thrombocytopenias, coagulation disorders, leukemias, and all solid tumors.

TREATMENT CENTERS

Dana-Farber/Children's Hospital Cancer Care (DF/CHCC) at Boston, MA

44 Binney Street, 3rd Floor

Boston, MA 02115

Tel: (617) 632-3000

Fax: (617) 632-4773

Children's Number: (855) 320-2090

Urgent After Hours: (617) 632-3852

www.danafarberchildrens.org

For more than fifty 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, Cancer Survivor Program, Histiocytosis, Hodgkin's Lymphoma, Leukemia, Non-Hodgkin's Lymphoma, or Solid Tumor Program.

The collaboration'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, DF/CHCC rapidly formed a transplant program, which is one of the most experienced, sophisticated, and accomplished multidisciplinary childhood transplant centers in the world.

Maria Fareri Children's Hospital at Westchester Medical Center

100 Woods Road

Valhalla, New York 10595

Tel: (914) 493-7000

Physician Referral: (877) 962-3627

www.worldclassmedicine.com

Maria Fareri Children's Hospital at Westchester Medical Center opened in September 2004, moving the Medical Center's renowned pediatric services into a building oriented for the child and family, while maintaining some of the most sophisticated facilities available. Highly trained oncologists and hematologists care for children and their families. These experienced children's physicians offer specialized programs in bone marrow transplant and experimental chemotherapy, as well as the most advanced therapies for sickle cell diseases, thalassemia, and other hematological disorders. A special ambulatory infusion center at the Children's Hospital has been designed to provide continuing specialized care when these patients are well enough to go home. There is also an in-house Ronald McDonald House with five family suites.

TREATMENT CENTERS

Memorial Sloan-Kettering Cancer Center

1275 York Avenue
New York, NY 10065
Tel: (212) 639-2000

Physician Referral: (212) 639-5954

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 information on diseases, as well as FAQ links for parents and children.

St. Jude Children's Research Hospital

262 Danny Thomas Place
Memphis, TN 38105
Tel: (901) 595-3300

Physician Referral: (866) 278-5833

www.stjude.org

St. Jude Children's Research Hospital is one of world's premier research and treatment centers for catastrophic diseases in children, primarily cancers. All patients accepted for treatment at St. Jude must be referred by their physicians and are treated regardless of the family's ability to pay.

Texas Children's Cancer Center and Hematology Service

6701 Fannin St., Suite 1420
Houston, TX 77030-2399
Tel: (832) 822-4240

Toll-free: (800) CANCER9 (800-226-2379)

www.txccc.org

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

The Johns Hopkins Childrens Center

1800 Orleans Street
Baltimore, MD 21287
Tel: (410) 955-5000

www.hopkinschildrens.org

Consistently ranked as one of the top four children's hospitals in the nation by U.S. News and World Report, The Johns Hopkins Children's Center offers one of the most comprehensive pediatric medical programs in the country. On May 1, 2012 the center opened a new children's hospital, the Charlotte R. Bloomberg Children's Center. This new facility offers the most advanced therapies and technically complex procedures.

TREATMENT CENTERS

The Children's Cancer Hospital The University of Texas M.D. Anderson Cancer Center

1515 Holcombe Blvd.

Houston, TX 77030

Tel: (713) 792-2121

Toll-Free: (877) MDA-6789 (877-632-6789)

www.MDAnderson.org/children

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. It is one of three-dozen nationally designated comprehensive cancer facility.

Yale-New Haven Children's Hospital Smilow Cancer Hospital

20 York Street

New Haven, CT 06510

Tel: (203) 688-4242

www.YNHH.org

Yale-New Haven Hospital has cared for more children than any other hospital in Connecticut. Yale-New Haven Children's Hospital, opened in 1993, is Connecticut's first comprehensive children's hospital. Inpatient, outpatient, emergency, primary and preventative care is provided to thousands of children and the hospital serves as one of New England's major referral centers for diagnosis and treatment of pediatric problems.

The Pediatric Oncology Program at Smilow Cancer Hospital offers the latest advances in diagnosing and treating childhood cancer and blood disorders, such as leukemia, lymphoma

(Hodgkin's Disease & Non-Hodgkin's Lymphoma) brain tumors, bone tumors (such as osteosarcoma & Ewing's Sarcoma), solid tumors such as Wilm's Tumor, neuroblastoma, rhabdomyosarcoma and kidney tumors. The Pediatric Oncology Program is supported by a multidisciplinary team of physicians in pediatrics, laboratory medicine, surgery, neurosurgery, orthopedics, pathology, therapeutic radiology, and diagnosis radiology, as well as nurses and social workers.

In addition to the expertise provided by the Pediatric Oncology team, many supportive care services are available, including child life, clown visitation, music therapy, and massage therapists to help both children and families cope with illness and treatment. The HERO's Clinic also offers children adolescents and adults a survivor clinic focused on wellness issues after treatment for childhood cancer.

BONE MARROW AND STEM CELL TRANSPLANTATION

BoneMarrowTest.com

Kashi Clinical Laboratories Inc.

10101 SW Barbar Blvd, Suite 200

Portland, OR 97219

Toll-Free: (877) 565-3287

Email: info@BoneMarrowTest.com

www.BoneMarrowTest.com

This website provides testing resources for patients who need stem cells from bone marrow, peripheral blood or umbilical cord blood. It is also focused on helping families, friends, communities and organizations find suitable donors to complete a stem cell transplant.

BMT InfoNet (Blood & Marrow Transplant Information Network)

2310 Skokie Valley Road, Suite 104

Highland Park, IL 60035

Tel: (847) 433-3313

Toll-Free: (888) 597-7674

Fax: (847) 433-4599

Email: help@bmtinfonet.org

www.bmtinfonet.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

515 Madison Ave., Suite 1130

New York, NY 10022

Tel: (212) 838-3029

Toll-Free: (800) 365-1336

Fax: (212) 223-0081

Email: TheBMF@BoneMarrow.org

www.BoneMarrow.org

This organization provides financial assistance, education and support to those facing bone marrow transplants. Assistance is not limited to a specific disease, type of transplant, or age range

National Bone Marrow Transplant Link

20411 W. Twelve Mile Road, Suite 108

Southfield, MI 48076

Toll-Free: (800) LINK-BMT

Tel: (248) 358-1886

Fax: ((248) 358-1889

Email: info@NBMTlink.org

www.NBMTlink.org

The National Bone Marrow Transplant Link provides a hot line, peer support groups, a library of educational booklets, and suggestions for financial assistance.

National Marrow Donor Program (NMDP)

3001 Broadway Street, NE, Suite 100

Minneapolis, MN 55413

Patient Advocacy: (888) 999-6743

Toll-Free Public Info: (800) 627-7692

Email: PatientInfo@nmdp.org

www.marrow.org

BONE MARROW AND STEM CELL TRANSPLANTATION

The NMDP has the world's largest computerized listing of potential bone marrow donors. The NMDP has cooperative search arrangements with many other registries worldwide.

Help Hope Live (Formerly NTAF)

2 Radnor Corporate Center

Radnor, PA 19087

Tel: (800) 642-8399

Fax: (610) 535-6106

www.helpohpelive.org

This fund provides assistance for fundraising activities, answers financial questions and concerns, and offers donor awareness material to transplant and catastrophic injury patients nationwide.

ORGANIZATIONS OFFERING ALTERNATIVE THERAPIES

Academy For Guided Imagery

30765 Pacific Coast Highway

Malibu, CA 90265

Tel: (424) 242-6369

Fax: (310) 589-9523

Email: info@AcadGI.com

www.AcadGI.com

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

American Institute for Cancer Research

1759 R Street NW

Washington, D.C. 20009

D.C. Tel: (202) 328-7744

Toll-Free: (800) 843-8114

Fax: (202) 328-7226

Email: AICRweb@AICR.org

www.AICR.org

This institute provides information in the field of diet, physical activity, and weight management as it relates to cancer. The toll-free number listed above serves as a nutrition hotline M-F 9am to 5pm ET.

American Society of Clinical Hypnosis

140 North Blomington Road

Bloomington, IL 60108-1017

Tel: (630) 980-4740

Fax: (630) 351-8490

Email: info@ASCH.net

www.ASCH.net

ASCH is membership-based organization for doctors, psychologists and dentists who use hypnosis in their practices. A search

feature on the website allows visitors to locate practitioners with memberships.

National Center for Complementary and Alternative Medicine (NCCAM)

9000 Rockville Pike

Bethesda, MD 20892

Toll-Free: (888) 644-6226

Hearing Impaired: (866) 464-3615

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. Their website offers live help with a health information specialist M-F, 8:30am to 5pm ET.

