The National Resource Guide for Families and Caregivers of Children and Teens with Cancer

KIDS' CANCER PAGES
The National Resource Guide for Families and Caregivers of Children and Teens with Cancer

FIFTH EDITION
Visit joyrx.org/kcp for a PDF of this Directory
About the Children’s Cancer Association

The Children’s Cancer Association knows that for seriously ill children and their families every moment is precious. That’s why our programs leverage music, nature, friendship, and resources to create transformative moments of joy for nearly 30,000 children, teens, and their family members each year. We believe kids deserve long, wonderful lives. Or at the very least, short wonderful lives. Unlike many organizations dedicated to the worthy goal of someday finding a cure for cancer, CCA is all about creating joy today. Visit us anytime at JoyRx.org.

We prescribe joy.

CCA is proud to be recognized by GuideStar, the nation’s premier non-profit database, as a Platinum level charity for our strong commitment to fiscal health and transparency. Less than 0.5% of participating non-profits worldwide have achieved this special distinction.

Donor contributions are the lifeblood of our organization; CCA receives no federal or state funding. That’s why we understand the importance of being a good steward of your financial support. For each dollar donated, 76 cents go directly into our programs.

You can help us deliver the healing power of joy to even more families by contributing today at JoyRx.org/Donate.

We look to our friends and community to help us keep the Kids’ Cancer Pages a vital and up-to-date directory. Please contact us to recommend new organizations you think would be valuable resources or to suggest edits to the next edition. Visit JoyRx.org/KCP for the most up-to-date version of this resource.
We believe kids deserve long, wonderful lives. Or, at the very least, short, wonderful lives. We believe cancer sucks. We’ve had it, or loved someone who did. We prescribe moments of joy for kids who are in the fight against all serious illness. We believe joy grows exponentially when it’s used collectively. We are music medicine pioneers. We believe in purple. We know joy comes in all colors, shapes, and sizes – just like the kids we help. We love to laugh. We are not afraid to cry. We spend every dollar wisely. We give hugs freely. We believe in today. We respect our history as a grassroots organization. We embrace our destiny as a global source of JoyRx. We believe these things matter.

Children’s Cancer Association Programs & Resources

CCA’s Kids’ Cancer Pages is provided to every pediatric hospital in the U.S. A hardcopy can also be mailed to any family or caregiver free of charge upon request. Visit JoyRx.org/KCP to view this resource online.

AVAILABLE TO QUALIFYING FAMILIES IN PORTLAND, OR:

MyMusicRx®
MyMusicRx delivers the healing power of music to kids facing cancer and other serious illnesses. Our bedside and digital* programs engage hospitalized children of all ages and diagnoses, relieving stress, anxiety, and perception of pain.

*MyMusicRx Digital is available nationwide at MyMusicRx.org.

Chemo Pal® Mentor
CCA’s award-winning Chemo Pal mentors play games, listen to music, share hobbies, or simply offer the comfort of companionship, relieving the anxiety, loneliness, and isolation experienced by children in treatment.

The Alexandra Ellis Caring Cabin™
Nestled in 24 acres of surrounding woods with plentiful wildlife and a serene lake, the Alexandra Ellis Caring Cabin provides children in treatment, and their extended families, with an essential health connection to nature and healing.

Link Program
CCA’s Link program takes the profound emotional and financial hardships of serious pediatric illness head on, engaging a network of caring people and organizations to provide families with essential needs assistance and support.

For more information, visit JoyRx.org/Programs.
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ACCURACY

When this directory was published, all resources were derived from the most current and authoritative publicly available national sources known to the author. If we inadvertently missed an organization or resource and/or an organization has changed contact information, please email Office@JoyRx.org.
Table of Contents

Where to Begin Your Search ..................... 1
Information and Resources ....................... 5
   Disease-Specific Resources .................. 7-11
       Bone ........................................... 7
       Brain ......................................... 7-8
       Breast ........................................ 8
       Endocrine .................................... 8
       Leukemia and Lymphoma .................. 8-9
       Liver .......................................... 9
       Lung .......................................... 9
       Nervous System .............................. 9
       Ocular ...................................... 9-10
       Oral, Head, and Neck ...................... 10
       Skin ........................................ 10
       Soft Tissue Sarcoma ......................... 10
       Urogenital ................................... 10
   Other Hematology/ Immune Deficiency
       Syndromes and Conditions ............... 10-11
   Caregiving and Home Care ................... 12
   Disability ...................................... 13-14
   Intercultural Resources ........................ 15
   Pain Management ................................ 16
   Reference and Accreditation ................ 17
   Support, Information, and Counseling ...... 18-20
       Find a Counselor or Therapist ............ 18
       Find Immediate Support .................... 18
       Organizations Offering Resources and
           Information ............................... 18-20
   Transplant and Donor Programs ............. 21
   Aid and Assistance ............................. 23
       Camps and Vacation Retreats .............. 25-26
       Community Forums and Friends .......... 26-27
       Child/ Teen Support and
           Community Forums ....................... 26
       Parent Support and
           Community Forums ....................... 26-27
       Sibling Support and
           Community Forums ....................... 27
       Educational Financial Aid .................. 27
       Employment and Legal Assistance ......... 28
       Financial and Aid Assistance .............. 29-30
       Fundraising and Social Networking .......... 31
       Insurance and Medical Assistance ......... 32
       Life After Cancer ............................ 33
       Odds and Ends ............................... 34-35
       Prescription Assistance .................... 36
       Travel and Lodging Assistance .......... 36-37
           Air Transport ............................ 36
           Ground Transportation .................. 37
           Lodging ................................... 37
       Wish Fulfillment Organizations .......... 38
       Wish Fulfillment for Young Adults ......... 39
   Support for End of Life ......................... 41
       Compassionate Care Resources .......... 43
       Funeral and Memorial Services .......... 44
       Grief and Bereavement ..................... 44-45
   Index ......................................... 47

How to Use This Resource Guide

Resources marked with this symbol have been identified as good places to begin your search within each section. This symbol does not indicate that Children’s Cancer Association is affiliated with these organizations and does not endorse the program and resources associated within each.

Resources marked by this symbol indicate that some, or all, of the information provided by the organization can be accessed in Spanish. Los recursos marcados con este símbolo indican que parte o toda la información proporcionada por la organización se puede acceder en español.
Where to Begin Your Search

When facing a diagnosis of pediatric cancer, families can be overwhelmed by fear, confusion, questions, grief, and hope. This section offers a place to begin your journey with national resources that provide comprehensive information related to your child’s cancer, treatment, support, and education.
Where to Begin Your Search

American Cancer Society
Location: Atlanta, GA
Phone: (800) 227-2345
Web: cancer.org

A nationwide, community-based health organization that assists people with cancer through research, education, advocacy, and service. Use live chat, call their information line, or search their ‘Find Support & Treatment’ section to find help including, but not limited to:
- Free publications regarding diagnosis, treatment, and nutrition
- Treatment Center Locator
- Counseling and emotional support
- Transportation and lodging assistance
- Help and support for home health care
- Blood programs
- Employment assistance

American Childhood Cancer Organization
Location: Kensington, MD
Phone: (855) 858-2226
Web: acco.org

Resources designed for children and families by those who have experienced pediatric cancer themselves. This resource provides services for kids, teens, and parents, organizes local assistance for families, and offers free books and resources. ACCO offers a 24/7 online parent peer support community.

