



Circle of Care
for families of children with cancer

The Purple Pages

Directory of Resources and Services

7th Edition

www.thecircleofcare.org

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

- Dr. Joseph McNamara

Circle of Care

for families of children with cancer

PO Box 32, Wilton CT 06897

203-663-6893

info@thecircleofcare.org

www.thecircleofcare.org

Our Story

Our story began with the words that no parent ever wants to hear: “Your child has cancer.” And anyone who has heard those words will agree...once you’ve heard them, your life is never the same. We’ve been there. We’ve felt what you’re feeling now, and we remember. Your life has been turned upside down, and you have more questions than you’ve ever had before. You’re overwhelmed. And uncertain. And scared. We quickly learned the tremendous impact that cancer has on your normal routine. Our sons, Carlos and Dan, were then ages three and ten, and luckily, we found each other in a support group for moms and siblings of children with cancer. We didn’t know what to expect, but we were both seeking comfort, knowledge, and a way to make sense of our new “normal.” We found that comfort in each other.

After all the tears and occasional laughter through the years of treatment, we knew we had to give back and share what we had learned so we could help those just beginning this difficult and often lonely journey. That is when Circle of Care was born. And that’s why we created this book.

The Purple Pages directory is a compilation of the many wonderful resources available to families of children with cancer -- on the Internet, in print, and in videos. We have sorted the resources into chapters based on different important topics 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.

The Purple Pages are just one of the many ways that Circle of Care will help you through your child’s cancer journey. We invite you to visit our website at www.thecircleofcare.org to find out about the many programs available to you. From a day of diagnosis bag filled with essentials to hospital and treatment center volunteers; from telephone peer support to dream room makeovers for your child and even emergency financial aide for families with critical financial needs, Circle of Care is here to help.

One final thought...while the resources in this book can be incredibly helpful, some information found on the Internet or in printed materials can be misleading, out of date, or simply not accurate. We will lead you to the best resources that we have found, but because each child’s diagnosis is unique in its own way, we suggest that you always speak with your child’s doctor.

Until no family has to hear the words, “your child has cancer,” we will be here for you.

Liz & Dawn
Founders

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NOTES



Carlos, diagnosed at age 2 1/2, is soon to graduate high school.

YOUR CHILD HAS JUST BEEN DIAGNOSED

FOR PARENTS

This resource guide includes invaluable information, compiled by people who faced the same situation that you are facing now. They, too, found themselves as parents of children diagnosed with cancer. No one can take this journey alone, and no one **SHOULD** take it alone. This book is full of information that has been gathered and edited carefully for different stages of treatment. Although we have broken the information down into sections, many have found it helpful to peruse all of the resources.

This first section is designated for parents, and contains useful sites – from those that enable you to set up a schedule for people to assist you (Lotsa Helping Hands) to camps for your child, siblings and even you! We are confident that you will find information in this guide that will point you in the right direction so that you may find the answers to many of your questions. At the beginning of each section, you will find one or two helpful tips from parents, and then you will be directed to our website where you will find additional information and parent tips. It may feel overwhelming. Take it day by day. And use this resource guide to help you through those tough days when you just wish you could find an answer. We have culled the knowledge from hundreds of parents who have been in your shoes, and if there is one common thread through all of their comments, it is “Wow, I wish someone had told me that.”

If you discover a gap somewhere in our resources, please call Circle of Care and let us know! We want our guide to be as thorough as possible and we welcome your suggestions. Although you may feel alone and blindsided by this diagnosis, we are here to help in whatever way we can.

TALKING TO YOUR CHILD ABOUT CANCER

Talking about illness is hard. Talking about illness to a child is even harder. The most important piece of advice that all parents offered when asked about how they handled speaking to their child about cancer, was to keep it simple, and only address the issue at hand. Young children don’t need to know what is going to happen on a long-term basis. They **DO** need to know what to expect in the short-term. Another piece of advice was to “accept what is happening today and be as positive as possible.” You might be dealing with anything from shots, shunts and nausea to long periods of bed rest in a hospital. Stay positive. Children will follow your lead. If you let them know that this situation is **NOT** forever, they will accept that. You should, too.

KEEPING EVERYONE INFORMED/ACCEPTING HELP

We live in a connected age. Facebook, Snap Chat and Instagram are the obvious ways to keep people informed. Parents react in various ways to stressful situations. By keeping people informed with **ONE** site, rather than through several channels, everyone who is interested can know what is happening as often as you care to tell them. Caringbridge.com is a **FREE** website that can keep friends and family informed.

YOUR CHILD HAS JUST BEEN DIAGNOSED

It is inevitable that you will need help. Whether it's help getting your other children to and from school and activities, or help with meals or cleaning, you should accept the assistance of others. Lotsahelpinghands.com is another FREE website that lets you list things you need help with – babysitting, rides, meals, sitting with your child during treatments – and allows friends to sign up for tasks on a common calendar. Visit the Circle of Care website at www.thecircleofcare.org to find other tips from parents who found ways to find help when the situation was overwhelming.

TAKING CARE OF YOU

“Be kind to yourself. Get enough sleep, eat properly and exercise! You are experiencing one of the greatest trials a parent can experience. Pamper body and spirit.”

Although it may seem as if all attention should be on the sick child, we are here to tell you that NEVER works for long. It is well documented that you as a person must be as centered and calm as you can before you can help others. It's OK to take time for yourself. Circle of Care was formed over 12 years ago by moms with children who had been diagnosed with cancer and met in a local support group. Finding the right group for you, whether a local group or one online, can literally change your life. We can think of no reason more compelling than this to find a support group! Our newly formed Circle of Care Parents Facebook Group is a place to ask and answer questions. Other ideas are to keep a journal with you (you will find one in your Bag of Love) or use the pages at the end of this resource guide. Sometimes simply jotting down how you are feeling can get you through a rough spot. Don't be afraid to cry when you need to, or allow yourself to laugh. Letting your emotions out is healthy. There are many other tips on our website.

DEALING WITH THE UNEXPECTED

Every child responds differently to treatment, so planning ahead as much as possible allows you to feel better prepared for unexpected challenges. It helps to keep a suitcase packed for emergencies and routine hospitalizations. A favorite stuffed animal or blanket to comfort your child can ease the stress of a late night trip to the ER. Keep your medical journal up-to-date with all the medications your child has received and any side effects. This will avoid confusion in case of an emergency. *It can also help to talk to other families whose child has had a similar diagnosis.* Join our Closed Facebook Parents Group or call us to be connected to another family. “It's a good idea to pack a bag for both you AND your child and keep it ready and in the car. If you have to go to the hospital unexpectedly, the last thing you want to do is pack.” Two simple ways to make this difficult time just a little bit easier:

- 1) Be as prepared as you can be and then let the rest of it go.
- 2) Let “They are doing the best they can, and so am I” be your mantra.

We love this quote from a mom: “My husband and I are closer now and even happier than before this happened. I can't believe that one myself.”

RESOURCES FOR PARENTS

CancerCare, Inc.

275 Seventh Avenue
New York, NY 10001
Toll-Free: (800) 813-HOPE (813-4673)

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:

111 East Avenue, Suite 207

Norwalk, CT 06851

Tel: (203) 854-9911

Email: ctinfo@cancercare.org

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, medication usage, and organizations to contact.

CancerQuest

2031 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.

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.

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 up-to-date on their relative's health.

RESOURCES FOR PARENTS

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 100 other families' stories to produce very informative guides for families of children with cancer.

Lotsa Helping Hands

118 North Peoria Street, Third Floor
Chicago, IL 60607

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 others who 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.

Nannies as Needed

243 Broad Street

Milford, CT 06460

Tel: (203) 874-4939 or (860) 992-3280

nanniesasneeded@aol.com

This company offers premier babysitting service, providing temporary, short term and emergency childcare services. They don't take HUSKY insurance, but they offer somewhat affordable fees. They are flexible and can respond to last minute/same day requests. The cost for an annual membership is \$75, which is a one-time fee. The fee per hour is \$18.

Supersibs!