Oncolink

www.oncolink.org

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

Quackwatch

www.quackwatch.com

This resource provides information on claims of complementary and alternative therapies proven to be unsafe, or the effectiveness of which has not been proven. The organization is now an international network of people who are concerned about health-related frauds, myths, fads, follies, and misconduct. The website provides valuable information that is otherwise difficult to find.

ORGANIZATIONS OFFERING ALTERNATIVE THERAPIES

Reiki

Reiki is a Japanese technique for stress reduction and relaxation that also promotes healing. It is administered by “laying on hands” and is based on the idea that an unseen “life force energy” flows through us and is what causes us to be alive. Yale Hospital has many child life specialists, OR nurses, and palliative care nurses that can offer this service to patients and families.

Acupuncture

Acupuncture is a traditional Chinese medicine that is used to relieve pain and other symptoms while generally improving the quality of life. It is often used to relieve vomiting and nausea from chemotherapy. It is administered using needles, heat, pressure, and other treatments to the skin at points known as acupuncture points. This practice is meant to simulate energy flow or “chi,” which is believed to circulate through the body along specific routes. Yale Hospital has a practitioner who administers acupuncture care.

DR. Rahul S. Anand

www.ynhh.org/physician-finder

RESOURCES FOR PARENTS

CancerCare, Inc.

275 Seventh Avenue
New York, NY 10001
Toll-Free: (800) 813-HOPE

Email: info@CancerCare.org

www.CancerCare.org

CancerCare is a national nonprofit organization with the mission of providing free professional help to people with all cancers through counseling, education, information, and referral, as well as directing financial assistance. The main CancerCare office for Connecticut is located at:

535 Connecticut Ave., Suite 104
Norwalk, CT 06854.

Email: CTinfo@CancerCare.or

CancerQuest

2017 Rollins Research Building
1510 Clifton Road, NE
Atlanta, GA 30322

Tel: (404) 727-0308

Fax: (404) 727-2880

Email: CancerQuest@Emory.edu

www.CancerQuest.org

CancerQuest provides reliable, current, and comprehensive information about the biology and treatment of cancer, in order to help empower the patient, survivors, students, healthcare workers, and caretakers

CaringBridge

1715 Yankee Doodle Road, Suite 301
Eagan, MN 55121

Tel: (651) 452-7940

Fax: (651) 681-7115

Question Line: (651) 789-2300

www.CaringBridge.org

This nonprofit organization helps visitors create a website for keeping friends and family updated on a patient's status. There is no charge for the use of this website. Creating a resource such as this can help alleviate phone bills and keep extended family aware of their relative's health.

Care Pages

345 Hudson Street, 16th Floor
New York, NY 10014

Tel: (646) 728-9500

Fax: (646) 728-9503

Email: info@everydayhealth.org

www.CarePages.com

Care Pages are free patient blogs that help to inform friends and family about a patient's situation and health status. The pages are used to share stories, pictures, and messages, and allow the patient to maintain a more supportive network. The Care Pages also provide articles, stories of inspiration and more resources.

Family Centers

The Center For Hope

590 Boston Post Road
Darien, CT 06820

Tel: (203) 655-0547

Fax: (203) 972-0556

www.familycenters.org

The Center for Hope offers professional counseling, support groups and educational programs, in an atmosphere of hope and renewal. Centers are also located in Greenwich, CT and Stamford, CT. It is a place for kids and their families to have someone to talk with, to meet other kids sharing similar

RESOURCES FOR PARENTS

experiences, and to find help with coping when someone is very ill or grieving. Support groups are offered on an ongoing basis for parents and siblings of children with cancer.

Children's Cancer Association

433 NW 4th Ave., Suite 100

Portland, OR 97209

Tel: (503) 244-3141

Fax: (503) 892-1922

Email: office@JoyRx.org

www.joyrx.org

This website provides information on end of life support, financial assistance, wish fulfillment, and youth connections. The association also offers several award-winning programs to seriously ill children.

Childhood Cancer Guides

P.O. Box 31937

Bellingham, WA 98228

www.childhoodcancerguides.org

This organization develops, maintains, and shares portions of books that help families of children with cancer and survivors for childhood cancer. They are also involved in advocacy.

CureSearch

Refer to the "Pediatric Healthcare and Cancer Organizations" section for more on this organization, and its contact information.

Coping Magazine

P.O. Box 682268,

Franklin, TN 37068

Tel: (615) 790-2400

Fax: (615) 794-0179

www.copingmag.com

Coping Magazine is a bimonthly publication for people whose lives have been affected by cancer, aimed to help with the coping that is involved during and afterward.

Coping With Chronic Illness: A Guide for Kids, Teens and Their Parents

<http://medicalassistantschools.org/resources/chronic.html>

This website has a list of resources for all members of the family that explains what chronic illnesses are and different ways of dealing with them.

Home Care Guide

500 University Drive

Hershey, PA 17033

Careline: (800) 243-1455

Tel: (717) 531-6955 Hospital Operator

www.PennStateHershey.org/web/pedsh-ematology/home

This website is very helpful for those at home caring for young persons with cancer. By searching their website for "home care guide," you can find and download a pdf version to your computer.

Never-Ending Squirrel Tales

deboracaron@squirreltales.com

www.squirreltales.com

This website offers practical tips and encouragement for the parents of kids with cancer, as well as a world famous guest book and humorous blogs. It also emphasizes the role of God in treatment and general wellness.

RESOURCES FOR PARENTS

Ronald McDonald House Charities (RMHC)

1 Kroc Drive
Oak Brook, IL 60523
Tel: (630) 623-7048
Fax: (630) 623-7488

www.rmhc.org

Email: info@RMHC.org

Local Chapter:

Ronald McDonald House in New Haven

501 George Street
Tel: (203) 777-5683
Fax: (203) 777-3082

RMHC provides information about local Ronald McDonald Houses on a national and international basis. The houses temporarily provide comfortable lodging for families of seriously ill children being treated away from home. The website has a feature that locates RMHC chapters and Ronald McDonald Houses.

In return for using the houses, families are asked to make a donation ranging from \$5 to \$20 per day, if possible; otherwise, the stay is free.

RxList

www.RxList.com

This website provides a general audience with information on specific medications, including those used by cancer patients.

Songs of Love Foundation

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

Email: info@SongsOfLove.org

www.SongsOfLove.org

Songs of Love is a nonprofit organization with a volunteer group of over 200 artists who produce personalized musical portraits for children with chronic or life-threatening diseases.

Starlight Children's Foundation

2049 Century Park East, Suite 4320
Los Angeles, CA 90067

Tel: (310) 479-1212

www.Starlight.org

The Starlight Children's Foundation is dedicated to developing projects that help seriously ill children combat the medical and emotional challenges they face on a daily basis. They provide an online social network using facebook, twitter, etc., allowing teens with serious illness and their siblings to meet kids in similar situations. Via their website, visitors may also access a series of online animated stories that can help young people learn how to cope with the challenges cancer poses.

Supersibs!

660 N. First Bank Drive
Palatine, IL 60067

Tel: (847) 462-4742

Fax: (847) 984-9292

info@SuperSibs.org

www.SuperSibs.org

Pediatric cancer affects everyone in the family. During the fight against cancer, siblings need to know that they, too, are special and important people, and that there is an organization to provide support for their unique needs. SuperSibs! Helps children redefine the "cancer sibling" experience by providing support services, and by helping to

RESOURCES FOR PARENTS

draw out the greater and important lessons that may benefit these children later in their lives.

The Stanford Health Library Main Branch

Hoover Pavilion
211 Quarry Road, Suite 201
Palo Alto, CA 94304
Toll-free: (800) 295-5177
Fax: (650) 725-1444

**Email: HealthLibrary@StanfordMed.org
www.HealthLibrary.Stanford.edu**

The Stanford Health Library provides scientifically based medical information to help visitors make informed decisions regarding healthcare and their health. Some services offered by the library include “Don’t know what to make of a new diagnosis?” and “Drowning in information?” All of their services are free.

Lotsa Helping Hands

288 Washington Street, Suite 316
Brookline, MA 02445

**Email: info@lotsahelpinghands.com
www.lotsahelpinghands.com**

When people say to a newly diagnosed family, “What can I do to help?” parents often don’t know how to answer. Lotsa Helping Hands does. Lotsa Helping Hands is a free service that creates communities of friends, neighbors, relatives, and more that rally around a family or person in need. Individuals can sign up for day to day tasks that the family may need help with, such as transportation or meals, and even automatically sends out email reminders. The site is also a platform for announcements and photos about the ill person, so everyone can stay up to date on his or her progress.

National Coalition for Cancer Survivorship

The Yale New Haven Children’s Hospital:

Pediatric Cancer Services and FAQs

20 York Street
New Haven, CT 06510
Tel: (203) 688-4242
Toll Free: (888) 700-6543

www.YNHH.org/pediatrics/cancer/parents.html

In addition to the child, cancer affects all of his or her family members and friends. This section of the Yale – New Haven Children’s Hospital’s website answers common questions these people may have, and gives them an opportunity to share and learn about others’ experiences.