Cancer.Net
Phone: (888) 651-3038
Web: cancer.net/cancer-types

A product of the American Society of Clinical Oncology (ASCO), this site was developed and approved by doctors to provide information regarding types of cancer, navigating cancer care, ways to cope with cancer, and resources regarding survivorship. Cancer.net also supports a searchable database of ASCO doctors, oncologist-approved cancer information from the American Society of Clinical Oncology, and information about diagnosis, treatment options, clinical trials, and side effects.

Children’s Oncology Group
Location: Monrovia, CA
Phone: (626) 241-1500
Web: childrensoncologygroup.org

Partners with research scientists worldwide in order to understand the causes of cancer and find more effective treatments, including clinical development of new therapies for children and adolescents with cancer.

CureSearch
Location: Bethesda, MD
Phone: (800) 458-6223
Web: curesearch.org
Mobile App: CancerCare by CureSearch

Offers up-to-date information about the various types of children’s cancer along with research trials; definitions and descriptions of tests, procedures, and treatments; and information to help families manage the emotional aspects of caring for a child with cancer. A series of interactive, print, and digital resources for patients and families are available at no cost on their website.

KidsHealth.org
Web: kidshealth.org

Provides information for parents as well as kids and teens about specific types of childhood cancer, important cancer terms, supporting a friend, as well as general information including nutrition, emotions and behavior, and visiting the hospital.

MedlinePlus.gov
Web: medlineplus.gov/cancerinchildren.html

Delivers information on many types of cancer treatment and where to get more information. Includes information that will help build an understanding of childhood cancer starting at basic and extending to the specific. This resource includes videos and tutorials, information about tests and diagnosis, as well as resources for helping a child understand cancer and their treatment journey.

National Cancer Institute
Location: Bethesda, MD
Phone: (800) 422-6237
Web: cancer.gov

General information, cancer topics, disease-specific information, clinical trials, lists of treatment centers by state, and more. This resource also offers an interactive chat option for additional support. Four potentially helpful NCI resources:
- List by State of Cancer Treatment Centers of Excellence
  Web: cancercenters.cancer.gov/Center/CCList
- Specific Cancer Types
  Web: cancer.gov/types/childhood-cancers
- Clinical Trials
  Web: cancer.gov/clinicaltrials

National Organization for Rare Disorders
Location: Danbury, CT
Phone: (203) 744-0100
Web: rarediseases.org

Provides current information on rare diseases, including numerous forms of pediatric cancer and a comprehensive listing of additional resources including health insurance information, patient assistance and financial assistance programs, and local resources or events. NORD also makes available a patient service line for assistance at 1-800-999-6673 (Hablar espanol 844-259-7178).

Oncolink
Location: Philadelphia, PA
Web: oncolink.org

Helps patients and families learn about what to do when first diagnosed, how to prepare for visits to the oncologist, as well as provides information about different types of treatment, and support for living with cancer. Oncolink also supports a variety of helpful PDFs that can help you organize appointments, treatment, medications, and more.
Information and Resources

Your child’s cancer diagnosis and treatment impacts everyone in your family. There are so many things to learn, so many things to do, all while recognizing the needs of your ill child and other family members, as well as taking care of yourself. This section will provide you with a variety of resources that can help you navigate treatment, family life, and more. These resources are organized as follows:

• Disease specific information and resources
• Opportunities for support and counseling
• Resources and organizations related to pain management
• Support and services for children with disabilities
• Registries and information for transplant and donor programs
• Support for caregiver and in-home care
• Resources to research doctors, facilities, trials, and tests
• Resources and support to help navigate cultural and language barriers
Disease-Specific Resources

Alphabetical listing of services and information related to specific types of pediatric cancer. Resources listed under ‘Where to Start’ are also good places to search for cancer-specific information.

**Bone**

The Cure Our Children Foundation
Phone: (310) 355-6046
Web: cureourchildren.org
Site is maintained by the family of a childhood Ewing’s survivor. It contains information about initial diagnosis, sibling support, preparing your home for a child undergoing chemo, and more.

The Liddy Shriver Sarcoma Initiative
Web: sarcomahelp.org
Provides information for the newly diagnosed Osteosarcoma patient and their families, as well as available treatment centers, information about current research, and stories of support. While the initiative is no longer active, the site provides helpful resources and information.

National Cancer Institute – Ewing Sarcoma for Patients
Web: cancer.gov/types/bone/patient/ewing-treatment-pdq
Includes general information, the stages of Ewing Sarcoma, treatment options, tests, clinical trials, and more.

St. Jude Children’s Research Hospital – Osteosarcoma
Web: stjude.org/disease/osteosarcoma.html
Includes general information about pediatric Osteosarcoma as well as current links to associated clinical trials.

Pediatric Oncology Resource Center – Bone Cancers
Web: ped-onc.org
Provides general information regarding childhood bone cancers and provides suggested additional resources related to identification, treatment, and more.

**Brain**

American Brain Tumor Association
Location: Chicago, IL
Phone: (800) 886-2282
Web: abta.org
Provides free services including publications about brain tumors, support group lists, caregiver resources, clinical trial connections, an online support community, and research support.

Brain Trust
Location: Everett, MA
Phone: (617) 876-2002
Web: braintrust.org
Focused on creating online support groups and resources for those affected by brain tumors and related conditions.

Brain Tumour Foundation of Canada
Location: London, ON, Canada
Phone: (800) 265-5106
Web: braintumour.ca
Includes a helpful overview of the brain and how it functions, facts about brain tumors, descriptions of types of tumors and cysts, an overview of current treatments, what to expect at the hospital and home, and a glossary of terms.

Children’s Brain Tumor Foundation
Location: New York, NY
Phone: (212) 448-9494
Web: cbtf.org
Offers critical information, free publications, support, and up-to-date research. CBTF has a Family 2 Family Network focused on connecting families facing similar situations.

Dana-Farber Cancer Institute Children’s Hospital Boston
Location: Boston, MA
Phone: (888) 766-7662
Web: dana-farber.org/childhood-brain-tumor-center
Provides information related to different types of childhood cancer, returning to school while in treatment, ethical consultations, and supports an in-depth library related to health topics.

Lash and Associates Publishing/Training Inc.
Location: Youngsville, NC
Phone: (919) 556-0300
Web: lapublishing.com
Resource for published materials related to the neurological, psychological, communicative, psychosocial, and educational impact of brain injuries among children, youth, and young adults.

Meningioma Mommas
Location: Highlands Ranch, CO
Web: meningiomamommas.org
Provides a support group for those affected by meningioma brain tumors and supports medical research on the topic.
Musella Foundation
Location: Hewlett, NY
Phone: (516) 295-4740
Web: virtualtrials.com
Supports brain tumor patients through emotional support, connections to treatment options, resources related to financial/insurance support, as well as support groups. The Musella Foundation also collects information related to identifying promising treatment options.