(Part of Alex's Lemonade Stand)

660 N. First Bank Drive

Palatine, IL 60067

Tel: (847) 462-4742

Fax: (847) 984-9292

info@supersibs.org

www.alexslimonadestand.org/campaign/supersibs

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 that provides support for their unique needs. SuperSibs! Helps children redefine the "cancer sibling" experience by providing support services, and by helping to draw out the greater and important lessons that may benefit these children later in their lives.

RESOURCES FOR TEENS AND YOUNG ADULTS

Being diagnosed with cancer sucks. Yes, we know. You already know that. But perhaps you don't know that you can get tips on style and make-up (Look Good...Feel Better) OR meet someone across the United States with your diagnosis and chat (Teens Living with Cancer). There are some things that can make your journey easier and, (dare we say it?) even interesting at times. No one can go through this without learning things and not all of them are bad. This section can help you navigate some of the things that will be coming down the road and offer a bit of diversion along the way. Please reach out to people. If you have something you think we need to add to this guide, do tell us; that way, the next teen won't have to!

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.

Cancer Care Young Adult Services

www.cancercare.org/tagged/young_adults

CancerCare provides free, professional support services for young adults affected by cancer, as well as cancer information and additional resources. Services include: counseling, support groups and educational telephone and online workshops.

Cancer Kids

www.CancerKids.org

Cancer Kids provides 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.

Fertile Action

(877) 276-5951

fertileaction.org

Fertile Action is a cancer charity working to ensure fertile women impacted by the disease can become mothers. They provide empowering education to patients and physicians, and offer fertility scholarships on a sliding-scale basis.

RESOURCES FOR TEENS AND YOUNG ADULTS

Livestrong Fertility

livestrong.org

If you want to become a parent after cancer, we have the tools and resources to help. LIVESTRONG Fertility is dedicated to providing educational information and access to resources that support cancer patients and survivors whose cancer and its treatment present risks to their fertility. Through the LIVESTRONG Fertility Discount Program, cancer survivors can access discounted rates on fertility preservation services.

Look Good...Feel Better

Tel: (800) 395-LOOK

www.lookgoodfeelbetter.org/2bme

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.

Planet Cancer

Email: ContactUs@PlanetCancer.org

livestrong.org/we-can-help/young-adults

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.

Stupid Cancer

40 Worth Street, Suite 808

New York, NY 10013

Tel: (877) 735-4673

Email: contact@stupidcancer.org

www.stupidcancer.org

Stupid Cancer, is the largest charity that comprehensively addresses young adult cancer through advocacy, research, support, outreach, awareness, mobile health and social media. Their innovative, award-winning and evidence-based programs and services serve as a global bullhorn to propel the young adult cancer movement forward

Teenagers Face to Face with Cancer

by Karen Gravelle and Bertram A. John

1986, ISBN 0-671-545493

In this book, 16 teenagers describe their experiences with cancer and how they deal with family, friends, and school while coping with their illnesses. These teenagers describe how they felt when they were diagnosed and how they felt with various forms of treatment, ranging from chemotherapy to limb amputation. Each teenager shares how he or she feels about 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.

Teens Living with Cancer

1000 Elmwood Avenue, Suite 300

Rochester, NY 14620

Tel: (585) 563-6221

Email: info@teenslivingwithcancer.org

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

RESOURCES FOR TEENS AND YOUNG ADULTS

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 their 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 opportunities to more deeply understand how a life is altered by serious disease.

The SAMFund

89 South Street, Suite LL02

Boston, MA 02111

Tel: (617) 938-3484

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

This fund provides support for young adult cancer survivors in the United States as they recover from the financial impact of cancer treatment. Through direct financial assistance and free online support and education, the SAMFund helps young adults move forward toward their personal, professional, and academic goals.

The Ulman Cancer Fund for Young Adults

Howard County

6770 Oak Hall Lane, Unit 116

Columbia, MD 21045

UCF Headquarters

1215 East Fort Avenue, Suite 104

Baltimore, MD 21230

Toll-Free: (888) 393-FUND (393-3863)

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. By using these free services, they hope young adults will benefit, as well as promote awareness and prevention of cancer.

VIDEOS

Sometimes a picture is worth a thousand words. The videos suggested here are created using past patients and some actors discussing their own journeys as well as fictional accounts of the many ups and downs of treatment and returning to school.

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, and even excited. And they're not alone. This documentary shares teens' stories and their advice for returning to school.

RESOURCES FOR TEENS AND YOUNG ADULTS

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!* 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, and undergoes hospitalization and chemotherapy. She then returns to school when she is 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 often 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)

RESOURCES FOR KIDS

Hi! Circle of Care is here to tell you some things that you can do during treatments to help you feel a little better. When you checked in, you got a bag that had some things that you might want to keep with you. Like some fuzzy socks, a soft blanket, maybe even a pillowcase, a little book and some colored pencils or crayons and of course soap, toothpaste and a toothbrush. And THIS book can tell you about online games, community events or camps that have other kids like you go to, and ways to pass the time during treatments. Plus, even how to get a pony ride!

American Brain Tumor Kids Page

Tel: (800) 866-2282

www.abta.org/adolescent-pediatric/

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.

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, Associate 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.

Chemo Angels

P.O. Box 1971

Julian, CA 92036

www.chemoangels.net

Having cancer can be very isolating and

RESOURCES FOR KIDS

even lonely, but Chemo Angels are there to provide encouragement for patients. Letters and small gifts in the mail lift a patient's spirits during treatment, and give them something to look forward to each day.

Chemo Duck

Gabe's My Heart, Inc.

5016 Spedale Court, Suite 129

Spring Hill, TN 37174

Tel: (615) 830-0126

Email: info@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 best to 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.

Personal Ponies

Cindy Pullen, National Director

Tel: (678) 773-6826

Email: cindy.pullen@gmail.com

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.

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, a national organization with a CT chapter, provides free events for children and families with cancer. Some events include a princess tea party, a Sesame Street Parade, snow tubing, and more.

BOOKS FOR KIDS

The following publications can be found at libraries, bookstores or online. 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.

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.

Chemo, Crazyness & Comfort: My Book About Childhood Cancer

By Nancy Keene and Trevor Romain

Candlelighters Childhood Cancer Foundation, 2002

ISBN: 0972404309

www.Candlelighters.org

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)

Chemo Girl: Saving the World One Treatment at a Time

by Christina Richmond

Jones & Bartlett, 1997

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)

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

Teenage brother and sister Tim and Tyler wrote this allegory about a sick hedgehog that is healed by the feared white wolf. Geared to help children cope with the physical discomforts and fears of prolonged medical 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)

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.

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 to 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)

Oncology Stupology... I Want to Go Home!

by Marilyn Hershey

This funny, 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.

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 very young children. (Ages 1-6)

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

by Karen Sue Foss

Centering Corporation, 1996

ISBN 1561230995

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

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 well-being 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, rewarding reading for cancer patients, their families, and healthcare professionals alike.

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.

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, and provides pictures and pages for your child to draw on and fill in the blanks. (Ages 6-16)

Why am I ImPORTant

by Jennifer Gretzema

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

SIBLINGS

While every part of you might be inclined to focus all attention on your sick child, it is important to spend time with your other healthy children, too. Family dynamics shift dramatically when dealing with an illness. Here are some helpful thoughts about siblings.

Be honest. “We were totally honest with all of our children about what was happening. We learned that people in the community will tell your children everything even if you don’t, so they need to hear it from you first!”

Reassure them. Tell them they didn’t do or say anything that caused their sibling’s cancer. Assure them that childhood cancer isn’t contagious and it is very rare. “One of the most difficult things I did following the diagnosis of my child with cancer was to leave his side to go home and be with his sisters. They REALLY needed it.”

Make time for family visits to the hospital. Let siblings visit the hospital. Don’t worry that the hospital will be too traumatic. Imagining what happens there is usually scarier than seeing a sick brother or sister.