Books

Eating Hints for Cancer Patients: Before, During, and After

This book, provided by the National Cancer Institute, is designed for patients, families, and caregivers. It addresses specific dietary needs during treatment and attempts to provide coping strategies for side effects that may have an impact on eating.

To purchase, or learn more about this book call (800) 422-6237, or visit www.cancer.gov/CancerInfo/EatingHints

The I-Can't-Chew Cookbook:

Delicious Soft Diet Recipes for People with Chewing, Swallowing, and Dry Mouth Disorders

By Randy J. Wilson

Online E-book also available!

The Cancer Survival Cookbook: 200 Quick & Easy Recipes with Helpful Eating Hints

By Donna L. Weihofen

This book has recipes for patients going through Chemotherapy and Radiation treatments. The recipes are excellent and easy. The nutritional information for each recipe is given, as well as hints on how to increase your calorie intake when needed.

What to Eat If You Have Cancer

By Daniella Chase and Maureen Keane

This book, written by two licensed nutritionists, discusses food that may reduce toxins left by Chemotherapy, and that may accelerate the body's recovery process. It covers many important topics that need to be understood when making dietary changes, such as supplement "dos and don'ts" and the benefits of natural foods.

Betty Crocker's Living with Cancer Cookbook: Easy Recipes and Tips Through Treatment and Beyond

By Betty Crocker

Websites

Nutritional Needs For Kids With Cancer www.kidshealth.org/parent/_cancer_centers/treatment/cancer_nutrition.html

For good information on how nutrition is important and what to eat during cancer.

RESOURCES FOR KIDS

American Brain Tumor Kids Page

www.abta.org/kids/

Crosslist: Resources for parents

Created by the American Brain Tumor Association, this website is designed for kids to use. They can learn about tumors, share their thoughts, take part in fun activities or find out how to volunteer. In the "Learning" section they can download a pdf file of the book, Alex's Journey, about a boy who is diagnosed with a brain tumor. There is also a free award-winning video of Alex's Journey, which can be ordered from the website.

(800) 866-2282

Bandaides and Blackboards

Joan Fleitas, Ed. D., R.N.

Associate Professor of Nursing,
Lehman College, Bronx, NY 10468

Email: Fleitas@OptOnline.net

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

Provided by Joan Fleitas, Associated Professor of Nursing at Lehman College, this website is designed to offer a child's perspective on growing up with a serious medical condition. It supports kids, teenagers and adults dealing with their medical and emotional issues and when returning to school. Visitors are advised on dealing with teasing, what to expect in the classroom and how to get back to normal life.

Blood Count Information for Kids with Cancer

www.pedspain.nursing.uiowa.edu/bcounts

The University of Iowa created this website to better explain blood counts to kids. It uses cartoon characters to do so in a fun, animated way.

Brave Kids

BraveKids c/o UCP

1825 K Street NW, Suite 600

Washington, DC 20006

Toll Free: (800) 872-5827

www.info@ucp.org

Brave Kids' mission is to help children with chronic, life-threatening illnesses or disabilities. There is a special section of the website called "Club Brave Kids," designed just for children dealing with cancer. It includes message boards for cancer patients and their siblings, weekly polls, news about other Brave Kids, medical info just for kids and teens, and games.

Kids Cancer Network

P.O. Box 4545

Santa Barbara, CA 93140

Email: info@KidsCancerNetwork.org

www.KidsCancerNetwork.org

In 1992 a young cancer survivor, Kenon Neal, founded this network to provide "a dose of hope" for kids and their families, who are often isolated by the rigors of childhood cancer treatment. He developed a "Fun Letter" for children with cancer, including games, pictures to color and ideas to share. Six issues are distributed per year.

Personal Ponies

Email: PersonalPonies@earthlink.net

www.PersonalPonies.org

Dedicated to the belief that the life of a child with disabilities can be immeasurably enriched by having a tiny pony to love and care for, Personal Ponies provides Shetland Ponies to families of disabled, special needs, and terminally ill children free of charge.

RESOURCES FOR KIDS

The Sunshine Kids Foundation (CT Chapter)

2 Hartford Square West
146 Wyllys Street, Suite 2-210
Hartford, CT 06106
Tel: (860) 904-5493
Fax: (860) 904-5268

Email: info@sunshinekids.org

www.sunshinekids.org

Sunshine Kids provides free events for Children and Families with Cancer, and are a national organization with a CT Chapter. Some events include a princess tea party, a Sesame Street Parade, snow tubing, and more.

Chemo Angels

P.O. Box 1971
Julian, CA 92036

Email: chemoangels@prodigy.net

www.chemoangels.net

Having cancer can be very isolating and even lonely, but Chemo Angels are there to provide encouragement for patients. Letters and small gifts in the mail pick up a patient's spirits during treatment, and give them something to look forward to.

Chemo Duck

Gabe's My Heart, Inc.

5016 Spedale Court PMB 129
Spring Hill, N 37174

Tel: (615) 830-0126

Email: Lu@chemoduck.org

www.chemoduck.org

This organization has a program that offers a cuddly, friendly stuffed animal duck that can be used to teach children about cancer and hospital treatments. The duck comes with a book for parents on how to best use the duck, as well as an activity book for kids.

Giant Kids

P.O. Box 499
Mahopac, NY 10541

Email: semenetz@giantkids.org

www.giantkids.org

Giant Kids provides awards for the brave kids who battle childhood cancer every day. They also have an annual Summer Fun Festival for kids of all ages, with animals, food, and activities for the whole family.

RESOURCES FOR TEENS

2bMe

Email: info@2BeMe.org

www.2bMe.org

Tel: (800) 395-LOOK

2bMe is a very funny, entertaining website for teens with cancer. (Must have or download Flash 5 Adobe.)

Look Good...Feel Better

**www.LookGoodFeelBetter.org/programs/
programs-for-teens**

Look Good...Feel Better is a free public service program that provides useful information and tips for men, women, and teens dealing with their physical appearance, altered by cancer treatment. The program acknowledges social stress resulting from this change in appearance.

Bandaides and Blackboards

Refer to "Resources for Kids" section for more information.

Blood Count Information for Kids with Cancer

Refer to "Resources for Kids" section for more information.

Cancer Kids

Email: WebMaster@CancerKids.org

www.CancerKids.org

Cancer Kids is an internet-based organization, founded with the simple goal of helping children with cancer tell the world their stories. This goal is accomplished by providing links to the personal websites of children who are battling cancer. These links can be found

in the "Stories" section of their website. On the organization's "Wall of Memory" the children whose personal stories do not end with "remission" or "cure" are honored.

Personal Ponies

Refer to the "Resources for Kids" section for more information.

Planet Cancer

Email: ContactUs@PlanetCancer.org

www.Myplanet.planetCancer.org

This organization's website is directed specifically toward young adults dealing with cancer. It includes real-world advice, discussion boards, and recommendations for books, music and films.

Starlight Children's Foundation

Refer to the "Resources for Parents" section for more information.

Teens Living with Cancer

1000 Elmwood Avenue, Suite 300

Rochester, NY 14620

Tel: (585) 563-6221

Info@TeensLivingWithCancer.org

This website provides social support for teens undergoing cancer treatment. It addresses issues, like body issues, nutrition, dealing with others, going back to school, and struggling to live a normal teenage life. This site connects teens as well, providing a network of cancer patients that can discuss and resolve their cancer-related issues.

The Ulman Cancer Fund for Young

Adults

Howard County

6770 Oak Hall Lane, Unit 116

Columbia, MD 21045

Baltimore City

921 East Fort Avenue, Suite 325

Baltimore, MD 21230

Toll-Free: (888) 393-FUND

Tel: (410) 964-0202

Fax: (888) 964-0402

Email: info@UlmanFund.org

www.UlmanFund.org

The Ulman Cancer Fund for Young Adults provides free support programs, education, and other resources. Through using these free services, they hope young adults will benefit, as well as promote awareness and prevention of cancer.

Stupid Cancer

40 Worth Street, Suite 808

New York, NY 10013

Tel: 877-735-4673

Email: contact@stupidcancer.org

www.stupidcancer.org

Founded by and for young adults affected by cancer, The I'm Too Young For This! Cancer Foundation is the nation's largest support community for the next generation of patients, survivors and caregivers between 15-40. Since their launch in 2007, they have helped bring the cause of 'cancer under 40' to the national spotlight and rallied a new crop of activists to give a much needed voice to this forgotten population.

SUPPORT GROUPS

Support Group for Families and Siblings

The Center for Hope

See Resources for Parents for information on programs and contact information.