National Institute of Neurological Disorders and Stroke
Location: Bethesda, MD
Phone: (800) 352-9424
Web: ninds.nih.gov
Supports and conducts research related to the brain, spinal cord, and peripheral nerves. Web provides news about research as well as a connection to clinical trials.

Pediatric Brain Tumor Foundation
Location: Asheville, NC
Phone: (800) 253-6530
Web: curethekids.org
Researches causes and treatments for childhood brain tumors. Provides educational and emotional support for children and families.

Pituitary Network Association
Location: Thousand Oaks, CA
Phone: (805) 499-9973
Web: pituitary.org
Provides information about finding a doctor who specializes in pituitary-related disorders, general information, as well as mental health and research resources.

Southeastern Brain Tumor Foundation
Location: Atlanta, GA
Phone: (786) 505-7283
Web: sbtf.org
Focuses on funding brain tumor research but also provides information, education, and support services for brain tumor patients and their families.

Breast
Breastcancer.org
Web: breastcancer.org
Information related to breast cancer diagnosis, treatment, living day-to-day, and risk factors. Also includes ‘Ask-the-Expert’ online forums, online discussion boards, and chat rooms.

National Lymphedema Network
Location: Berkeley, CA
Phone: (510) 809-1660
Web: lymphnet.org
Provides education, management, and prevention information to membership subscribers. Non-members can use their searchable treatment finder, read a selection of publications, and utilize their support hotline at (800) 541-3259.

Susan G. Komen for the Cure
Location: Dallas, TX
Phone: (877) 465-6636
Web: komen.org
Provides extensive support, education, and resources to patients and families including a helpline at (877) 465-6636.

Endocrine
Carcinoid Cancer Foundation
Location: White Plains, NY
Phone: (888) 722-3132
Web: carcinoid.org
Provides comprehensive and up-to-date resources with information about carcinoid and neuroendocrine tumors. Other resources include support finding a doctor, diagnosis, treatment, videos, and group chat/support.

Hirshberg Foundation for Pancreatic Cancer Research
Location: Los Angeles, CA
Phone: (310) 473-5121
Web: pancreatic.org
Focused on research as well as supporting patients and their families, HFPCR provides resources related to financial aid, legal advocacy, counseling and support for kids, and clinical trial information. This site also includes links to free materials for caregivers and patients.

Lustgarten Foundation for Pancreatic Cancer Research
Location: Bethpage, NY
Phone: 866-789-1000
Web: lustgarten.org
Provides information and support for pancreatic cancer patients, their families, and friends, including information for those newly diagnosed. Searches for clinical trials, and links to additional resources.

MedlinePlus.gov — Testicular Cancer
Web: nlm.nih.gov/medlineplus/testicularcancer.html
From the National Institutes of Health and National Library of Medicine. Site suggests links to disease information, discusses diagnosis, treatment, prevention, and provides links to support organizations. Includes a section on children and teens.

Pancreatic Cancer Action Network
Location: Manhattan Beach, CA
Phone: (877) 573-9971
Web: pancan.org
Provides free one-on-one support and information through a patient and caregiver help line at (877) 573-9971, as well as information related to clinical trials and general pancreatic cancer information.

Leukemia & Lymphoma
Childhood Leukemia Foundation
Location: Brick, NK
Phone: (888) 253-7109
Web: clf4kids.org
Provides practical information for caregivers, siblings, and patients including financial aid, homecare, transportation, a support network, and more.
Children’s Leukemia Research Association
Location: Garden City, NY
Phone: (516) 222-1944
Web: childrensleukemia.org
Supports a patient aid program to help pay for leukemia medication not covered by insurance. This site also includes information and resources about diagnosis and treatment.

International Myeloma Foundation
Location: North Hollywood, CA
Phone: (800) 452-2873
Web: myeloma.org
Provides up-to-date and in-depth information about myeloma including research and treatment advances, a patient infoline at (800) 452-2873, and resources for newly diagnosed patients.

Leukemia & Lymphoma Society 💚
Location: White Plains, NY
Phone: (800) 955-4572
Web: lls.org
Provides access to information, specialists, support groups, peer-to-peer support, and many additional resources and suggested readings. Financial assistance is also available through LLS for medications, treatment, and additional costs.

Leukemia Research Foundation
Location: Northfield, IL
Phone: (847) 424-0600
Web: leukemia-research.org
Offers access to up-to-date research, financial assistance, educational opportunities, and discusses available treatment options.

Lymphoma Research Foundation
Location: New York, NY
Phone: (800) 500-9976
Web: lymphoma.org
Offers information for patients on new treatments, general information on lymphoma, support group listings, clinical trial information, a helpline, and resources related to financial assistance.

Multiple Myeloma Research Foundation
Location: Norwalk, CT
Phone: (203) 229-0464
Web: community.themmrf.org
Offers information about myeloma, resources for dealing with side effects, access to clinical trials, research, quick facts, and links to other resources. MMRF also provides a nurse specialist line at 1-866-603-6628.

Liver

American Liver Foundation 💚
Location: New York, NY
Phone: (212) 943-1059
Web: liverfoundation.org
Includes important information related to identifying and treating liver cancer. This website also provides a mailing list and list of relevant medical terms.

Children’s Liver Association for Support Services 💚
Location: Valencia, CA
Phone: (877) 679-8256
Web: classkids.org
Provides information about pediatric liver disease including a telephone helpline (877) 679-8256, a seasonal newsletter, financial support resources, and educational materials.

Lung

American Lung Association 💚
Location: Washington, D.C.
Phone: (800) 548-8252
Web: lung.org
Includes resources related to diagnosis and treatment, living with lung cancer, and shared stories.

Lung Cancer 101 💚
Location: New York, NY
Phone: (800) 813-4673
Web: lungcancer.org
Provides free counseling, support groups, financial assistance, educational workshops, and publications to anyone coping with lung cancer.

Nervous System

Children’s Neuroblastoma Cancer Foundation 💚
Location: Bloomingdale, IL
Phone: (866) 671-2623
Web: cnchope.org
Acts as a liaison between health care providers and families by providing information about neuroblastoma, what to do when newly diagnosed, and what happens after treatment.

Children’s Tumor Foundation
Location: New York, NY
Phone: (800) 323-7938
Web: ctf.org
Focuses on neurofibromatosis (NF): providing resources for what to do after diagnosis, how to join the NF registry and engage in research efforts, as well as finding a specialized doctor.

Neuroblastoma Children’s Cancer Society
Location: Hoffman Estates, IL
Phone: (800) 532-5162
Web: neuroblastomacancer.org
Provides a handbook containing relevant information as well as helpful links to additional resources and a NCCS newsletter.

Neuroblastoma Society
Web: nsoc.co.uk
Offers downloadable booklets for parents, as well as general information and treatment options.

Ocular

American Association for Pediatric Ophthalmology and Strabismus 💚
Location: San Francisco, CA
Phone: (415) 561-8505
Web: aapos.org
Provides a doctor search, information about childhood eye disorders, and additional resources. Available in Spanish and Chinese.
Eye Cancer Network
Location: New York, NY
Phone: (212) 832-8170
Web: eyecancercure.com
Provides information about the diagnosis and treatment of ocular tumors, eye cancer, and orbital diseases for patients and their families. Includes a search for specialist doctors.