Encourage them to express their feelings. “To help our girls (ages 6 and 8) at the time of our son’s diagnosis, we started a new game after dinner where the girl’s dolls and stuffed animals put on a show for us to tell us how they were feeling about his being sick. Especially about how much time and attention he needed. The girls would comfort their dolls by telling them what we had told them – he would get better, cancer was not contagious, and that he isn’t going to die. At first, they were tenuous and timid but as more and more dolls came forward to share their feelings we all learned something from each other. It made us all feel better and safer. Sometimes the stuffed animals would break into song – so we had some good laughs, as well.”

Talk about your family situation with teachers. Teachers can be a tremendous support to children during the day and can act as your eyes away from home. Give them needed information and you will find them ready to help.

Ask your hospital child life specialist for help. There are many sibling programs and camps both in and out of the hospital. Go to our website for more parent tips.

RESOURCES FOR SIBLINGS

Circle the Sun! - a camp for siblings

Email: info@camprisingsun.com

Email: info@thecircleofcare.org

In partnership with Camp Rising Sun, Circle of Care offers a sibling camp in Colebrook, CT the last week in August. This camp is free for siblings ages 8-14 whose sibling is attending Camp Rising Sun the same week.

Supersibs!

(Part of Alex's Lemonade Stand)

660 N. First Bank Drive

Palatine, IL 60067

Tel: (847) 462-4742

Fax: (847) 984-9292

info@supersibs.org

www.alexslimonadestand.org/campaign/supersibs

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 that provides support for their unique needs. SuperSibs! helps children redefine the "cancer sibling" experience by providing support services, and by helping to draw out the greater and important lessons that may benefit these children later in their lives.

BOOKS

Hi, My Name is Jack

by Christina Beall-Sullivan

www.himynameisjack.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 story, written through the eyes of six-year-old Oliver, focuses on the many questions 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 an excellent book for the child's schoolmates and other groups to become familiar with before your child returns to regular activities. It can be found through the Candlelighters Childhood Cancer Foundation, or the Leukemia & Lymphoma Society.

SIDE EFFECTS

Treatment isn't easy – There are many side effects and, just as every child is unique, their reactions to treatment are, too. Many parents have found it helpful to keep a journal. "After the first few months, we learned our son's rhythm with the chemo drugs and being able to anticipate his low counts, nausea, headaches and fatigue made them much easier to manage. Keeping a journal really helped."

Other side effects that you might not expect and which may happen are: weight gain, nausea (keep a roll of paper towels and a bucket in the car), increased or loss of appetite, increased temper (due to steroids), hair loss (more on this later). On our website, you will find other parent tips – from eating sweets the day before chemo to timing of temper tantrums and raging appetites. Learning from other parents can help you to be more prepared for treatments.

GIVING MEDICINE

During treatment, your children will need to take A LOT of medicine. Babies, toddlers, even some young adults have never had to swallow pills, and getting the medicine in them leads to some pretty creative maneuvers by parents. Everything from applesauce to brownies to berries has been used to get children to swallow their meds. It is important to remember to check for reactions to drugs and what you are putting them in, but mostly anything goes if it is sweet and masks the taste. This is a large section on our website but here are a few ideas from past parents.

- "I give my 5 year old son ice and have him suck on it for a bit before giving him his medicine. It helps numb his taste buds so the medicine goes down smoothly."
- "We crush all of the meds and put them in super sweet liquids."
- "They make gel caps that have no taste so we would crush up the prednisone and put them in there."
- "Highly recommend Jell-O jigglers! Make Jell-O cut into small cubes, make a slit in the top and insert gel cap."
- "We use Motts apple berry sauce."
- "One of the oncology nurses dissolved the pills in liquid and then sucked it up in a syringe and squirted it in the mouth of my child. We followed it with some M&M's and that has worked for 6 months!"

Please DO go to our website, where we have many more suggestions for you.

TIPS FOR TREATMENT

NUTRITION

We all know that eating the right foods can have many benefits, from our physical size to our mental health. Now, more than ever, nutrition is top priority. Unfortunately, the drugs that will be working to fight your child's illness can often make them feel like not eating ANYTHING- let alone things that are good for them. This section will give you pointers on what sorts of foods might be more palatable and how you can combat nausea, dry mouth and numerous other issues. Everyone needs new recipes, and there are several complete cookbooks you can download. If you find something that works especially well for you, please share it with us and we can add it to our nutrition resources section below.

BOOKS

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

By Kris Ghosh, Linda Carson, and Elyse Cohen

Healing Meals Community Project
P.O. Box 501

Simsbury, CT 06070

Tel: (860) 264-5864

www.healingmealsproject.org

This nonprofit prepares and delivers organic meals for families in health crises while supporting young chefs with leadership skills, job readiness skills, nutrition and wellness education, and the joy of supporting the community.

Eating Hints for Cancer Treatment: 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**.*

Nutritional Needs For Kids With Cancer **www.kidshealth.org/en/parents/cancer-nutrition.html**

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

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.

TIPS FOR TREATMENT

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.

What to Eat If You Have Cancer: Heal- ing Foods That Boost Your Immune System

By Daniella Chace 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.

LIVING WITH LOW BLOOD COUNTS

Your child will be immune-suppressed at many times during treatment. Basic hand washing and avoiding crowds are your best first line of defense. Nature is your friend and good for all of you. Get outside and go for walks or, if you are both exhausted, simply drive to a nearby pond or park and sit on a bench for a while. Mother Nature supplies an endless variety of birds, wildlife, plants and beetles. Just a change of scenery is often good.

"After many weeks at home, we found some fun things to do to pass the time. Sometimes we would have the whole family camp out in the living room, we had picnics on the porch. She learned to cook, plant seeds, and do crafts."

"Sometimes on Sundays we would go to my husband's office when no one was there just for a change of scenery."

"Never feel embarrassed about the measures you have to take to keep your child healthy. Some friends may have been offended when I left a play date because their child had suspicious drainage from their nose, but I would always wait a day (until I wasn't so upset!) and call and explain – AGAIN – that our daughter could not be exposed to common childhood illness if at all possible. Your goal is to help your child and sometimes that means taking the time to educate the other parents whose children are important to your child."

ABOUT HAIR LOSS/WIGS & ACCESSORIES

Many have seen the dramatic depictions of losing your hair during cancer in movies and television shows... Hair loss from chemo and radiation can be one of the most difficult side effects for children, especially teens. Preparing yourself and your child can help to make the transition a bit easier. It is important to keep in mind that it will grow back. This section shows you where to look for things you possibly never even knew existed. A good wig? One that doesn't scream, "I'm wearing a wig!" to every passerby, definitely does exist and, for some, makes life easier. It is important to remember that the hair will grow back. Don't be afraid to address the obvious. Talk about the loss of hair and why it is happening. Let your child make the decision to get a wig or not.

"At first our daughter was very self-conscious about losing her hair so we got her a wig. It looked very nice on her but after a few occasions she decided she was happier without it. Having the wig was important because SHE got to decide whether she would have hair or not. That meant a lot to her."

"My son lost all but about 30 strands of hair; he brushed it every day and was very happy to have it."

The important thing here is that the child be allowed to react and feel whatever he or she wants. Try to be open about the process with everyone. There is nothing worse than friends stopping by for a visit and being unprepared for the new look your child is sporting.

"My son said that once he lost his hair, no one in the elevator or walking through the halls of the hospital would look at him. I learned to always look at the children, say hello and treat them as normally as possible."

Others find colorful scarves, bandanas or the very kid-friendly baseball hat to be a better option. This section points you in the right direction for both decisions.

Lastly, we can only hope to have this parent's situation:

"When my 10-year-old son returned to school, all of his friends had shaved their heads so he wouldn't feel different. That was an amazing day."

Hip Hats with Hair

4707 North Nebraska Avenue

Tampa, FL 33603

Tel/Fax: (877) 447-4287

Email: info@hatswithhair.com

www.hatswithhair.com

Hip Hats with Hair is 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.