Forum for Parents to receive Education & Support

Toll-free: (888) 282-9465

Tel: (203) 789-3946

This group, intended for the parents of children with cancer, features guest speakers on issues like follow-up care, concerns about lasting effects of treatment, and diagnostic tests for hormonal studies or learning disabilities. It meets four times per year in room CH201 of the Yale – New Haven Children’s Hospital. Connie Nicolosi and Carolyn Demsky are the facilitators.

Lotsa Helping Hands

288 Washington Street, Suite 316

Brookline, MA 02445

Email: info@LotsaHelpingHands.com

www.LotsaHelpingHands.com

This website allows visitors to create a free, private, web-based community for free to organize family, friends, neighbors, and colleagues. When going through catastrophic experiences, Lotsa Helping Hands understands that a strong social network is critical to the well-being of every individual. Their website makes it easy to coordinate activities, manage volunteers, communicate and share information using announcements, message boards, and photos.

Support Group for Teens

Connecticut Children’s Medical Center

Toll-free: (888) 282-9465

CCMC offers a monthly support group for teens undergoing cancer treatment every first Thursday of the month from 6:00pm to 8:00pm. Their meetings are held in the CCMC’s Hematology/Oncology clinic, located at 2J 282 Washington Street, Hartford, CT. The group facilitator is Christine Tatum, a Child Life Specialist.

More Support Groups

CancerCare

www.cancercare.org

info@cancercare.org

Tel: (800) 813-4673

This organization offers free support groups for families of children with cancer throughout Connecticut. Contact them to learn more about the locations and times of these meetings.

Refer to the “Resources for Parents” section for more information on this organization, and its contact information.

Barbara Greenspan MHSA, PsyD

Madison area: (203) 535-5522

New London area: (860) 443-1396 ext. 1597
Barbara Greenspan is a clinical psychologist with expertise in psycho-oncology. She works with individuals, couples, and families of all ages to help them learn skills to manage

SUPPORT GROUPS

and live with a serious illness. The treatments focus on recovery and relapse, terminal phases of illness, the process of dying, death, and caregiver burden.

More Support Groups

Ann's Place, The Home of I CAN

80 Saw Mill Road
Danbury, CT 06810
Tel: (203) 790-6568
Fax: (203) 797-1726

Email: ican@annsplace.org

www.annsplace.org

Ann's Place provides counseling for individuals and families, as well as various support groups, wellness programs, peer support, and more.

NOTES

FINANCIAL HELP

American Financial Solutions/Genus Credit Management

263 4th Street
Bremerton, WA 98337
Toll-Free: (888) 282-5844
Credit Counseling: (888) 282-5899
Fax: (888) 282-5495

www.myfinancialgoals.org

This nonprofit credit counseling agency offers free debt management and educational programs that help financially distressed families. Counselors are available by phone Monday through Friday, 6:00am to 7:00pm PST.

Cancer Financial Assistance Coalition (CFAC)

www.cancerfac.org

The Cancer Financial Assistance Coalition (CFAC) is a coalition of organizations that help cancer patients manage their financial challenges by educating them about existing resources. Patients or health care providers can search the CFAC database for organizations that help with specific cancer diagnoses or that provide a specific type of assistance or need. CFAC is a coalition of organizations and cannot respond to individual requests for financial assistance via e-mail or telephone. Financial Assistance Type: Cancer Treatment (includes side effects, late effects), Children/Young Adults, Health Insurance/Co-Payments, Lodging (during treatment), Medication, Practical Needs (mortgage, rent, food, transportation)

Cancer Fund of America

2901 Breezewood Lane
Knoxville, TN 37921

Toll-Free: (800) 578-5284

Email: info@CFoA.org

www.CFoA.org

This organization helps to defray cancer-related expenses that are not covered by insurance. They do so by sending products free of charge.

CancerCare

CancerCare provides free professional help to people with any cancer and their families in Connecticut through counseling, education, information, referral and direct financial assistance.

Refer to the “Resources for Parents” section for more information on this organization, and its contact information.

Children’s Leukemia Research Association (CLRA)

585 Stewart Avenue, Suite 18

Garden City, NY 11530

Tel: (516) 222-1944

Fax: (516) 222-0457

Email: info@ChildrensLeukemia.org

www.childrensleukemia.org

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

Children’s Cancer Association

See resources for parents for more information.

FINANCIAL HELP

Circle of Care

Email: info@thecircleofcare.org

www.thecircleofcare.org

The Danny Fund

PO Box 8271

Pelham, NY 10803

Tel: (914) 843-8553

www.TheDannyFundNY@gmail.com

Danny Fund provides financial, emotional, support and advocacy for children with catastrophic illness or injury.

Friends of Karen, Inc.

New York City office:

116 East 16th Street, 5th Floor

New York, NY 10003

Tel: (212) 308-1378

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: (613) 473-1768

Email: info@FriendsOfKaren.org

www.FriendsOfKaren.org

Friends of Karen is dedicated to providing emotional and financial support, as well as advocacy to children with life-threatening illnesses and their families. They have served children throughout the New York metropolitan area, including Fairfield County, CT for over twenty-five years. The Friends of Karen's Family Support Program provides comprehensive family case management to

children with catastrophic illnesses and to their families. Their social workers access and coordinate all available public and private resources and/or provide referrals to these resources. The organization may also provide direct financial assistance for medical care and other illness-related expenses.

Leukemia & Lymphoma Society Connecticut Chapter

See Pediatric Healthcare and Cancer Organizations for more information.

Medical Bill Detectives

376 Belden Hill Road

Wilton, CT 06897

Email: info@MedicalBillDetectives.com

www.MedicalBillDetectives.com

This group was founded to assist anyone with medical or hospital bills. Their goal is to spot and correct medical billing errors, and to encourage fair billing and compliance practices.

National Children's Cancer Society (NCCS)

Refer to the "Pediatric Healthcare and Cancer Organizations" section for more on this organization, and its contact information.

Kacey Rose Foundation

PO BOX 4412

Wallingford, CT 06492

Tel: (203) 439-0035

www.kaceyrose.com

This CT based foundation was created in memory of Kacey Rose Mitchell. Their mission

FINANCIAL HELP

is to provide assistance to families affected by childhood cancer and spread awareness of Cord Blood Donation.

New England SERVE

Email: info@NESERVE.org

www.NESERVE.org

Written by experienced parents, New England SERVE offers tips on financial healthcare 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 healthcare. Several helpful publications can be downloaded from their website.

Sparrow Clubs USA (National Office)

906 NE Greenwood Ave, Suite#2

Bend, OR 97701

Tel: (541) 312-8630

Fax: (541) 312-8632

info@SparrowClubs.org

www.SparrowClubs.org

Sparrow Clubs USA is establishing an organization of school-based clubs to help local children in medical crises and to promote youth compassion. The organization provides a grant for an ill child that local healthy children, schoolmates and friends earn by doing community service or fundraising.

The Susan Fund

8 Hilly Field Lane

Westport, CT 06880

Tel: (203) 226-4145

www.TheSusanFund.org

The Susan Fund is dedicated to assisting

Fairfield County residents diagnosed with cancer pursue their educational goals through a scholarship grant.

Freedom Disability

19 Forest Parkway

Shelton, CT 06484

Tel: (866) 761-5942

Email: jmayhew@freedomdisability.com

www.freedomdisability.com

Freedom Disability is a social advocacy company that helps find assistance programs for individuals. These assistance programs might range from helping eligible people qualify for Social Security, Medicaid, Medicare, Pharmacy assistance programs, medical transportation, etc.

Family Reach Foundation

2001 Route 46, Suite 310

Parsippany, NJ 07054

(973) 384-1411

www.familyreach.org

Family Reach provides financial support to families with a child or young adult fighting cancer. Eligible families can receive support for home mortgage, utilities, insurance, transportation expenses, child care, palliative care and other special patient needs. Ask your social worker for assistance in completing their application.

The Tommy Fund for Childhood Cancer Yale-New Haven Children's Hospital

20 York Street

New Haven, CT 06511-3202

Tel: 1-800-974-5559

Email: TommyFund@ynhh.org

www.tommyfund.org

The Tommy Fund provides both direct and indirect financial assistance for families dealing with childhood cancer, as well as funding various hospital initiatives.

The Connecticut Sports Foundation

455 Boston Post Road

Suite 203 B

Old Saybrook, CT 06475

Phone: 860-388-0788

Fax: 860-288-5408

www.sportsfoundation.org

Founded in 1987 their mission is to financially assist cancer patients and their families and to fund cancer research. CSF provides funds to Connecticut cancer patients for rent/mortgage, utilities, transportation, medications and more. Patients are referred to CSF via a network of oncology social workers at Connecticut hospitals and cancer centers. Resources are provided with dignity and privacy, helping patients maintain self-respect while lessening the stress that may inhibit their recovery.