Melanoma Research Foundation
Location: Washington, D.C.
Phone: 800-673-1290
Web: melanoma.org/understand-melanoma/pediatric-melanoma
Provides information about Melanomas, discusses treatment options, and provides opportunities for community support and financial assistance.

Urogenital
National Ovarian Cancer Coalition
Location: Dallas, TX
Phone: (214) 273-4200
Web: ovarian.org
Provides information related to ovarian cancer in general, caregiver support, clinical trial connections, emotional support, a specialist search option, peer-to-peer support, and a helpline at (888) 682-7426.

Oral, Head & Neck
Head and Neck Cancer Alliance
Location: Charleston, SC
Phone: (866) 792-4622
Web: headandneck.org
Provides support to patients, education to children and adults on the disease process, treatment of head and neck cancer, financial support opportunities, and provides an online support community.

Oral, Head and Neck Cancer Support
Location: Locust Valley, NY
Phone: (800) 377-0928
Web: spohnc.org
Provides the opportunity for support through local chapters and volunteer networks, as well as offering resources, links, clinical trial information, and answers to general questions. Additional resources include emotional support, nutritional guidance, and caregiver support.

Soft Tissue Sarcoma
Northwest Sarcoma Foundation
Location: Portland, OR
Phone: (503) 781-0921
Web: nwsarcoma.org
Supports and educates those who are living with sarcoma and other rare bone tumor diseases. Provides comprehensive resources related to caregiver support, financial assistance, support groups, and information for new patients.

Sarcoma Alliance
Location: Mill Valley, CA
Phone: (415) 381-7236
Web: sarcomaalliance.org
Offers guidance, education, and support to patients and families. Information relates to treatment, clinical trials, sarcoma specialist search, nutrition, personal tools, and access to support groups and a chat room.

Skin
American Academy of Dermatology
Location: Schaumburg, IL
Phone: (866) 503-7546
Web: aad.org
A professional association that also provides information for the general public under “Public and Patients.” Through the AAD you can find a dermatologist, learn about skin cancer, visit chat rooms, find treatment options, and visit kid’s resources.

Aplastic Anemia and MDS International Foundation
Location: Rockville, MD
Phone: (800) 747-2820
Web: aplastic.org
Provides assistance, education, and emotional support for patients and caregivers. Includes educational materials and support for aplastic anemia, myelodysplastic syndromes, and paroxysmal nocturnal hemoglobinuria.
Fanconi Anemia Research Fund
Location: Eugene, OR
Phone: (541) 687-4658
Web: fanconi.org
Provides information related to diagnosis, research, treatment, and support for families and caregivers through online groups.

Histocytosis Association of America
Location: Pitman, NJ
Phone: (856) 589-6614
Web: histio.org
Provides resources specific to this disease and offers care to patients and their families through support groups, educational materials, videos, and a physician directory.

Mesothelioma Web
Phone: (877) 367-6376
Web: mesotheliomaweb.org
Discusses the causes, symptoms, and treatments for mesothelioma. Covers both juvenile and adult cancer providing information related to how to choose a doctor, clinical trials, support groups, and treatment options.

National Cancer Institute – Unusual Cancers of Childhood
Web: cancer.gov/types/childhood-cancers/patient/unusual-cancers-childhood-pdq
Provides information on unusual cancers in children.

National Organization for Rare Disorders
Location: Danbury, CT
Phone: (800) 999-6673
Web: rarediseases.org
Provides resources related to the identification and treatment of rare disorders through education, advocacy, research, and service. Provides prescription assistance, networking options, a resource guide, and a library of links. Additional resources include news and information, and databases of diseases, organizations, and subscriptions.

Neutropenia Support Association Inc.
Location: Winnipeg, Manitoba, Canada
Phone: (800) 663-8876
Web: neutropenia.ca
Provides information regarding Neutropenia, and offers a registry for a worldwide database related to treatment and Neutropenia. Available in English and French.

National Lymphedema Network
Location: Berkeley, CA
Phone: (800) 541-3259
Web: lymphnet.org
Provides information related to treatment options (including a treatment finder), general information, insurance assistance, clothing assistance, support groups, and helpful additional information.

Von Hippel Lindau Family Alliance
Location: Boston, MA
Phone: (800) 767-4845
Web: vhl.org
The VHL Alliance offers information and support to families with the rare familial disorder Von Hippel Lindau Syndrome. Includes a reference handbook for people with VHL, general information, treatment options, and caregiver support.
Caregiving and Home Care

Resources regarding home care, assistive equipment, home nursing, respite care, caregiving support, and related services.

AbleData
Location: Falls Church, VA
Phone: (800) 227-0216
Web: abledata.com
Delivers information on thousands of assistive devices for those living with disabilities. This searchable database includes information on products and manufacturers, prices, names, and contact information for equipment suppliers.

Cancer Care, Inc.
Location: New York, NY
Phone: (800) 813-4673
Web: cancercare.org
Offers group, individual, family, and bereavement counseling (in person, online, and through telephone); information and referral to local community resources; supplementary financial assistance for home care, transportation, and pain medication; volunteer visitor program; community education programs; technical assistance to professionals regarding psychosocial aspects of cancer; as well as an African-American and Hispanic Outreach Program.

Caregiver Action Network
Location: Washington, D.C.
Phone: (202) 454-3970
Web: caregiveraction.org
Provides comprehensive information for family caregivers. Information includes resources related to education, support, respite care and advocacy for caregivers. Toll-free information line provides referrals to caregiver support groups and a resource guide.

Caregiver Survival Resources
Location: Fort Lauderdale, FL
Phone: (954) 893-0550
Web: caregiver.com
Provides comprehensive resources linking caregivers to tips, additional resources, up-to-date information, publications, and more.

Lotsa Helping Hands
Location: Chicago, IL
Web: lotsahelpinghands.com
Creates an online platform for requesting support from the community around you. Requests can include meal assistance, rides to medical appointments, or company.

Oley Foundation
Location: Albany, NY
Phone: (800) 776-6539
Web: oley.org
Provides education, outreach services, conference activities, and emotional support for people with home IV and tube feedings and their families.

Pediatric Services of America
Location: Atlanta, GA
Phone: (770) 441-1580
Web: psahealthcare.com
Offers comprehensive services designed to address the full range of home health care needs of pediatric patients, particularly the needs of medically fragile children dependent upon sophisticated nursing care and medical technology.

Visiting Nurse Association of America
Location: Arlington, VA
Phone: (888) 866-8773
Web: vnaa.org
Members provide cost-effective home health and hospice care. Their services include home care services, specifically skilled nurses, therapists, and home health care aids.
Disability

The following organizations provide support, information, and/or services to families who have a child with a disability. Your child may qualify for help from these organizations if he or she has disabling effects associated with cancer.

**AbleData**
Location: Falls Church, VA
Phone: (800) 227-0216
Web: abledata.com

Provides information on thousands of assistive devices for those living with disabilities. This searchable database includes information on products and makers, prices, names, and contact information for equipment suppliers.