Hot ILids

Email: HotILids@yahoo.com

www.HotILids.com

This website has hundreds of styles of hats, and more in their Kids Lids section. HotILids.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, creative way to cope with losing your hair. The kits contain child-safe arts and crafts supplies for creating one hat. The assorted kits contain fabric

TIPS FOR TREATMENT

markers, ribbons, patches, glue, kid's scissors, and one hat of your choice. For every 20 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](http://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](http://www.WigsForKids.org)

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

GOING BACK TO SCHOOL

Negotiating the difficulties of having a child out of school for extended periods of time are considerable. The Department of Education has guidelines for advocating for your child to make sure they don't fall behind. Sometimes getting back to the normal day-to-day habits of school seem overwhelming. Here are some practical tips/resources for what you might want to consider before the actual day that your child returns to school.

Before returning to school, meet with the school administration, your child's teachers and the school nurse. Explain your child's diagnosis and treatment plan in detail. Don't be afraid to ask for accommodations for your child's needs, including, but not limited to, unexpected absences, school policies about homework completion, in-home tutoring, permission or special plans to go to nurse or restroom when necessary, wearing hats or head scarves, etc. You know your child best. Some children thrive on attention and want to share every detail of their ordeal, while some want no attention at all. Talk to them and lay out the different scenarios. Be aware that many children (and adults!) don't know how to deal with sickness. Getting back into the swing of school can be challenging, but keeping open lines of communication between you and your school's administration is KEY.

"I drafted a lengthy letter explaining his illness, treatment, strengths, weaknesses, as well as the things I wanted the school to do. I tried to take on as much responsibility for those requests as possible. I found that by making my concerns clear and trying to assist the school in doing the things I wanted, I was met with great cooperation and my son's re-entry went smoothly."

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.

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.

The Learning Foundation of Fairfield County

1109 Brookside Drive

Fairfield, CT 06824

Tel: (203) 520-2070

Email: susan@learningfoundation.net

www.learningfoundation.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 skills workshops. Her background as an educator 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, from which the patient will benefit.

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

www.ils.org/events/the-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.

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 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 and beyond. This edition covers changes in disability laws, including the Americans with Disabilities Act and Individuals with Disabilities Education Act. 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.

UNIQUE OPPORTUNITIES

Part of many children's lives is a camp experience. Perhaps the most well known camp for children with illnesses is Hole in the Wall, founded by Paul Newman; but there are many others. Your child might now have special needs, but there are still many wonderful options for both a child dealing with illness, and even for that child's siblings. Some have smaller fees and many are free to children with cancer. You are going through an extremely stressful time; one of these camps can give the whole family a short time off to refuel and relax.

In addition to camps, there are other organizations that can make a child's dream come true. Who doesn't love to see a child get their wish fulfilled? From meeting astronauts and sports stars to trips to Disneyland and beyond, all sorts of fantasies have been fulfilled by these organizations. We love to see children smile, jump up and down with glee and hoot with delight. These groups can help make that happen for you.

CAMPS

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

P.O. Box 472
Branford, CT 06405
Tel: (203) 481-7277
Fax: (203) 654-7886

Email: info@camprisingsun.com
www.camprisingsun.com

This camp was created for children diagnosed with cancer. Children attend the camp for free, and all staff members are dedicated volunteers who 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, a 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, Third Floor
New York, NY 10001
Tel: (877) CHAI-LIFE or (212) 699-6661

Email: info@campsimcha.org
www.campsimcha.org

MOVING FORWARD

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 children and young adults (ages 5-20) who come from throughout North America, Europe, and Israel who have encountered serious illness.

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 week-long 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 40081
Augusta, GA 30909
Tel: (404) 661-5753

Email: don.golden@cocai.org
www.cocai.org

COCA-I is an international assembly of people and more than 65 camps providing

programs for children with cancer. Camps are located in the USA, Canada, Australia, New Zealand, and Europe.

Circle the Sun! - a camp for siblings

Email: info@camprisingsun.com

Email: info@thecircleofcare.org

In partnership with Camp Rising Sun, Circle of Care offers a concurrent sibling camp in Colebrook, CT the last week in August. This camp is free for siblings ages 8-14 whose sibling is attending Camp Rising Sun the same week.

First Descent World Headquarters

3001 Brighton Boulevard, Suite 623
Denver, CO 80216

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

www.holeinthewallgang.org

The Hole in the Wall Gang Camp, founded by Paul Newman in 1988, is a nonprofit

MOVING FORWARD

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 and adolescents (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: info@josephsjourney.org
www.josephsjourney.org

Inspired by their young son's ambitions, hardships, and endurance, Joseph's parents founded this camp. Because 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, and climbing, all of which are led by experienced, qualified guides.

Lighthouse Family Retreat

45 Technology Parkway South, Suite 225
Norcross, GA 30092
Tel: (678) 290-2955

Email: info@lighthousefamilyretreat.org
www.lighthousefamilyretreat.org

Founded in 1999, Lighthouse Family Retreat continues to serve families living through child-

hood cancer by enabling them to laugh, restore family relationships, and find hope in God.

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. The Foundation's mission is to provide peer support, respite, mentoring, and recreational programs to meet the needs of all family members. Okizu offers a variety of camps for kids, teens, young adults ages 18 or older, siblings, and families.

Silver Lining Ranch

Little Star Foundation

174 Watercolor Way, Suite 103, B343
Santa Rosa Beach, FL 32459
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, whitewater 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.

WISHES

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.

Caroline's Miracle Foundation

P.O. Box 285
Old Lyme, CT 06371
Tel: (860) 434-2246

Email: miracles@carolinesmiraclefoundation.org

www.carolinesmiraclefoundation.org

This organization helps children with inoperable brain tumors.

Children's Hopes and Dreams-Wish Fulfillment Foundation

138 Cloudland Road
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. Fulfilled wishes have included visits with celebrities, visits with favorite relatives, puppies, Disney World, shopping sprees, and other fun activities.

Children's Wish Foundation International

8615 Roswell Road
Atlanta, GA 30350
Tel: (770) 393-WISH
Toll-Free: (800) 323-WISH

Email: info.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.

Dream Come True of Western Connecticut, Inc.

P.O. 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.

Little Wonder

4 Science Park
New Haven, CT 06511

www.littlewonder.org

sharon@littlewonder.org

Little Wonder is a 501(c)(3) non-profit organization dedicated to enriching the lives of patients suffering from cancer by providing them tickets to local concerts, family

MOVING FORWARD

entertainment, live theater, and sporting events. Thousands of these tickets go unused every day and our goal is to reserve those empty seats on behalf of patients undergoing treatment for cancer and their families. This experience is completely free of charge to the people we serve.

We believe that the opportunity to create positive memories with family and friends can be a powerful experience for a family dealing with the unimaginable struggles of a cancer diagnosis.

LIVFREE

www.livfreetoday.org

Our mission at LIVFREE is to provide 100 families that are battling pediatric cancer and its treatments, tickets to attend an event of their choice. As parents of a child currently fighting cancer, we know how important family time is.

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 and adolescents (ages 0-18) with life-threatening illnesses throughout the state of Connecticut.

The Marty Lyons Foundation, Inc.

354 Veterans Memorial Highway, Second Floor

Commack, NY 11725

Tel: (631) 543-9474

Fax: (631) 543-9479

The Marty Lyons Foundation, Inc. is a nonprofit 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 be treated in the following geographic areas: Connecticut, Florida, Georgia, Maryland, Massachusetts, New Jersey, New York, North Carolina, Pennsylvania, South Carolina, or Texas. MLF provides a first and second wish. The Second Wish Program is for children who have received a first wish 24 months prior, have exhausted all medical options, and are essentially at end-of-life stage or are receiving hospice care.

Special Wishes

P.O. Box 391 Oakville, CT 06779

Tel: (860) 274-5224

Fax (860) 274-1598

Special Wishes, Inc. was founded in 1986 out of love and compassion for children stricken with life-threatening illnesses. Our mission is to make a dream come true for children whose horizons are measured in

MOVING FORWARD

months or days, and whose dreams of what they will become when they grow up are secondary to dreams of getting well.

Special Wishes, Inc. gives Connecticut children between the ages of 3 and 21 whatever happiness we can - a moment of joy - by making a wish come true. Whether it be a trip to Disney World or another special destination, tickets to a rock concert or sporting event, a day with a favorite movie star or professional athlete, or a special shopping spree, we make wishes come true.