Candlelighter's Childhood Cancer Foundation

Refer to the "Pediatric Healthcare and Cancer Organizations" section for more on this organization, and its contact information.

Centers for Medicare and Medicaid Services (CMS)

Tel: (877) 267-2323

www.CMS.HHS.gov

CMS provides information on Medicare and Medicaid hospice benefits.

The Childhood Brain Tumor Foundation

This organization offers their Childhood Cancer Ombudsman Program, which provides complaint investigation and resolution for families of children with cancer. It offers aid in health insurance analysis and application, employment and educational difficulties that may arise during or after treatment.

Refer to the "Pediatric Healthcare and Cancer Organizations" section for more on this organization, and its contact information.

First Hand Foundation

2800 Rockcreek Parkway

Kansas City, MO 64117

Tel: (816) 201-1569

Email: FirstHandFoundation@cerner.com

www.FirstHandFoundation.org

First Hand Foundation is a philanthropic nonprofit foundation established by the Cerner Corporation. It helps the families of children with health problems address the financial aspects of their child's healthcare. They give free community health assessments for those who can't afford it.

Healthcare for Uninsured Kids and Youth (HUSKY)

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 in Connecticut. Many parents don't have health coverage for children through work, but with HUSKY, children can always be covered. HUSKY is funded by the state and federal governments and administered by the Department of Social Services.

Insure Kids Now!

Toll-free: (877) 543-7669

www.InsureKidsNow.gov

The U.S. 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.

Patient Advocate Foundation

421 Butler Farm Rd

Hampton, VA 23666

Tel: (800) 532-5274

Fax: (757) 873-8999

Email: help@patientadvocate.org

www.PatientAdvocate.org

This foundation provides publications, helps with insurance problems, advises on job retention and debt crisis, and gives referrals to attorneys.

Social Security Administration

Toll-free: (800) 772-1213

www.ssa.gov

Contact the Social Security Administration in order to receive disability income for your child.

State of Connecticut Insurance Department Consumer Affairs Division

P.O. Box 816, Hartford, CT 06142

Tel: (860) 297-3900

Toll-Free: (800) 203-3447

Fax: (860) 297-3872

www.ct.gov/cid/cwp/view.asp?q=254350

The Insurance Department's mission is to protect the consumer by administering and enforcing the insurance laws in the most responsive and cost effective manner to ensure the financial reliability of all regulated entities. This website contains information for the consumer on their rights.

The National Association of Insurance Commissioners (NAIC)

1100 Walnut Street, Suite 1500

Kansas City, MO 64108-2662

Tel: (816) 842-3600

Fax: (816) 783-8175

www.NAIC.org

This organization is composed of state insurance regulators from every state, the District of Columbia, and five U.S. territories. They regulate the conduct of insurance companies in each of their respective states.

DRUG REIMBURSEMENT

Centers for Medicare & Medicaid Services – Prescription Drug and Other Assistance Programs (Medicare)

7500 Security Boulevard
Baltimore, MD 21244-1850
Tel: (800) MEDICARE

www.Medicare.gov

The Prescription Drug and Other Assistance Programs section of this website provides information on public and private programs that offer discounted or free medication, programs that provide assistance with other healthcare costs, and Medicare healthcare plans that include prescription coverage

NeedyMeds, Inc.

P.O. Box 219
Gloucester, MA 01931
Help Line: (800) 503-6897
Fax: (206) 260-8850

info@NeedyMeds.com

www.NeedyMeds.com

Many drug manufacturers have what's called Patient Assistance Programs. These programs are designed to help people obtain medicine for low or no cost when they otherwise would not be able to afford it. This website contains the latest, most complete, and most accurate information on patient assistance programs available. The site has a database for "drugs" and "programs."

Partnership for Prescription Assistance (PPA)

Toll-free: (888) 477-2669

www.PPARx.org

The Partnership for Prescription Assistance brings together America's pharmaceutical companies, doctors, and other healthcare organizations to help qualify patients who lack prescription coverage get the medications they need through the public or private program that's right for them. Through this website, PPA creates easy access to more than 475 public and private patient assistance programs, including more than 150 programs offered by pharmaceutical companies.

RxHope Inc.

P.O. Box 42886
Cincinnati, OH 45242
Tel: (877) 267-0517

[Email: CustomerService@RxHope.com](mailto:CustomerService@RxHope.com)

www.RxHope.com

RxHope is a resource for prescription assistance programs. They describe themselves as a helping hand for those struggling to obtain necessary medications.

Together Rx Access, LLC

One Outlet Lane, Suite 107
Bald Eagle Court
Lock Haven, PA 17745
Tel: (800) 444-4106

www.togetherrxaccess.com

With Together Rx Access®, individuals and families without prescription drug coverage can gain access to immediate savings on hundreds of brand-name and generic prescription products right at their neighborhood pharmacies. We also connect you with resources about access to coverage options and more.

FREE AIR SERVICES

Air Care Alliance

2060 State Highway 595
Lindrith, NM 87029
Toll-Free: (888) 260-9707
Fax: (815) 572-9192

Email: mail@AirCareAll.org
www.AirCareAll.org

ACA is a nationwide association of humanitarian flying organizations that provide flights for healthcare, compassion, and community service. Volunteer pilots fly for patient transport, disaster relief, and for other public service missions.

Corporate Angel Network, Inc. (CAN)

Westchester County Airport
1 Loop Road
White Plains, NY 10604-1215
Tel: (866) 328-1313 or (914) 328-1313

Email: info@corpangelnetwork.org
www.CorpAngelNetwork.org

CAN is a nationwide nonprofit program that uses empty seating on corporate jets to fly cancer patients to treatment centers. Their services are free of charge to the patient. 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. CAN will also fly donors. There is no cost or financial need requirements.

Mercy Medical Airlift

The National Patient Travel Center

4620 Haygood Road, Suite 1
Virginia Beach, VA 23455
Patient Helpline: (800) 296-1217
Fax: (800) 550-1767

Email: info@nationalpatienttravelcenter.org
www.PatientTravel.org

Mercy Medical Airlift provides free transportation to medical treatment for those who can't afford the transportation, or tolerate it due to their health. Their website also provides information on similar organizations.

Miracle Flights for Kids

2764 N. Green Valley Parkway, #115
Green Valley, NV 89014-2120

Tel: (702) 261-0494
Toll-Free: (800) FLY-1711
Fax: (702) 261-0497

www.MiracleFlights.org

This organization purchases commercial airline tickets, uses private aircraft, and combines resources from individual donors to provide free transportation to medical treatment centers all across America. Visitors may contact the organization via its website, and the flight coordinator through the email address FlightCoordinator@MiracleFlights.org.

Patient AirLift Services

120 Adams Boulevard
Farmingdale, NY 11735

Tel: 888-818-1231

www.palservices.org

E-mail: info@palservices.org

Patient AirLift Services covers flights in the entire northeast United States as far west as Ohio and as far south as Virginia for patients who must travel great distances for treatment or are too fragile to endure a regular flight.

Bandaides and Blackboards

Refer to the “Resources for Teens” section for more on this organization, and its contact information.

Candlelighters Childhood Cancer Foundation

Refer to the “Pediatric Healthcare and Cancer Organizations” section for more on this organization, and its contact information.

Cells Alive

Contact: Jim Sullivan

Email: cellsalive@gmail.com

www.CellsAlive.com

This website is helpful for explaining cells to older elementary and teenage students. There is a colorful slide presentation with images that may be used in the classroom. The website addresses the cellular aspects of cancer.

Children’s Brain Tumor Foundation

Refer to the “Pediatric Healthcare and Cancer Organizations” section for more on this organization, and its contact information.

Connecticut State Department of Education

165 Capitol Avenue

Hartford, CT 06106

Tel: (860) 713-6543

www.sde.ct.gov

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

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 normal activities, including attending school. Informative videos and literature are available through The Leukemia & Lymphoma Society. Refer to the “Pediatric Healthcare and Cancer Organizations” section to learn more about The Leukemia & Lymphoma Society.

National Dissemination Center for Children with Disabilities

Refer to the “Pediatric Healthcare and Cancer Organizations” section for more on this organization, and its contact information.

Outlook

Refer to the “Insurance Help” section for more on this organization, and its contact information.

The Learning Foundation of Fairfield Country

1109 Brookside Drive

Fairfield, CT 06824

Tel: (203) 520-2070

Email: susan@LearningFoundation.net

www.learning-foundation.net

Susan Bemus provides tutoring and educational consulting to families of children with learning issues. Her services range from evaluation, testing, IEP and 504 plan review and development, tutoring and social skill workshops. Her background as an educator

SCHOOL RELATED ISSUES

and work in special education, as well as her personal experience with pediatric cancer, make her an invaluable resource for families of children facing back to school issues. She can assist families who wish to work with their child's school to develop a good working home-school relationship, which the patient will benefit from.