**American Society for Deaf Children**
Location: Washington, D.C.
Phone: (800) 942-2732
Web: deafchildren.org

Offers support, encouragement, and information to families with hearing-impaired children. Has resources for parents and families, educators, and service providers. Includes resources related to parent support groups, deaf and hearing role models, and an extensive resource guide.

**About Face**
Location: North York, Ontario, Canada
Phone: (800) 665-3223 ext. 21
Web: aboutface.ca

Offers information, support services, educational programs, outreach and public awareness for people living with facial differences. AboutFace hosts a variety of retreats and camps for kids and adults, peer-to-peer networking, and caregiver support.

**American Academy of Audiology**
Location: Reston, VA
Phone: (800) 222-2336
Web: audiology.org

A professional organization that provides a database search for audiologists.

**American Council of the Blind**
Location: Alexandria, VA
Phone: (800) 424-8666
Web: acb.org

Provides information and referral on all aspects of blindness including computer products, public education assistance and awareness, trainings, guide dog resources, manuals and handbooks, braille, useful products, and other low-vision resources.

**Amputee Coalition of America**
Location: Manassas, CA
Phone: (888) 267-5669
Web: amputee-coalition.org

Advocates for the rights of people with limb loss. This includes access to information, quality care, devices, reimbursement, and the services required to lead empowered lives. Through the ACA Limb Loss Resource Center you can access resources by state/topic/specific groups, or through the ask an information specialist option. ACA also offers a free inMotion magazine.

**ARCH: National Respite Network**
Location: Chapel Hill, NC
Phone: (703) 256-2084
Web: archrespite.org

Offers a National Respite Locator that can help caregivers of children with special needs find emergency or planned temporary relief. Additional resources include webinars and training resources, consumer information, and local events.

**Center for Parent Information and Resources**
Location: Newark, NJ
Web: parentcenterhub.org

A resource for information and products available through Parent Training Information Centers and Community Parent Resource Centers. This website has a searchable resource for community resource centers at the local and state level.

**Disability Rights Education and Defense Fund**
Location: Berkeley, CA
Phone: (510) 644-2555
Web: dredf.org

Focuses on civil right and policy education, training and technical support. This website provides information on legal advocacy, healthcare access, and special education.

**Disabled Sports USA**
Location: Rockville, MD
Phone: (301) 217-0960
Web: dsusa.org

A nationwide sports rehabilitation program for anyone with a permanent physical disability. This program engages sports as a rehabilitation process and offers both summer and winter sports programs.

**Federation for Children with Special Needs**
Location: Boston, MA
Phone: (800) 331-0688
Web: fcsn.org

Provides information and referrals to a variety of services, parent training and family education, support groups, community engagement, parent networking, special education information, and additional resources.

**BEGINNINGS**
Location: Raleigh, NC
Phone & TTY: (919) 715-4092
Web: ncbegin.org

Provides resources for parents, professionals, and kids and teens related to hearing loss, and the diverse needs of children who are deaf or hard of hearing. This website also has age-specific information, ways to connect with other parents, and hearing systems.
Genetic Alliance  
Location: Washington, D.C.  
Phone: (202) 966-5557  
Web: geneticalliance.org

Information and Resources

Offers information on genetic counseling and genetic conditions, and organizes a network of more than 1,200 disease-specific advocacy organizations. This organization seeks to empower individuals and organizations to help better the lives of those living with genetic conditions.

HEATH Resource Center  
Location: Washington, D.C.  
Web: heath.gwu.edu

Aims to assist people with disabilities in learning about and accessing postsecondary education. Provides information about educational support services, policies, procedures, adaptations, and opportunities at American campuses, vocational-technical schools, and other postsecondary training entities.

Lighthouse for the Blind  
Location: New York, NY  
Phone: (800) 284-4422  
Web: lighthouse.org

Offers information related to vision and healthcare organizations as well as education and community outreach. Specifically offers resources related to vision rehabilitation, behavioral health, education, advocacy, research, scholarships, and more.

Medlineplus.gov — Hearing Disorders and Deafness  
Web: medlineplus.gov/hearingdisordersanddeafness.html

Offers links to information, support organizations, specific treatments and assistive devices.

Miracle Ear Children's Foundation  
Location: Minneapolis, MN  
Phone: (877) 268-4264  
Web: miracle-ear.com/foundation

Provides hearing aids to individuals who do not qualify for public assistance. This foundation offers information on alternative communication and offers a variety of educational materials and brochures.

National Center for Learning Disabilities  
Location: New York, NY  
Web: ncld.org

Provides advocacy and programs related to personalized support, tools for learning and developing literacy, and resource guides for parents and educators. NCLD offers support for children and young adults with learning disabilities.

National Federation of the Blind  
Location: Baltimore, MD  
Phone: (410) 659-9314  
Web: nfb.org

Provides information and referral services, scholarships, publications, aids and adaptive equipment, advocacy services, and support for the blind and their families.

National Lekotek Center  
Location: Chicago, IL  
Phone: (773) 528-5766  
TTY: (773) 248-9174  
Web: lekotek.org

Focuses on using toys and play to help children with disabilities reach their potential and to increase inclusion. Nationwide, there are 37 centers that offer family play sessions, toy lending libraries, Compuplay family computer centers, and other innovative community-specific programming.

National Library Service for the Blind and Physically Handicapped  
Location: Washington, D.C.  
Phone: (202) 707-5100  
TTY: (202) 707-0744  
Web: loc.gov/nls/

A free library program of Braille and audio materials circulated to eligible borrowers in the United States by postage-free mail. It includes a Kids Zone and links to local participating libraries.

Professional Association of Therapeutic Horsemanship International  
Location: Denver, CO  
Phone: (800) 369-7433  
Web: pathintl.org

Fosters therapeutic equine activities through education, communication, standards, and research for people with and without disabilities. Promotes more than 650 equine-facilitated therapy and activity programs in the United States and Canada.

United Ostomy Association  
Location: Kennebunk, ME  
Phone: (800) 826-0826  
Web: ostomy.org

Provides information and support for those who need ostomy resources. This website includes information about ostomies, support groups, diet and nutrition, and other resources. UOA also provides a free information and resource magazine.

Wheel to Walk Foundation  
Location: Portland, OR  
Phone: (503) 257-1401  
Web: wheeltowalk.com

Provides access to medical equipment and services not provided by insurance. The foundation purchases many different types of assistive devices that could help improve the quality of life for a child or young adult with special needs.
**Intercultural Resources**

Organizations that offer support and help transcend cultural and language barriers associated with medical care issues.

**The Asian American Cancer Support Network**
Location: Sunnyvale, CA  
Phone: (650) 968-8488  
Web: aacsn.org

Provides an educational, supportive, and diverse network of resources for Asian Americans affected by cancer. They provide workshops addressing cancer and fatigue, Eastern medicine, relaxation and health exercises such as Qi Gong and Tai Chi, and nutrition.