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.

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 and adolescents (ages 3-18) across the country.

SCHOLARSHIPS

Beyond the Cure Ambassador Scholarship Program

500 North Broadway, Suite 1850
St Louis, MO 63102
Tel: (314) 241-1600
Fax: (314) 241-1996

www.thenccs.org/scholarship

The National Children's Cancer Society awards college scholarships to childhood cancer survivors who have demonstrated the ability to overcome the difficult challenges of cancer with determination and motivation. Forty \$3,500 scholarships will be awarded each academic year.

Financial Aid Information

www.finaid.org

This website offers information about college scholarships, loans and other types of financial aid.

National Collegiate Cancer Foundation

www.collegiatecancer.org/

This foundation offers \$1,000 competitive awards based upon financial need, quality of essay and recommendations, displaying a "Will Win" attitude, and overall story of cancer survivorship.

Patient Advocate Foundation

421 Butler Farm Road
Hampton, VA 23666
Tel: (800) 532-5274
Fax: (757) 873-8999

www.patientadvocate.org

They award \$3,000 competitive scholarships

to those diagnosed with and/or been actively treated for a life-threatening disease within the past 5 years.

Pediatric Brain Tumor Foundation

302 Ridgefield Court
Asheville, NC 28806
Tel: (800) 253-6530

www.curethekids.org/family-resources/scholarships/

This foundation offers a one-year award of \$500 to childhood brain tumor survivors.

The SAMFund

89 South Street, Suite LL02
Boston, MA 02111
Tel: (617) 938-3484

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

info@thesamfund.org

<http://www.thesamfund.org/get-help/grants/>

The SAMFund provides financial assistance to young adults as they move forward with their lives after cancer. Their grants can be used toward medical bills, insurance premiums, tuition, loans, computers, etc.

The Ulman Fund for Young Adults

1215 East Fort Avenue, Suite 104
Baltimore, MD 21230
Tel: (410) 964-0202

info@ulmanfund.org

<http://ulmanfund.org/scholarships/>

The Ulman Fund for Young Adults offers \$2,500 scholarships for those 15-39 years old during their own diagnosis/treatment or during the diagnosis/treatment of a parent or sibling.

Tim and Tom Gullikson Foundation

Tel: 1-(888) GULLIKSON

Tim and Tom Gullikson Foundation Scholarships are available to brain tumor patients/survivors and/or children of brain tumor patients/survivors. Extra consideration is given to applicants who have an affiliation or connection to the tennis community.

The Susan Fund

8 Hilly Field Lane
Westport, CT 06880

thesusanfund.org

Dedicated to providing educational scholarships to Fairfield County Students diagnosed with cancer.

FINANCIAL RESOURCES

Being ill is EXPENSIVE but Circle of Care is here to help along the way, and so are many other organizations. We have broken this section down into categories we think will help.

FINANCIAL HELP

For assistance with paying bills during your cancer journey, these organizations can be very helpful. They can provide you with advice and aid in filing papers and give you a timeline for reimbursement.

American Financial Solutions/Genus Credit Management

263 4th Street

Bremerton, WA 98337

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, 6:00 a.m. to 7:00 p.m. PST.

Cancer Financial Assistance Coalition *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 to patients free of charge.

CancerCare

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

Candlelighters - Childhood Cancer Family Alliance

www.candle.org

Candlelighters Childhood Cancer Family Alliance provides emotional, educational and practical support to families of children with

FINANCIAL RESOURCES

cancer. Candlelighters serves all children with cancer and their families, long term survivors of childhood cancer, adult survivors of childhood cancer and their families, and bereaved families treated at The University of Texas MD Anderson Cancer Center Children's Cancer Hospital and Texas Children's Cancer Center. There are no fees charged for any services provided by Candlelighters.

Children's Cancer Association

1200 NW Naito Parkway, Suite 140

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.

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.

Circle of Care

P.O. BOX 32

Wilton, CT 06897

Tel: (203) 663-6893

Email: info@thecircleofcare.org

www.thecircleofcare.org

Circle of Care supports children with cancer and their families from day of diagnosis through treatment and beyond, providing direct, practical, emotional and financial support. This website contains information about their resources and programs including: Bags of Love, a day of diagnosis care package; Lifeline, a parent to parent support program; Hospital Volunteers: Room makeovers, and financial assistance.

The Danny Fund

P.O. Box 8271

Pelham, NY 10803

Email: info@thedannyfund.org

www.thedannyfund.org

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

Family Reach Foundation

2001 Route 46, Suite 310

Parsippany-Troy Hills, NJ 07054

Tel: (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 mortgages, utilities, insurance, transportation expenses, child care, palliative care and other special patient needs. Ask your social worker for assistance in completing their application.

FINANCIAL RESOURCES

Friends of Karen, Inc.

118 Titicus Road
North Salem, NY 10560
Tel: (914) 277-4547

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 more than 25 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.

Go4theGoal

215 Cuthbert Boulevard, Suite 150
Cherry Hill, NJ 08002

www.go4thegoal.org

Go4theGoal's mission is to improve the lives of children battling cancer by providing financial support, developing and implementing unique hospital programs, funding innovative research, and granting personal wishes. Through the group's firsthand experience with pediatric cancer and our medical background, Go4theGoal provides helpful information to patients, their families, and the hospitals and staff that care for them.

Lea's Foundation

150 Trumbull Street, 2nd floor
Hartford, CT 06103
Tel: (860) 727-8998

www.leasfoundation.org

Lea's Foundation for Leukemia Research was established in 1998 to fund research into the causes of, and cures for, leukemia and its related cancers of Lymphoma, Hodgkin's Lymphoma and Myeloma. Additionally, the Foundation seeks to increase public awareness of these cancers and to provide patients and their families with limited direct financial assistance.

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

Resource Center: (800) 955-4572

Time: M-F 9 a.m. - 9 p.m. EST

Email: infocenter@lls.org

www.lls.org

This organization funds research, sponsors national education programs for the public and the medical community, and publishes a large number of booklets on cancer-related topics. Financial assistance is also available to families through this organization.

Medical Bill Detectives

376 Belden Hill Road
Wilton, CT 06897

Email: info@MedicalBillDetectives.com

www.MedicalBillDetectives.com

FINANCIAL RESOURCES

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

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

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 SCOTTY Fund

P.O. Box 1080

Bethel, CT 06801

Tel: (203) 743-1388

www.scottfund.org

THE SCOTTY Fund is a non-profit, charitable organization, which provides financial and family support to children with life-threatening and critical illnesses and their families.

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

20 York Street

New Haven, CT 06511-3202

Tel: (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. It also funds various hospital initiatives.

INSURANCE HELP

Insurance, Co-pays, deductibles: what's covered and what's not can be tough to focus on. Understanding your plan and available resources can make your financial life more manageable. Whether you have insurance, or your insurance doesn't seem to cover you entirely, you will find sites in this section that can help.

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.

FINANCIAL RESOURCES

First Hand Foundation

2800 Rockcreek Parkway

Kansas City, MO 64117

Tel: (816) 201-1569

Email: FirstHandFoundation@cerner.com

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

55 Farmington Avenue

East Hartford, CT 06105

Tel: (877) 284-8759

www.[huskyhealth.com](http://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 are always covered. HUSKY is funded by the state and federal governments and administered by the Department of Social Services.

HealthWell Foundation

P.O. Box 220410

Chantilly, VA 20153-0410

Tel: (800) 675-8416

Email: grants@healthwellfoundation.org

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

When health insurance is not enough, HealthWell can fill the gap. They help patients living with chronic and life-altering

illnesses pay their share of prescription drug copayments, deductibles, and health insurance premiums.

Insure Kids Now!

Toll-free: (877) 543-7669

www.[InsureKidsNow.gov](http://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.

The National Association of Insurance Commissioners (NAIC)

1100 Walnut Street, Suite 1500

Kansas City, MO 64106-2197

Tel: (816) 842-3600

Fax: (816) 783-8175

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

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

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](http://www.patientadvocate.org)

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

FINANCIAL RESOURCES

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/site/default.asp

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 consumers on their rights.