For more information on organizations and resources that aid in the process of reintegrating into school, please refer to the "Books/Printed Materials" section.

American Cancer Society (ACS) Cancer Camps

www.Cancer.org

ACS sponsors free camps for children who have, or had, cancer. These camps are equipped to handle the special needs of children undergoing treatment, or are in remission. Contact the local ACS office in your area to learn more about the camps. Individual camps will have more information about specific dates for the camp sessions.

Refer to the "Pediatric Healthcare and Cancer Organizations" section for more on the ACS, and its contact information.

Camp Mak-a-Dream

P.O. Box 1450

Missoula, MT 59806

Tel: (406) 549-5987

Fax: (406) 549-5933

Email: Camp@Montana.com

www.CampDream.org

Camp Mak-a-Dream is operated by Children's Oncology Camp Foundation and is a free, medically supervised camp for cancer patients (ages 6-25) and their siblings (ages 6-17). Their facilities include modern cabins, fully accessible pool, art studio, health center, archery range, and more.

Camp Rising Sun Charitable Foundation

P.O. Box 472

Branford, CT 06405

Tel: (203) 481-7277

Fax: (203) 654-7886

Email: info@camprisingsun.com

www.CampRisingSun.com

Sponsored by the American Cancer Society, this camp was created for children diagnosed with cancer. Children attend the camp for free, and all staff members are dedicated volunteers that show compassion and concern for the child's well-being and enjoyment of life. Located on the shores of Triangle Lake in the Northwestern hills of Connecticut, Camp Jewell YMCA offers modern, heated cabins with fireplaces, carpeting and lounges, waterfront with sandy beaches, 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. The camp has a pediatric oncologist and three nurses on campus on duty 24 hours a day, 7 days a week.

Camp Simcha

151 West 30th Street

New York, NY 10001

Tel: (877) CHAI LIFE

Email: info@chailifeline.org

www.CampSimcha.org

Since 1987, Camp Simcha has been a pioneer in kosher camps for children with cancer and other medically catastrophic illnesses. The grounds are located in Glen Spey, NY on the Jack and Moishe Horn Campus, which spans 125 acres. The camp runs two-week sessions for persons (ages 5-20) that come from throughout North America, Europe, and Israel who have encountered serious illness.

Camp Simcha

Summer Address/Contact Information
The Jack and Moishe Horn Campus
430 White Road
Glen Spey, NY 12737
Camp Office: (845) 856-1432
Camp Fax: (845) 858-8388
General Email: camp@chailifeline.org
Email: info@chailifeline.org

Camp Sunshine

35 Acadia Road
Casco, ME 04015
Tel: (207) 655-3800
Fax: (207) 655-3825
Email: info@CampSunshine.org
www.CampSunshine.org

This is the only camp 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 weeklong camp sessions, which includes meals, on-site medical services, counseling services, and recreational activities. While at camp, each family stays in a private suite, and is sponsored by an individual, civic group, corporation, or foundation. This enables them to attend camp for free.

Children's Oncology Camping Association International (COCA-I)

P.O. Box 7553
Augusta, GA 30357
Tel: (404) 661-5753
Email: west@cocai.org
www.cocai.org

COCA-I is an international assembly of people and over 65 camps providing programs for children with cancer. Camps are located in

the USA, Canada, Australia, New Zealand, and Europe.

First Descent World HQ

767 Santa Fe Drive
Denver, CO 80204
Tel: (303) 945-2490
Fax: (303) 474-3005
Email: info@FirstDescents.org
www.FirstDescents.org

First Descents is a free, Seven-day kayak camp for young adults ages 18 or older with cancer. Started by professional kayaker and Nike ACG athlete, Brad Ludden, the organization uses kayaking and other outdoor activities to help campers face challenges and overcome obstacles in preparation for those posed by cancer. In 2009, the program won The Cancer Fighters Award.

Hole In The Wall Gang

565 Ashford Center Road
Ashford, CT 06278
Tel: (860) 429-3444
Fax: (860) 429-7295
Email: Ashford@HoleInTheWallGang.org
www.HoleInTheWallGang.org

The Hole in the Wall Gang Camp, founded by Paul Newman in 1988, is a nonprofit residential summer camp. It is 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 (ages 7-15) from across the country and abroad attend each year for free. The camp also offers a week for siblings in the summer.

Joseph's Journey

P.O. Box 150453

Lakewood, CO 80215-0453

Tel: (303) 989-5710

Email: JosephsJourney@aol.com

www.JosephsJourney.org

Inspired by their young son's ambitions, hardships, and endurance, Joseph's parents founded this camp. Because of Joseph's dream to embark on a caribou hunt was left unfulfilled—the investments for which (a box of pocket change) his parents found after his death—this camp is dedicated to providing wilderness experiences to children with life-threatening illnesses. Their adventures include hiking, fishing, camping, hunting, climbing, and are led by experienced, qualified guides.

The Okizu Foundation

16 Digital Drive, Suite 130

Novato, CA 94949

Tel: (415) 382-9083

Fax: (415) 382-8384

Email: info@Okizu.org

www.Okizu.org

Okizu is committed to the continuing support of the Oncology and Siblings camping programs. Their mission is to provide peer support, respite, mentoring, and recreational programs to meet the needs of all family members. They offer a variety of camps for kids, teens, young adults ages 18 or older, siblings, and families.

Silver Lining Ranch

Little Star Foundation

Little Star Foundation

256 Rancho Milagro Way

Hesperus, CO 81326

Toll-Free: (800) 543-6565

Email: info@LittleStar.org

www.LittleStar.org

The Benedict-Forstmann Silver Lining Ranch program is home for up to twenty children per 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 24 hours per day.

Lighthouse Family Retreat

45 Technology Parkway South, Suite 225

Norcross, GA 30092

Tel: (678) 290-2955

Email: info@lighthousefamilyretreat.org

www.lighthousefamilyretreat.org

NOTES

WISH FULFILLMENT ORGANIZATIONS

Believe in Tomorrow Children's Foundation

6601 Frederick Road
Baltimore, MD 21228

Tel: (800) 933-5470

Fax: (410) 744-1984

info@BelieveInTomorrow.org

www.BelieveInTomorrow.org

Previously known as Grant a Wish, this organization is a national children's charity that provides supportive services to children (ages 0-17) who are battling life-threatening illnesses.

Children's Hopes and Dreams - Wish Fulfillment Foundation

138 Cloudland Rd

Dahlonega, GA 30533

Tel: (706) 482-2248

Fax: (706) 482-2289

www.HelpingNow.org

This organization serves over 14,000 seriously ill children each year. Fulfillment of wishes has 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: (770) 393-WISH

Toll-Free: (800) 323-WISH

E-mail: Jacque Niles

Jniles@ChildrensWish.org

www.ChildrensWish.org

This foundation has fulfilled the wishes of children (ages 18 and younger) with life-threatening illnesses in 32 countries around the world. For children too young to express their wishes, the organization's Young Minds Program can help determine what their wishes might be.

The Marty Lyons Foundation, Inc.

326 West 48th St, New York, NY 10036

Tel: 212-977-9474

Fax: 212-977-1752

www.martylyonsfoundation.org

Mary Ann Canapi, Executive Director

mac@martylyonsfoundation.org

E-mail: Wanda Pichardo

wpichardo@martylyonsfoundation.org

The Marty Lyons Foundation, Inc. (MLF) is a not-for-profit, tax-exempt 501(c) (3) organization established to fulfill the special wishes of children who have been diagnosed with a life-threatening or terminal illness. The wish applicants must reside or treated in the following geographic areas – Connecticut, Florida, Georgia, Maryland, Massachusetts, New Jersey, New York, North Carolina, Pennsylvania, South Carolina and Texas. MLF provides a 1st wish and a 2nd wish. The 2nd Wish Program is for children who have received a first wish 24 months prior and have exhausted all medical options and are essentially at end-of-life stage or receiving hospice care.

WISH FULFILLMENT ORGANIZATIONS

Make-a-Wish Foundation of America CT Chapter

126 Monroe Turnpike
Trumbull, CT 06611
Tel: (203) 261-9044
Toll-Free: (877) 203-9474
Fax: (203) 268-2168

Email: Conn@CT.Wish.org

Email: nancydiehi@ctwish.org

www.Wish.org

The Make-A-Wish Foundation has enriched the lives of children with life-threatening medical conditions through its wish-granting work since 1980. The foundation's mission reflects the life-changing impact that a Make-A-Wish experience has on children, families, referral sources, donors, sponsors and entire communities. This chapter grants wishes to children (ages 0-18) with life-threatening illnesses throughout the state of Connecticut.