**American Indian Cancer Foundation**
Location: Minneapolis, MN  
Phone: (612) 314-4848  
Web: americanindiancancer.org

Dedicated to eliminating the cancer burdens on American Indian families through education, prevention, early detection, treatment and survivor support.

**CancerQuest ❤️**
Location: Atlanta, GA  
Phone: (404) 727-0308  
Web: cancerquest.org

Provides easy-to-understand and accurate information about cancer biology and treatment.

**Intercultural Cancer Council**
Location: Nashville, TN  
Web: interculturalcancercouncil.org

Promotes policies, programs, partnerships, and research to eliminate the unequal burden of cancer among racial and ethnic minorities and medically underserved populations. Provides publications specific to cancer, ethnic and racial groups, and pediatric cancer diagnoses.

**KidsHealth.org ❤️**
Web: kidhealth.org

Provides information for kids, teens, and parents regarding a variety of health topics including: nutrition, emotions and behavior, doctors and hospitals, school and family life, and more. This website also offers all resources in English and Spanish.

**National Coalition for Latinxs with Disabilities ❤️**
Web: latinxdisabilitycoalition.com

Works to affirm, celebrate, and collectively uplift Latinxs with disabilities through community building, advocacy, protection of rights, resources, and education.

**National Alliance for Hispanic Health ❤️**
Location: Washington, D.C.  
Phone: (202) 387-5000  
Web: healthyamericas.org

Focuses on ensuring the best health outcomes for all through research, services, and policy. They provide information and resources specifically related to improving the health of the Hispanic community.

**Native American Cancer Research**
Location: Pine, CO  
Phone: (800) 537-8295  
Web: natamcancer.org

Dedicated to helping improve the lives of Native American cancer patients and survivors. This site offers resources for caregivers, genetic education, and resources about cancer treatment, diagnosis, and support.

**Office of Minority Health ❤️**
Phone: (204) 453-2882  
Web: minorityhealth.hhs.gov

Dedicated to improving the health of racial and ethnic minority populations through resources, programs, campaigns, and initiatives.

**Parent Advocacy Coalition for Educational Rights (PACER) Center ❤️**
Location: Bloomington, MN  
Phone: (952) 838-9000  
Web: pacer.org/es/

A parent training and information center for families of children and youth with all disabilities from birth to young adults. Parents can find publications, workshops, and other resources to help make decisions about education, vocational training, employment, and other services for their children with disabilities.

**Padres Contra El Cáncer ❤️**
Location: Los Angeles, CA  
Phone: (888) 441-0056  
Web: iamhope.org

Supports the needs of children and families impacted by cancer within the Latino community. This organization aims to promote understanding, knowledge, emotional health, and family education through culturally relevant and linguistically appropriate programs.
Pain Management

The following organizations offer support and information on managing pain associated with cancer, cancer treatment, and palliative care.

**American Chronic Pain Association ❤️**
Location: Rocklin, CA  
Phone: (800) 533-3231  
Web: theacpa.org  

Offers resources including treatment recommendations and information, clinical trials, and support groups. Includes thorough and practical pain management tools.

**American Pain Society ❤️**
Location: Chicago, IL  
Phone: (847) 375-4731  
Web: painmed.org/patientcenter  

Offers a patient resource center that includes a physician search, facts about pain, patient education, current research, and additional links to organizations dedicated to people experiencing pain.

**Cancer.Net**
Phone: (888) 651-3038  
Web: cancer.net  

Provides many articles and resources related to managing pain, treating pain with medication, pain during and after treatment, and more.

**The Coalition Against Pediatric Pain**
Location: Marshfield, MA  
Phone: (508) 546-0253  
Web: tcapp.org  

Provides support and information for caregivers, physicians, and children related to pediatric pain. Support includes school and education advocacy, disability information, medical equipment and medication guides, and more.

**CureSearch.org**
Location: Bethesda, MD  
Phone: (800) 458-6223  
Web: curesearch.org/pain  

Includes resources and techniques to help when the focus is on providing both physical and emotional comfort to a child and their family. The search function can offer access to resources related to pain management, palliative care, and talking with your child about care.

**Get Palliative Care**
Web: getpalliativecare.org  

Helps patients and families facing serious illness find relief from pain, fatigue, nausea, loss of appetite, shortness of breath, and more. This resource also includes additional information about what palliative care is, if it is right for your child, additional resources, and caregiver help.

**National Cancer Institute - Cancer Information Service 🌟**
Location: Bethesda, MD  
Phone: (800) 422-6237  
Web: cancer.gov  

Provides a variety of resources and publications with information about pain side effects, supportive care, and additional cancer-related resources. Topic-specific information can be found through the search option. Cancer.gov also offers help immediately through the LiveHelp Chat, and their telephone helpline at (800) 422-6237.

**National Hospice and Palliative Care Organization 🌟**
Phone: (800) 658-8898  
Web: caringinfo.org  

Offers information regarding pain management and palliative care, including frequently asked questions, additional resources, and caregiving.

**Oncolink: Pain Management 🌟**
Location: Philadelphia, PA  
Phone: (215) 349-8895  
Web: oncolink.org  

Use Oncolink’s search function to find helpful information related to pediatric cancer pain management, treatment-related pain, post-treatment pain, as well as palliative care.

**U.S. Pain Foundation**
Location: Middletown, CT  
Phone: (800) 910-2462  
Web: uspainfoundation.com  

Offers resources regarding pain awareness, volunteer support, a resource library with diagnosis and pain education, and information for those currently dealing with pain.

* Additional resources related to palliative care can be found under the section of Compassionate Care Resources on page 43.
Reference and Accreditation

Online resources that help you research doctors, facilities, medicines, medical terms, and lab tests. Other resources listed under “Information & Resources” often also have disease specific information related to these topics.

American Medical Association — Doctor Finder ❤
Web: apps.ama-assn.org/doctorfinder/html/patient.jsp

Supports a searchable database of physicians within the United States who are members of the AMA. More than 814,000 doctors can be found through this search, covering nearly every licensed doctor in the US. The database gives you the option to search for a specific doctor or find someone who specializes in a particular field.

American Pediatric Surgical Association
Location: Oakbrook Terrace, IL
Phone: (847) 686-2237
Web: eapsa.org/parents

A professional association that also provides a searchable database for specialized pediatric surgeons. This website allows you to search for a specific condition, location, or doctor.

Best Doctors
Location: Boston, MA
Phone: (800) 223-5003
Web: bestdoctors.com

A service that utilizes a database of more than 53,000 medical professionals to help people ensure that they are receiving the right care. This service can review current medical cases, give advice on treatment, or help you find a doctor. This service is accessible via health insurance coverage.

Cancer.Net
Web: cancer.net/find-cancer-doctor

Offers a searchable database for finding a cancer doctor by location and specialty.

Castle Connolly
Location: New York, NY
Phone: (212) 367-8400
Web: castleconnolly.com

Provides a searchable database of “top doctors” and “top hospitals.” Additional information includes: doctor disciplinary search, regional guides, and an individual membership program.

Healthgrades.com ❤
Web: healthgrades.com/find-a-doctor

Allows you to search for information related to where a doctor went to school, when and where they completed their residency, license status, or disciplinary actions. This site also includes ratings from other patients who had experiences with this physician, specialization searches, as well as ratings and information for hospitals.