DRUG REIMBURSEMENT

Some of the drugs that your child will be taking are expensive. Here are a few prescription assistance program sources that can help you manage this part of treatment.

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.

FINANCIAL RESOURCES

RxHope Inc.

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

Email: 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.

RxList

www.rxlist.com

This website provides information on specific medications, including those used by cancer patients.

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 at their neighborhood pharmacies. It also connects you with resources about access to coverage options and more.

FREE TRAVEL SERVICES

Sometimes the services you need are halfway across the country in a different treatment center. Fear not! You might be eligible for free flights. The organizations in

these pages can help you get those air miles at no cost, or greatly reduced cost. These sites are updated on our website so check there frequently for special deals and ideas.

Air Care Alliance

2060 State Highway 595
Lindrieth, 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
Fax: (914) 328-3938

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 are no costs or financial need requirements.

FINANCIAL RESOURCES

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

5740 S. Eastern Avenue, Suite 240
Las Vegas, NV 89119
Tel: (702) 261-0494
Toll-Free: (800) FLY-1711
Fax: (702) 261-0497

Email: flightcoordinator@miracleflights.org
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.

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.

Wings – Flights of Hope

P.O. Box 872, Orchard Park, NY, 14127
Phone: 1-(866) 61-WINGS(94647)
Phone: 1-(716) 525-0229

Email: wingsflight@gmail.com
www.wingsflight.org

Commercial flights often restrict patients from travel, due to germs and schedule. This is where Wings Flight can fly the patient as the aircrafts are continually taking in fresh air through the flights. Patients are allowed to keep their oxygen with them and in use on all Wings Flights.

Wings Flights are available to all that may need medical attention. Many of our patients are children, however adults of all ages are also flown FREE of charge. All patients have the option to have family members join them on the flights, also FREE of charge.

FINANCIAL RESOURCES

PLACES TO STAY

There are several low cost places to stay if you are in treatment far from home.

In Boston:

AstraZeneca Hope Lodge Center

125 S. Huntington Avenue

Jamaica Plain, MA 02130

Tel: (617) 396-5500

<http://www.cancer.org/treatment/support-programsservices/hopelodge/boston>

This state-of-the-art facility serves as a “home away from home” for patients traveling more than 40 miles to their outpatient treatments. There is no charge to stay at Hope Lodge, for either the patient or his or her caregivers.

The center allows patients to focus on their recovery by providing 40 private patient suites, each with a sitting room, bathroom, and bedroom with two beds; common areas including a library, courtyards, and a meal preparation and dining area; transportation to treatment; and the on-site resources of an American Cancer Society Quality of Life Center American Cancer Society. There is often a 1-2 month wait.

Christopher’s Haven

One Emerson Place, Suite 2-N

Boston, MA 02114

Tel: (857) 233-4178

Fax: (857) 753-4734

<http://christophershaven.org>

Christopher’s Haven is a home for kids and their families while they battle cancer. The home is a support system to help with things

large and small, and a community where families can be together, share a laugh, be comforted, and comfort others.

Ronald McDonald House

229 Kent Street

Brookline, MA 02446

Tel: (617) 734-3333

www.ronaldmcdonaldhouseboston.org

For pediatric patients and their families.

\$10 per night.

In New York City:

Ronald McDonald House

405 East 73rd Street

New York, NY 10021

Tel: (212) 639-0100

<http://www.rmh-newyork.org>

When families must travel to New York for their child’s lifesaving cancer treatment, Ronald McDonald House New York offers them a safe, clean, and supportive “home away from home” in close proximity to major hospitals. They provide private bedrooms, family rooms, kitchens, a library, computer rooms, a playroom, laundry facilities, tutoring, activities, and transportation services.

In Connecticut:

Ronald McDonald House

501 George Street

New Haven, CT 06511

Tel: (203) 777-5683

Fax: (203) 777-3082

FINANCIAL RESOURCES

www.rmhc-ctma.org

A comfortable house with 12 guest rooms to support the needs of families with sick children.

The Suites at Yale New Haven

Tel: (203) 654-7500

www.ynhh.org/patients-visitors/amenities/suites.aspx

This is a new hotel offering rooms for families and caregivers of patients who are being admitted for short- or long-term inpatient hospital care. It is located two blocks from the Smilow Center Hospital at Yale New Haven. The cost is \$89 per night and includes dinner three nights a week, daily breakfast, a shuttle that goes between Smilow and the suite. The suite has a fully stocked kitchen, full living room with a fireplace, a large bedroom, a full bathroom and a yard to play in.

PEDIATRIC CANCER ORGANIZATIONS

American Academy of Pediatrics

104 Hungerfort Street

Hartford, CT 06106

Tel: (860) 525-9738

www.ct-aap.org

The American Academy of Pediatrics is an organization of 66,000 pediatricians committed to the optimal physical, mental, and social health and well-being for all infants, children, adolescents, and young adults.

American Cancer Society

Southern New England Region

38 Richards Ave

Norwalk, CT 06854

Tel: (203) 563-1500

Fax: (203) 563-0738

www.cancer.org

www.cancer.org/myacs/newengland

The American Cancer Society is a national network of employees and volunteers that implements research, and offers educational and patient service 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. The organization helps shape policy, research, and programs on a national level. A quarterly newsletter and various informational handbooks are available online.

American Pediatric Surgical Association's Complete Parent & Family Resource Center

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 near 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

Fax: (847) 375-6483

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 solely dedicated to the professional development and interests

PEDIATRIC CANCER ORGANIZATIONS

of subspecialists in pediatric hematology/oncology. Their primary goals are to further communication among 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. The website provides patients and families with a source of current peer-reviewed scientific and clinical information.

Ann's Place

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

Email: info@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.

Brady's Smile

P.O. Box 320921
Fairfield, CT 06825

Email: info@bradyssmile.org or annie@bradyssmile.org

Brady's Smile was created to promote, improve, protect and sustain the health, emotional well-being and social development of children in need, including children suffering from illness or disability, children at risk and under-served children. Their focus is to help make life easier for children (and their families) who are in the intensive care units at children's hospitals.

Brain Tumor Foundation for Children, Inc. (BTFC)

6065 Roswell Rd. NE, Suite 505
Atlanta, GA 30328
Tel: (404) 252-4107
Fax: (404) 252-4108

Email: info@braintumorkids.org
www.braintumorkids.org

BTFC promotes the public education of brain tumors and related diseases. It provides grants for research and education, as well as financial assistance for patients and their families, with the hope of improving their quality of life. Also organizes patient support activities.

CancerCare, Inc.

275 Seventh Avenue
New York, NY 10001
Toll-Free: (800) 813-HOPE (813-4673)

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:

111 East Avenue, Suite 207
Norwalk, CT 06851
Tel: (203) 854-9911

Email: ctinfo@cancercare.org

CancerQuest

2031 Rollins Research Building
1510 Clifton Road, NE
Atlanta, GA 30322

PEDIATRIC CANCER ORGANIZATIONS

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.

Children's Brain Tumor Foundation

1460 Broadway Avenue

New York, NY 10036

Tel: (866) 228-HOPE (228-4673)

Email: info@cbtf.org

www.cbtf.org

This foundation 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 that pairs experienced parents with those of newly diagnosed children. It also offers co-sponsorship of conferences and seminars for families, survivors, and healthcare professionals.

Children's Cancer Association

1200 NW Naito Parkway, Suite 140

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 of childhood cancer. They are also involved in advocacy.

Childhood Leukemia Foundation (CLF)

807 Mantoloking Road, Suite 203

Brick, NJ 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, joyful experiences, giving them a sense of normalcy despite their challenging circumstances.

Children's Leukemia Research Association, Inc.

244 5th Avenue, Suite 2969

New York, NY 10001

Tel: (212) 491-1200

Email: info@childrensleukemia.org

www.childrensleukemia.org

This nonprofit organization is dedicated to raising funds to support efforts toward finding the causes of and cures for leukemia. CLRA provides financial aid for treatment, medications, and lab fees for leukemia patients, as well as public and professional

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education, and research grants to medical professionals.