Sunshine Foundation

1041 Mill Creek Drive
Feasterville, PA 19053
Tel: (215) 396-4770
Fax: (215) 396-4774

Email: Philly@SunshineFoundation.org

www.SunshineFoundation.org

This foundation grants wishes to chronically or terminally ill, physically challenged, and abused children (ages 3-18) across the country

The Starlight Children's Foundation NY – NJ – CT

1560 Broadway Suite 600
New York, NY 10036
Tel: (212) 354-2878

Email: info@StarlightNYC.org

www.Starlight-NewYork.org

*The mission of the Starlight Starbright Children's Foundation NY*NJ*CT is to brighten the lives of seriously ill children, and their families, through imaginative and resourceful programs and services that empower, educate and inspire. Each year, this foundation serves over 250,000 critically, chronically and terminally ill children throughout New York, New Jersey and Connecticut.*

Dream Come True of Western Connecticut, Inc.

PO Box 2415
Danbury CT 06813
Tel: (203) 790-7333

Email: dreamcometruect@yahoo.com

www.dreamcometruect.org

Dream Come True of Western Connecticut was founded in 1984 with one purpose in mind: to grant dreams to seriously, chronically, and terminally ill children from Fairfield, Litchfield, and New Haven counties. Some dreams that have been granted include trips to Disney World, meeting celebrities, skydiving, and shopping sprees.

WIGS AND ACCESSORIES

HotLids

Email: HotLids@yahoo.com

www.HotLids.com

This website has hundreds of styles for hats, and more in their Kids Lids section. HotLids.com also offers personalized hats and hat making kits. They work well as party favors, or as an activity during parties. It's a fun and creative way to cope with losing your hair. The kits contain fun, child-safe arts and crafts supplies for creating one hat. Kits are assorted, but will contain fabric markers, ribbons, patches, glue, kid's scissors and one hat of your choice. For every twenty hats sold, one hat is donated to a child through the American Cancer Society.

Locks of Love

234 Southern Boulevard
West Palm Beach, FL 33405

Tel: (561) 833-7332

Toll-Free: (888) 896-1588

Fax: (561) 833-7962

Email: info@LocksOfLove.org

www.LocksOfLove.org

Locks of Love provides high quality hair pieces to financially disadvantaged children (ages 0-18) suffering from long-term medical hair loss as a result of any diagnosis.

Wigs for Kids

24231 Center Ridge Road

Westlake, OH 44145

Tel: (440) 333-4433

Fax: (440) 835-1084

Email: info@WigsForKids.org

www.WigsForKids.org

Wigs for Kids is a nonprofit organization that provides hair replacement solutions for children affected by medical hair loss.

Hip Hats with Hair

4707 North Nebraska Avenue

Tampa, FL 33603

Tel/Fax: 1-877-447-4287

Email: info@hatswithhair.com

www.hatswithhair.com

Hip Hats with Hair are a more comfortable, versatile, and cost effective way to deal with hair loss. Only soft, stretchy fabric touches your head. Hats can even be made with your own hair!

BOOKS / PRINTED MATERIALS

The following publications can be found at libraries, bookstores or on the Internet. Most of these publications are available new or used at Amazon.com, BarnesAndNoble.com, or Chapter.Indigo.Ca. ISBN identification codes are provided for publications that have them to make online searching easier. When using an ISBN code, no other search criteria is needed. Additional book sources for children with cancer are www.CancerKids.com and www.CureSearch.org

Books for Patients

Armfuls of Time:

The Psychological Experience of the Child with a Life-Threatening Illness.

by Barbara M. Sourkes, PhD.

University of Pittsburgh Press, 1996.

ISBN 0822955652

This book reviews the general psychological effects of cancer and explains the therapeutic process.

This resource book provides practical advice for children diagnosed with cancer. Funny illustrations and easy 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. It offers tools and journal space to help children deal with the physical and emotional impacts of the cancer and the treatment. (Ages 6-12)

Cancer Patient Workbook:

Everything You Need to Stay Organized and Informed.

by Joanne Willis and Diane Blumenson

ISBN 0789467828

This interactive guide helps cancer patients stay organized with treatment tips, laymen's explanations of medical terms and treatments, inspirational and humorous insights. Their worksheets help track doctor visits, use of medication and organizations to contact.

Chemo Girl: Saving the World One Treatment at a Time

by Christina Richmond

Jones & Bartlett, 1997, 24 pages

ISBN: 0763703141

This fictional tale of a superhero, with cartoon-like illustrations, was written to help children cope with chemotherapy treatments. It presents a positive, non-threatening side of chemotherapy and a sense of hope. (Ages 4-8)

Chemo, Craziiness & Comfort: My Book About Childhood Cancer

By Nancy Keene and Trevor Romain

Candlelighters Childhood Cancer Foundation, 2002

ISBN: 0972404309

www.Candlelighters.org

Childhood Leukemia

Helping Your Child in the Hospital

Working with Your Doctor

A Parent's Guide to Solid Tumor

Cancers

All by Nancy Keene

Nancy Keene wrote the books above. She is a renowned writer in the field of childhood Cancer. As the mother of a cancer survivor, she took her experience and melded it with over one hundred other families' to produce very informative guides for families of children with cancer.

Fuzzy and Frankie

by Susan Murray
Goetz Printing Co.
ISBN: 91-60256

Department of Hematology/Oncology
Children's National Medical Center
111 Michigan Avenue, NW
Washington, DC 20010-2970
Tel: (202) 745-2140

This story is told from the unique perspective of a teddy bear, Fuzzy, belonging to a sick boy named Frankie. Fuzzy is going to the hospital with Frankie, when Fuzzy realizes from the grim faces around him that something is very wrong with his friend. 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. Soon, Frankie gets well, and he is able to go home. The book is also full of beautiful illustrations. (Ages 8-11)

Going to the Hospital.

By Fred Rogers
G.P. Putnam's Sons, 1997
PBS's "Mr. Rogers" introduces children to hospitals in this book. (Ages 3-8)

Henry and the White Wolf

By Tyler and Tim Karu
Workman Publishing, 2000
ISBN: 0761121358

Teenaged brother and sister, Tim and Tyler, wrote this allegory about a sick hedgehog that is healed by the feared white wolf. Geared up to help children cope with the physical discomforts and fears of prolonged medical treatments, this book can also be useful to children whose parents and friends are ill. A stone, which is used as a symbol in the story, comes with the book for children to grip during hard times. (Ages 4-8)

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

By Jason Gaes
Melius & Peterson Publishing Corp, 1987
524 Citizens Building
Aberdeen, SD 57401
ISBN: 0-937603-04-X

In his autobiography, Jason Gaes encourages kids to have a positive attitude, and stresses the fact that not all kids with cancer die. He gives advice on how to get through injections, nightmares, treatments and side effects of all sorts. He describes how his Uncle discovered Jason's 'cancer' and the entire process of the cancer treatment. He gives his opinions on the different types of treatment and medicines that he took over the duration of his cancer. He also tells kids about what he thinks are the positive side of cancer and having no hair. As a survivor of cancer, Jason's perspective is genuine. The book is appropriate for children suffering from cancer, who are afraid and have many difficult questions to ask and to answer.

While the book does touch on religion, it also sends a general message accessible to everyone. (Ages 7-14)

Some Things Change and Some Things Stay the Same

By Fred Rogers

The American Cancer Society, 1989

Tel: (800) ASC-2345

This book reassures children with cancer that it is okay to express their feelings as their lives change. The book lets children know that some of the changes they experience will be hard, and sometimes they will need to cry or hold a loved one's hand. It shows children that they can become used to the hospital environment, around their new friends, caring doctors and nurses. Most of all, this book lets children know that they can still enjoy certain things, and make them aware of the support provided by their loved one's. (Ages 7-12)

Stevie's New Blood

By Kathryn Ulberg Lilleby

Illustrator: Chad Chronick

Oncology Nursing Press, 2000

ISBN: 1890504173

www.ONS.org/publications/books

Stevie is undergoing a bone marrow transplant 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 stem cell transplantation from a child's perspective. The book is adaptable to different age groups, to children whose parents are undergoing a transplant, or to the friend of a child undergoing one. (Ages 4-8)

The Amazing Hannah: Look at Everything I Can Do!

By Amy Klett

Friends of Hannah Klett and Growing Hope, 2001

www.acco.org

This story was 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. (Ages 1-6)

The C Word: Teenagers and Their Families Living with Cancer.

By Elena Dorfman

NewSage Press, 1993

ISBN: 093916521X

Five teens with cancer, their families, and best friends are interviewed. They share how the disease affected their lives. Both fears and realities concerning relationships and chemotherapy are addressed with frankness. Patients and their loved ones should be comforted by the similarities of shared experiences. Students researching for reports, as well as general readers, are provided with an opportunity to more deeply understand how a life is altered by serious disease.