Joint Commission on Accreditation of Healthcare Organizations
Location: Oak Brook, IL
Phone: (630) 268-7400
Web: jcaho.org

Accredits more than 21,000 health care organizations nationwide by using the Quality Check database. On the website you can find facilities and organizations that have received this level of accreditation.

Lab Tests Online
Web: labtestsonline.org

Offers information about how to read lab results, where/how laboratory tests are conducted, helpful information about specific lab tests, and cancer doctors listed by location and specialty.

Medterms
Web: medicinenet.com/medterms-medical-dictionary/article.htm

An online, searchable medical dictionary. This site provides easy-to-understand language to help explain over 16,000 medical terms and conditions.

RxList ❤
Web: rxlist.com

An online medical resource that includes a comprehensive and up-to-date listing of pharmaceutical information. Includes information related to side effects, precautions, pill identification, and more.

WebMD — Physician Directory
Web: doctor.webmd.com

Provides a searchable database to help you find a doctor near you who specializes in a particular area, or the option to search by procedure. This database also includes information related to patient satisfaction measures, readmission rates, mortality rates, and average reimbursement rates.
Support, Information, and Counseling

National resources and organizations that offer professional and peer support for families affected by cancer. These resources are organized by:

- Resources to help find counseling or therapy
- Options for immediate emotional support
- Organizations offering access to support

Find a Counselor or Therapist

American Counseling Association

Location: Alexandria, VA
Phone: (800) 347-6647
Web: counseling.org

A professional resource that also offers a ‘find a counselor’ feature to help you discover the right kind of support for you.

American Family Therapy Academy

Location: Washington, D.C.
Phone: (202) 483-8001
Web: afta.org

Provides resources for professional family therapists as well as a therapist search to help families find the right support for them.

GoodTherapy.Org

Location: Olympia, WA
Phone: (888) 563-2112
Web: goodtherapy.org

Serves as a database for therapists and counselors all over the US. In addition, this site offers information regarding different types of counselors, helpful terms defined, and crisis lines.

Find Immediate Support

American Cancer Society

Phone: (800) 227-2345
Web: cancer.org

Offers 24/7 support on their phone line and support during business hours via chat on their Web. This service can help you get information, locate resources, or find general support coping with cancer.

Cancer Support Hotline

Phone: (888) 793-9355
Web: cancersupportcommunity.org

Licensed counselors provide guidance, support, and resources regarding treatment as well as emotional assistance.

Lifeline Crisis Chat

Web: crisischat.org

Offers a free 24/7 emotional support chat for anyone needing extra support for any reason.

National Crisis Hotline

Phone: (800) 273-8255
Phone: (877) 784-2432 (Spanish)
Phone: (800) 799-4889 (Hearing impaired)

Provides 24/7 over the phone emotional support for anyone needing extra support for any reason.

National Parent Helpline

Location: Claremont, CA
Phone: (855) 427-2736
Web: nationalparenthelpline.org

Provides 24/7 emotional support for parents via a helpline as well as online resources about talking to teens and children about difficult subjects, physical and mental health, as well as parenting and co-parenting tips.

Organizations Offering Resources & Information

American Cancer Society

Location: Atlanta, GA
Phone: (800) 227-2345
Web: cancer.org

A nationwide, community-based health organization that assists people with cancer through research, education, advocacy, and service. Offers a 24/7 information line at (800) 227-2345 or a live chat that can answer questions related to diagnosis, treatment, coping skills, pain control, and nutrition as well as arrange for lodging or transportation, and more.

American Childhood Cancer Organization

Location: Kensington, MD
Phone: (855) 858-2226
Web: acco.org

Provides information, local support groups and specialized information to families and caregivers of children with cancer. ACCO aims to help families cope with the emotional stresses of their experiences, provide information on camps for children with cancer, and provide resources to assist families and survivors with education, employment, or insurance.

Association of Cancer Online Resources (ACOR)

Location: New York, NY
Phone: (212) 226-5525
Web: acor.org

Provides access to mailing lists, chat rooms and online communities that offer support, information, and community to everyone affected by cancer and related disorders. Develops and hosts state-of-the-art, internet-based knowledge systems that allow the public to find and use credible information relevant to their situation.
Association of Pediatric Hematology/ Oncology Nurses
Location: Chicago, IL
Phone: (855) 202-9760
Web: aphon.org
A professional organization for registered nurses caring for children with cancer and their families. Although this site is directed toward nurses, parents can find helpful information and learn a nurse's perspective on childhood cancer as well as the standard of care that is expected of them.

Association of Pediatric Oncology Social Workers
Web: aposw.org/html/family-resources.php
A professional organization for pediatric oncology social workers. Found under the ‘Resources’ tab, this site provides information and general resources for patients and families. This site might also be a helpful resource in learning about the standards of practice and expectations of Pediatric Oncology Social Workers.

Bandaids & Blackboards
Web: lehman.cuny.edu/faculty/jfleitas/bandaides/
Provides insight into what it’s like to grow up with medical issues from the perspective of kids and teens. These kids have become experts at coping with problems that most people have never heard of. The contents are divided into three sections: one for kids, one for teens, and one for adults.

Cancer Care, Inc. ♥
Location: New York, NY
Phone: (800) 813-4673
Web: cancercare.org
Offers group, individual, family, and bereavement counseling (in person, online, and through telephone); information and referral to local community resources; supplementary financial assistance for home care, transportation and pain medication; volunteer visitor program; community education programs; technical assistance to professionals regarding psychosocial aspects of cancer; and both an African-American and Hispanic Outreach Program.

Cancer Hope Network
Location: Chester, NJ
Phone: (877) 467-3638
Web: cancerhopenetwork.org
Offers free, confidential, one-on-one support from cancer survivors to those currently affected by cancer. This organization is intended to support adult cancer patients and the loved ones of cancer patients and would be best used to assist families or caregivers in looking beyond the diagnosis and coping with treatment.

Cancer Knowledge Network ♥
Web: cancernet.org
Offers information and support for children, young adults, parents, and caregivers related to cancer treatment, creative and integrative therapies, end-of-life care, patient advocacy, and more.

Cancer.Net
Location: Alexandria, VA
Phone: (703) 299-0150
Web: cancer.net
Provides information regarding types of cancer, navigating cancer care, ways to cope with cancer, and resources regarding survivorship. Cancer.net also supports a searchable database of ASCO doctors.

Chai Lifeline ♥
Location: New York, NY
Phone: (877) 242-5433
Web: chailifeline.org
This organization maintains a large network of free emotional, social, psychological, and financial assistance services for seriously ill children, teens, and their families.

Childhood Cancer Guides
Web: childhoodcancerguides.org
Up-to-date resource books written to help children and families with many types of cancer and in many different situations. These books are designed to help families and survivors learn and cope.

Childhood Leukemia Foundation
Location: Brick, NJ
Phone: (888) 253-7109
Web: clf4kids.org
Provides practical information and support for caregivers, siblings, and patients including financial aid, homecare, transportation, and emotional support systems.