Children's Oncology Group

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 is an NCI-supported clinical trials cooperative 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 information about the long-term effects of cancer treatment.

Circle of Care

P.O. BOX 32

Wilton, CT 06897

(203) 663-6893

www.thecircleofcare.org

Circle of Care supports children with cancer and their families from day of diagnosis through treatment and beyond, providing direct, practical, emotional and financial support. This website contains information about their resources and programs including: Bags of Love, a day of diagnosis care package; Lifeline, a parent to parent support program;

Hospital Volunteers; Room makeovers; and financial assistance.

Colin's Crew

P.O. Box 4097

Wallingford, CT 06492

Tel: (203) 494-7838

Email: info@colins-crew.org

www.colins-crew.org

Colin's Crew was originally formed to provide financial and emotional support to the family of a brave boy named Colin who was diagnosed with Acute Lymphoblastic Leukemia. As he continues to do well, Colin's Crew works on fundraisers to assist families in the same situation.

Coping Magazine: Coping with Cancer

P.O. Box 682268,

Franklin, TN 37068

Tel: (615) 790-2400

Fax: (615) 614-3986

www.copingmag.com

Coping Magazine is a bimonthly publication for people whose lives have been affected by cancer, aimed to help them cope during and after their illness.

CT Brain Tumor Alliance

P.O. Box 370514

West Hartford, CT 06137

Tel: (860) 264-5776

Fax: (860) 516-4876

Email: info@ctbta.org

www.ctbta.org

The Connecticut Brain Tumor Alliance is a non profit organization dedicated to offering support and compassion to those affected by brain tumors.

PEDIATRIC CANCER ORGANIZATIONS

Curesearch

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 and the National Childhood Cancer Foundation 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 with information on new treatments and psychosocial support.

Family Centers

The Center For Hope

590 Boston Post Road

Darien, CT 06820

Tel: (203) 655-0547

Fax: (203) 655-3452

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 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.

IACR Foundation

125 Old Litchfield Road

Washington Depot, CT 06794

Email: ckennedy@iacrfoundation.org or

dalex@iacrfoundation.org

iacrfoundation.org

Innovative Advanced Cancer Research Foundation is committed to supporting dedicated physicians and scientists achieve their goals of advancing cancer treatment through innovative groundbreaking research.

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

Resource Center: (800) 955-4572

Time: M-F 9 a.m. - 9 p.m. EST

Email: infocenter@lls.org

www.lls.org

This organization funds research, sponsors 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.

Mikey Czech Foundation

P.O. Box 1717

New Canaan, CT 06840

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www.mikeyczech.org

This foundation is dedicated to pediatric brain tumor research.

National Cancer Institute (NCI)

BG 9609 MSC 9760

9609 Medical Center Drive

Bethesda, MD 20892-9760

Tel: (800) 422-6237

Time: M-F 8 a.m. - 8 p.m. 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 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. 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

500 North Broadway, Suite 1850

St. Louis, MO 63102

Tel: (314) 241-1600

Fax: (314) 241-1996

www.thenccs.org

The National Children's Cancer Society 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. It also has an online community at nccsonlinecommunity.ning.com for parents, caregivers, and survivors of childhood cancer to connect and share with one another.

National Organization for Rare Disorders

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

This organization is a unique syndicate of voluntary health organizations dedicated to helping people with rare "orphan" diseases, and to assisting the organizations that serve them. It is 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

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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 to encourage additional research and funding until a cure can be found.

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 more than 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. Visitors may also access a series of online animated stories that can help young people learn how to cope with the challenges cancer poses.

Team IMPACT

3 Batterymarch Park, 5th Floor
Quincy, MA 02169
Tel: (617) 801-0248

Email: info@goteamimpact.org
www.goteamimpact.org

Team Impact improves the quality of life for children facing life-threatening and chronic illnesses through the power of team by matching these courageous kids with local college athletic teams. Team IMPACT children are drafted onto the team and become an official member of the team from Draft Day through to Graduation. The child joins the athletic team and the student athletes join the child's support team.

The Children's Cause for Cancer Advocacy

122 C Street NW, Suite 240
Washington, DC 20001
Tel: (202) 304-1850

info@childrenscause.org
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 website provides information about FDA guidelines, NCI cancer policies, medical privacy issues, current clinical trials, and key resources.

The Stanford Health Library Main Branch

Hoover Pavilion
211 Quarry Road, Suite 201
Palo Alto, CA 94304

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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.

TREATMENT CENTERS

Children's Hospital of Philadelphia

34th Street and Civic Center Boulevard

Philadelphia, PA 19104-4399

Tel: (800) 879-2467

New Patients: (267) 426-0762

Physician Referral Service: (800) 879-2467

www.chop.edu

The Children's Hospital of Philadelphia is a pediatric hospital and research facility staffed by internationally recognized pediatric oncologists and teams with expertise in every type of pediatric cancer. The hospital's experts, who have experience treating both the most common and the most rare childhood cancers, work together to diagnose and treat patients using an evidence-based approach backed by the latest research advancements.

Connecticut Children's Medical Center

282 Washington Street

Hartford, CT 06106

Tel: (860) 545-9000 or (800) 243-1552

Kidsline: (800) 243-1552

www.connecticutchildrens.org

The goal of Connecticut Children's Medical Center is to provide medical care for children and families. 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. It provides diagnosis and management services for children with anemias, neutropenias, thrombocytopenias, coagulation disorders, leukemias, and all solid tumors.

Dana-Farber Boston Children's Hospital Cancer Care

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.danafarberbostonchildrens.org

For more than 50 years, Dana-Farber Boston Children's Hospital has treated children with cancer 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 hospital'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.

TREATMENT CENTERS

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

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.

Memorial Sloan-Kettering Cancer Center

1275 York Avenue

New York, NY 10065

Tel: (212) 639-2000

Pediatrics: (212) 639-5954

Physician Referral: (866) 218-8132

www.mskcc.org

Sloan-Kettering has treated more children with cancer than any other institution in the world. Its 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 full of information on diseases, as well as FAQ links for parents and children.

New York-Presbyterian Morgan Stanley Children's Hospital

3959 Broadway Avenue

New York, NY 10032

Tel: (212) 305-5437

www.hyp.org/morganstanley

Building a reputation for more than a century as one of the nation's premier children's hospitals, Morgan Stanley Children's Hospital is affiliated with the Department of Pediatrics at Columbia University College of Physicians and Surgeons, and is Manhattan's only hospital dedicated solely to the care of children and one of the largest providers of children's health services in the tri-state area. It is also a major international referral center, meeting the special needs of children from infancy through adolescence worldwide.

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.

TREATMENT CENTERS

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.txch.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 Children's Center

1800 Orleans Street

Baltimore, MD 21287

Tel: (410) 955-5000

www.hopkinschildrens.org

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.

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 facilities.

Yale-New Haven Children's Hospital Smilow Cancer Hospital

20 York Street

New Haven, CT 06510

Tel: (203) 688-4242

www.ynhh.org

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 therapy to help 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 & STEM CELL TRANSPLANTS

There are specific needs and challenges for this type of care. These sites can educate you in the aspects of bone marrow and stem cell transplants that are different than other cancer care treatments.

Be The Match

www.bethematch.org

Be The Match is a global leader in bone marrow transplantation. They conduct research to improve transplant outcomes, provide support and resources for patients, and partner with a global network. They also have good resources for helping you to prepare for your child's transplant.

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.

BMT InfoNet (Blood & Marrow Transplant Information Network)

1548 Old Skokie Road, Suite 1

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 searchable Transplant Center database, a resource directory, a drug database, book recommendations, a patient support network, help with insurance difficulties, and a quarterly newsletter.

BoneMarrowTest.com

Kashi Clinical Laboratories Inc.