Teenagers Face to Face with Cancer

by Karen Gravelle and Bertram A. John

1986, ISBN 0-671-545493

In this book, sixteen teenagers describe their experiences with cancer and how they deal with family, friends, and school while coping with their illness. These teenagers describe how they felt when they were diagnosed and

how they felt with various forms of treatment, ranging from chemotherapy to amputation of a limb. Each teenager shares how he or she feels about their plans for the future, and coming to terms with the fact that they might die. In the end, they feel that their battle with cancer has left them stronger in various ways.

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

by Karen Sue Foss

Centering Corporation, 1996.

ISBN 1561230995

This is the account of a group of friends, and how they must cope with one of them undergoing cancer treatment and losing their hair.

They Never Want to Tell You: Children Talk About Cancer.

by David J. Bearison,

Harvard University Press, 1991.

ISBN 0674883705

Bearison, a developmental psychologist and psychotherapist, is aware of the psychological impact of cancer on children, particularly as the battle with cancer continues and complex treatments intensify. The concern eventually becomes about the emotional wellbeing of children, and not just their physical improvement. This book transcends the negative metaphors and clichés of life-threatening disease to give voice to the culture of cancer, and to the behavior and attitudes of patients, medical professionals, family, and friends functioning within that culture. In the course of these stories, the children reveal not

only their will to survive and their extraordinary capacity to understand themselves under their condition, but also their altruistic desire to share that understanding with other children and adults with cancer. They Never Want to Tell You is rich and rewarding reading for cancer patients, their families, and healthcare professionals alike.

When You Have An Operation On Your Head or Back

by Henrietta Egleston Hospital Nursing Staff
Egleston Hospital

1405 Clifton Road, NE

Atlanta, GA 30322

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

Oncology Stupology... I Want to Go Home!

By Marilyn Hershey

This funny and brightly colored book shows the true emotional frustration that children can experience while undergoing cancer treatments. Appropriate for children of all ages. Fun illustrations make the material even more accessible for children.

When Someone You Love Has Cancer

by Alaric Lewis

This book shows kids what feelings they might have when a family member has cancer, and has step by step realistic outcomes. Fun illustrations make the material even more accessible for children.

What's My Line

By Jennifer Gretzema

This book features Chris, a kid who has a secret: He has a central line. Kids interact with three-dimensional Chris, and learn about what a central line is, what it does, how it works, and how to care for it.

Why am I ImPORTant

By Jennifer Gretzema

This book also features Chris, a kid who has a port. Through interacting with a pop-up Chris, kids learn what a port is, what it does, how it works, and how to care for it.

Home in Time for my Birthday

By Lynn Ducoff Belkin

A book about a six year old girl with a brain tumor, written by a cancer survivor. It explains her treatments in a way that kids can understand, and has fun illustrations.

BOOKS FOR SIBLINGS

Hi, my name is Jack

By Christina Beall-Sullivan

www.HiMyNamesJack.com

This book for children addresses the issues encountered by the healthy siblings of chronically ill, disabled or dying children. These issues include loneliness, anger, worry, jealousy, and guilt. This book does not specify the illness being experienced by the ill child, allowing it to focus on the healthy siblings and their feelings.

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

By Michael Dodd

Published by Candlelighters Childhood Cancer Foundation, 2004

ISBN: 0972404341

www.Candlelighters.org/BooksKids.stm

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. Get a free copy through the Candlelighters National office. (Ages 4-10) Refer to the "Pediatric Healthcare and Cancer Organizations" section for more on this organization, and its contact information.

What About Me? When Brothers or Sisters Get Sick.

By Alan Peterkin

Magination Press, 1992.

ISBN 0945354495

Finding out a brother or sister has cancer is very difficult. This booklet describes how other teens dealt with this tough time. It shows ways teens can help themselves and their families, provides information about cancer treatments, ways to learn how to cope, as well as where to go for more support. (Ages 4-8)

Why Charlie Brown, Why?

By Charles Schultz

Tel: (800) 955-4572

This story is about a child whose friend has cancer. It comes highly recommended for younger school-age children. It is excellent for the child's schoolmates and other groups to be familiar with before your child returns to regular activities. It can be found through the Candlelighters Childhood Cancer Foundation, or the Leukemia & Lymphoma Society. Refer to the "Pediatric Healthcare and Cancer Organizations" section for more on this organization, and its contact information.

SCHOOL RELATED BOOKS

Educating the Child with Cancer, a Guide for Parents and Teachers

Tel: (800) 366-2223

www.aceo.org

This is an essential resource for families who have faced a childhood cancer diagnosis. Written by top researchers in the field, and balanced with parent's personal experiences, this resource of 322 pages covers learning issues from infancy through adulthood. One free copy is available to families of children with cancer and one for the child's teacher.

James Bounces Back

By Debra Giugliano Trezza

Illustrator: Daisy Doahnos

ISBN: 0-972-6425-1-X

James Bounces Back is an educational book for boys diagnosed with cancer and their classmates. It may be ordered through the School Re-entry Program at Stony Brook University Hospital. To contact this program, call (631) 444-7720.

Negotiating the Special Education Maze: A Guide for Parents and Teachers

By Winifred Anderson, Stephen Chitwood, and Deirdre Hayden

Woodbine House, 1997

ISBN: 0933149727

Now in its third edition, this book is one of the best tools available to Parents and teachers for developing an effective education program for their child or student. Every step is explained, from eligibility and evaluation to

the Individualized Education Program (IEP) and beyond. This edition covers changes in disability laws, including the Americans with Disabilities Act (ADA) and Individuals with Disabilities Education Act (IDEA). It reviews early intervention services for children from birth to age three; and, for those who have young adults with special needs, it also covers transitioning out of school.

Trish Greene Back-To-School program for Children with Cancer

The Leukemia & Lymphoma Society

Tel: (800) 955-4572

www.LLS.org

This book provides information on how to increase communication among healthcare professionals, parents, patients and school personnel to assure youngsters a smooth transition from active treatment back to school.

Refer to the "Pediatric Healthcare and Cancer Organizations" section for more on the Leukemia and Lymphoma Society, and their contact information.

VIDEOS

Back to School for Teens

The Starlight Children's Foundation

Tel: (800) 315-2580

www.Starlight.org

When patients go back to school after a long absence, they can be scared, nervous, even excited. And, they're not alone. This video shares teens' stories and their advice for returning to school in a documentary fashion. Refer to the "Resources for Parents" section for more on this organization, and its contact information.

I'm Still Me!

The Leukemia & Lymphoma Society

Tel: (800) 955-4572

www.LLS.org

This video is for children with cancer and their classmates. It includes a guide for medical personnel and teachers. The overarching goal of I'm Still Me!, however, is to help children with leukemia and other cancers successfully reintegrate into the classroom after their diagnosis and during their treatment.

My Hair's Falling Out... Am I Still Pretty?

ASIN: 0965083209

This Childhood Cancer Education Video is a fictional, solo performance, which tells the story of a young girl who is diagnosed with leukemia, undergoes hospitalization and chemotherapy. She then returns to school with her cancer in remission. Although the story deals with difficult issues, it remains upbeat, and clearly portrays accurate information about hospitals and cancer, while remaining suitable for school-age children.

Plastic Eggs or Something!?:

Cracking Hospital Life

The Starlight Children's Foundation

Tel: (800) 315-2580

www.Starlight.org

Teenagers dealing with a serious illness, probably have a lot of questions. This video gives the inside scoop on what other kids have experienced. In this video, teens get the straight story on everything from communicating with hospital staff to making themselves as comfortable as possible in the hospital environment. (Ages 10-18)

Refer to the "Resources for Parents" section for more on this organization, and its contact information.

Long-Term Effects of Childhood Cancer Treatment

www.CancerSurvivorChild.org

This site provides overviews of the essential components of physical concerns, psychosocial care, and future issues that a survivor, his or her family, and healthcare provider need to consider. It also provides personal stories of the survivors.

National Coalition for Cancer Survivorship (NCCS)

1010 Wayne Avenue, Suite 770
Silver Spring, MD 20910

Tel: (301) 650-9127

Toll-Free: (888) 650-9127

Fax: (301) 565-9670

Email: info@CancerAdvocacy.org

www.CancerAdvocacy.org

This organization addresses the needs of long-term cancer survivors, and advocates for change in healthcare to maximize the survivor's access to optimal treatment and support. It also provides an extensive list of helpful publications.

Heros Clinic

Yale New Haven Children's Hospital

20 York Street

New Haven, CT 06510

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 and enjoy healthy, active lifestyles; however, they are left at an increased risk for subsequent neoplasms, congestive heart failure, osteoporosis, decreased fertility, PTSD, and learning disabilities. This clinic was established to exclusively help children and adults who were treated for cancer over five years ago. Patients are seen twice a month to supplement care given by their primary doctors.

For more information and a pamphlet call (203) 688-2000, or toll-free (888) 700-6543.