10101 SW Barbur 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.

Delete Blood Cancer

100 Broadway

6th Floor

New York, NY 10005

Tel: (212) 209-6700

www.dkms.org

DKMS, founded in 1990, is an international not for profit organization dedicated to

Bone Marrow Foundation

515 Madison Ave., Suite 1130

New York, NY 10022

Tel: (212) 838-3029

SPECIALIZED CARE

the fight against blood cancer and blood disorders by: creating awareness; recruiting bone marrow donors to provide a second chance at life; raising funds to match donor registration costs; supporting the improvement of therapies through research; and supporting patients from day one of their diagnoses.

Help Hope Live (Formerly NTAF)

2 Radnor Corporate Center, Suite 100
Wayne, PA 19087

Tel: (800) 642-8399

Fax: (610) 535-6106

www.helphopelive.org

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

National Bone Marrow Transplant Link

20411 W. Twelve Mile Road, Suite 108
Southfield, MI 48076

Toll-Free: (800) LINK-BMT (546-5268)

Tel: (248) 358-1886

Fax: (248) 358-1889

Email: info@nbmtlink.org

www.nbmtlink.org

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

National Marrow Donor Program

500 North 5th Street

Minneapolis, MN 55401

Patient Advocacy: (888) 999-6743

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

Email: patientinfo@nmdp.org

bethematch.org

The National Marrow Donor Program has the world's largest computerized listing of potential bone marrow donors and offers cooperative search arrangements with many other registries worldwide.

Yale New Haven Children's Hospital

The pediatric blood and marrow transplantation program offers bone marrow, peripheral blood stem cell and cord blood transplants. Children are cared for by a highly trained and knowledgeable medical team that understands the application of research-based therapies and the care needed for pediatric patients undergoing transplantation.

COMPLEMENTARY THERAPIES

What works for some may not work for others. The important thing is to find out what works for YOU and YOUR situation. Others have found that some of the practitioners in this section have been able to help them through this particular period of illness. Here is where you might want to discuss some of these things with a buddy you have met in a support group or online group. Always check with your doctor before beginning any alternative therapy.

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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.

Reiki

Reiki is a Japanese healing technique based on the principle that the therapist can channel energy into the patient by means of touch to activate the natural healing processes of the patient's body and restore physical and emotional well-being.

Academy For Guided Imagery

30765 Pacific Coast Highway, Suite 355

Malibu, CA 90265

Tel: (424) 242-6369

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 purchase.

American Institute for Cancer Research

1759 R Street NW

Washington, D.C. 20009

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

Nutrition Hotline (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.

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 a 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.

Baktulyfe Body Therapies

Licensed massage therapist Karen Dawson, at

Yale New Haven Children's Hospital

Tel: (203) 915-0128

http://baktulyfe.massagetherapy.com/home

Integrative Medicine at Yale University

2 Church Street South, Suite 300

New Haven, CT 06519

Email: integrativemedicine@yale.edu

medicine.yale.edu/integrativemedicine/

Integrative Medicine at Yale is a program de-

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signed to provide a sustainable, central forum at Yale for interdisciplinary, inter-institutional, and international collaboration, research and education in complementary, alternative and integrative medicine.

Kula for Karma

Tel: (888) 545-9642

Email: info@kulaforkarma.org

Kula for Karma offers therapeutic yoga programs, through a dedicated network of specially trained volunteer instructors, at no cost to people with physical, mental and emotional challenges. We work with the medical community to complement traditional approaches to healing those with illness, disease and chronic pain, and those recovering from abuse, trauma and addiction.

National Center for Complementary and Integrative Health

9000 Rockville Pike

Bethesda, MD 20892

Toll-Free: (888) 644-6226

Hearing Impaired: (866) 464-3615

Email: info@nccih.nih.gov

www.nccih.nih.gov

The National Center for Complementary and Integrative Health is dedicated to exploring complementary and alternative healing practices, training complementary and alternative medicine researchers, and disseminating information to the public and professionals. Their website offers live help with a health information specialist Monday through Friday, 8:30 a.m. to 5 p.m. EST.

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.

LIFE AFTER CANCER

Fantastic! You have completed treatment and been given the go ahead to resume normal life. But wait a minute. What IS normal now? This section is here to guide you as you get ready to move forward. Everyone's journey is different. And each family faces their own challenges, but rest assured that someone, somewhere, is feeling just as you are now. Talking through how you will manage all of the "what if" scenarios you have in your head can be helpful. Just as you did in the beginning of this journey do not be afraid to ask questions and accept help.

Connecticut Challenge

250 Pequot Avenue

Southport CT 06890

Tel: (203) 292-8722

www.ctchallenge.org

CT Challenge provides programs for children, young adults and adults post treatment. The vision of the CT Challenge is linked to our deep history of blending sports with a passion for supporting cancer patients and survivors. By building community support through first class events such as the CT Challenge Charity bike event, our goal is to provide avenues to attract energetic people who share our mission to empower cancer survivors to live healthier, happier and longer lives.

Heros Clinic

Yale New Haven Children's Hospital

20 York Street

New Haven, CT 06510

Yale-New Haven Children's Hospital has 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 more than 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.

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 providers 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](mailto: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.

Reach for the Stars

Eileen Gillan, Medical Director
Pediatric Oncology Department
Connecticut Children's Medical Center
282 Washington Street
Hartford, CT 06106
Tel: (860) 545-9630

Email: STARSSurvivorship@Gmail.com
www.starssurvivorshipclinic.com

We believe that individuals who have survived cancer, and its therapy, have been strengthened by their experience and strive to make the most of their life. Our cancer "Survivors Tackle All Roadblocks Successfully!" and "REACH for their own STARS" in life.

The "REACH for the STARS Survivorship Clinic" at Connecticut Children's Medical Center recommends individualized periodic evaluations and medical follow-up directed at current and potential late effects. The clinic emphasizes education for young adults transitioning to managing their health with a goal of medical autonomy and a healthy lifestyle. Our clinic will provide a comprehensive summary of all your treatments, summarized in your web STAR Passport. As you tackle transitioning to adulthood, you will be taking fun quizzes with rewards to encourage you to learn about your disease, its treatment, long

term side effects, and health and wellness. The recommendations for your future surveillance and care will be based on the comprehensive Children's Oncology Group (COG) CureSearch Healthy Links.

SUGGESTED READING

As with most new experiences there are others who have gone before you. We have included books for patients of all ages that can be read to little ones and read by teens. This section also gives you some practical resources that can give you in-depth answers in the form of books, articles and periodicals on subjects as varied as how to talk to your family about cancer and a patient workbook that provides everything you need to stay organized and informed. Information is power. Get it and use it!

I Can Survive

For the Survivor in Each of Us!

By Jennifer May Allen

ISBN 9780944235768

The poetry, optimism, and humor in this award-winning book will encourage cancer patients young and old and their families to find and cherish the small moments and be inspired to express love and support.

My Cancer Days

By Courtney Filigenzi

ISBN 9781604430912

This picture book blends vibrant watercolors with a touching story to show the emotional ups and downs of a little girl going through

cancer treatment. This realistic but hopeful look at a child's experience with cancer can help children express themselves, and it can help the adults in their lives offer the support they need.

The Survivorship Net
A Parable for the Family, Friends, and
Caregivers of People With Cancer

By Jim Owens

ISBN 9781604430189

The author of this beautifully illustrated book uses the parable of circus life to underscore the importance of family, friends, and caregivers in the life of every cancer patient. At once a children's book and a book for "children of all ages," it delivers a powerful and inspiring message to one and all.

NOTES

This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

The information in this book contains
online resources for parents and families of children with cancer.
Each resource has been checked for accuracy at the time of printing.
Check our website for updates. www.thecircleofcare.org

Before making any changes to your routine and/or medical care
always seek the advice of your child's doctor.

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The Purple Pages, a Childhood Cancer resource for families.



Circle of Care
for families of children with cancer

Circle of Care for families of children with cancer, inc is a non-profit 501C(3) organization founded by a group of families whose children have battled and survived cancer. We are dedicated to supporting children with cancer and their families from the time of diagnosis to recovery.

Until no parent has to hear the words "your child has cancer," **we'll be here.**