Family Voices ♥
Location: Albuquerque, NM
Phone: (888) 835-5669
Web: familyvoices.org
Provides resources and support to families to make informed decisions, advocate for themselves in the medical arena, and promote family-centered care. This website includes parenting resources, advocacy and support, publications, and culturally specific support.

Imerman Angels ♥
Location: Chicago, IL
Phone: (866) 463-7626
Web: imermanangels.org
Provides one-on-one support, connecting cancer patients, survivors, and caregivers. This organization matches a person touched by cancer (either a patient or a caregiver) with someone who has fought and survived the same type of cancer, or a caregiver who has faced a similar situation.

KidsHealth.org ♥
Web: kidshealth.org
Provides information for kids, teens, and parents regarding a variety of health topics, including psychological and emotional support designed with each group in mind. KidsHealth is particularly helpful regarding talking about feelings, being afraid, stressed, or losing a loved one.

LiveStrong Foundation
Location: Austin, TX
Phone: (866) 673-7205
Web: livestrong.org
Provides the practical information and tools for those who just received a diagnosis, are in treatment, post treatment, or end of life. Each of these areas offers additional categories of information including: practical needs, feelings and emotions, money and insurance, and more. LiveStrong also offers a free cancer support line at (855) 220-7777.
Med Help International
Web: medhelp.org
Connects people with the leading medical experts and others who have similar experiences. Med Help has a variety of forums available related to specific types of cancer, as well as parenting and behavior resources.

The National Children’s Cancer Society ♥
Location: St. Louis, MO
Phone: (314) 241-1600
Web: thenccs.org
Provides financial support and advocacy on behalf of children related to bills, home care needs, insurance companies, hospitals, and other agencies. Support services and education about childhood cancer and nutrition are also available.

National Mental Health Association
Location: Alexandria, VA
Phone: (703) 684-7722
Web: nmha.org
Provides programming and information related to mental health issues including offering a variety of online screening tools for adults and children, providing assistance in finding a mental health provider, and has a crisis hotline at (800) 273-8255.

National Parent to Parent Support and Information System
Location: Washington, D.C.
Phone: (800) 651-1151
Web: p2pusa.org
Offers parent-to-parent support to families of children who have special needs. Find state chapters, or be matched with a trained mentor parent who can offer support, resources, guidance, and information.

Parent Advocacy Coalition for Educational Rights (PACER) Center
Location: Bloomington, MN
Phone: (952) 838-9000
Web: pacer.org
Focused on providing training and information to families of children and youths living with disabilities. Hosts a wide variety of programs including: resources for grandparents, special education information, multicultural services, and children’s mental and emotional health resources.

Padres Contra El Cáncer ♥
Location: Los Angeles, CA
Phone: (888) 441-0056
Web: iamhope.org
Supports the needs of children and families impacted by cancer within the Latino community. This organization aims to promote understanding, knowledge, emotional health, and family education through culturally relevant and linguistically appropriate programs.

Parents Helping Parents ♥
Location: San Jose, CA
Phone: (408) 727-5575
Web: phponline.org
Offers practical support, emotional guidance, education, and resources to families who have children with special needs. This website is available in Spanish and Vietnamese.

Pediatric Oncology Resource Center
Web: ped-onc.org
Designed for parents, friends, and families of children who have or had childhood cancer. This organization supports a resource center with information about treatment, survivorship, grief, and more.

Psych Central
Location: Newburyport, MA
Web: psychcentral.com
Provides resources and information related to mental, emotional, and neurological health. This website offers a catalog of support groups and mailing list groups organized by disability and condition, as well as an “Ask a Therapist” option, and a guide for finding help.

R.A. Bloch Cancer Foundation
Location: Kansas City, MO
Phone: (800) 433-0464
Web: blochcancer.org
Offers resources including free books, articles, a support hotline, and relaxation audio with the understanding that a positive mental outlook can affect cancer treatment.

Special Love
Location: Winchester, VA
Phone: (888) 930-2707
Web: speciallove.org
Offers cancer families a network of support, made up of other patients and families who know and understand the trials and triumphs of fighting cancer. This organization provides resources related to camps for patients, survivors, siblings, and families, along with financial relief options, and survivor education scholarships.

Starlight Children’s Foundation
Location: Los Angeles, CA
Phone: (310) 479-1212
Web: starlight.org
Serves seriously ill children (ages 4-18) with wish granting and in-hospital entertainment. This organization aims to address the pain, fear, loneliness, and depression that can negatively impact an illness.

The Ulman Cancer Fund for Young Adults
Location: Baltimore, MD
Phone: (888) 393-3863
Web: ulmanfund.org
Provides age-specific resources for teens and young adults through various patient navigation programs, as well as community support opportunities and survivor resources.

Vital Options International
Phone: (818) 508-5657
Web: vitaloptions.org
Aims to support a global conversation about cancer by bringing together cancer advocates and experts to share stories through their multiple communication platforms.
Transplant and Donor Programs

A listing of registries offering donor and transplant information. Many organizations will also help families with fundraising efforts if transplants are not covered through insurance.

American Kidney Fund
Location: Rockville, MD
Phone: (800) 638-8299
Web: akfinc.org
Provides direct financial aid to kidney patients in need. Also provides information on organ donations and kidney related diseases. Some of the services provided: patient grants, patient emergency funds, children's camp grants, pharmacy programs, and equipment.

American Liver Foundation
Location: New York, NY
Phone: (212) 668-1000
Web: liverfoundation.org/abouttheliver/info/transplant
Facilitates, advocates and promotes education and support related to liver health. Additionally, this website provides basic information related to liver transplants.

Blood & Marrow Transplant Information Network
Location: Highland Park, IL
Phone: (847) 433-3313
Web: bmtinfonet.org
Provides accurate and easy-to-understand information on blood and marrow transplants. This site has searchable databases related to finding a doctor, information related to specific medications, transplant centers, and finding a donor.

Children's Liver Association for Support Services
Location: Monaca, PA
Phone: (724) 888-2568
Web: classkids.org
Dedicated to serving the emotional, educational, and financial needs of families coping with childhood liver disease and transplantation. CLASS has a telephone helpline, financial aid opportunities, and educational materials.

Children's Organ Transplant Association
Location: Bloomington, IN
Phone: (800) 366-2682
Web: cota.org
Delivers support to families in need of financial assistance related to a child's need for organ or tissue donation. This organization has fundraising guidance for families and communities, negotiates with hospitals and transplant centers on behalf of patients, and will send a representative at no cost into the individual’s community to initiate and organize fundraising activities.

Help, Hope, Live
Phone: (800) 642-8399
Web: helphopelive.org
Offers support for people with unmet medical expenses due to cell and organ transplants. The organization uses professional fundraising coordinators to help families start a campaign, conduct fundraising, and then manages paying bills directly from the funds raised.

Medlineplus.gov – Organ Transplantation
Web: nlm.nih.gov/medlineplus/organtransplantation.html
Includes significant information related to organ transplants of many kinds. Specific links for types of organ transplants and information for children who are undergoing a transplant.

National Foundation for Transplants
Location: Memphis, TN
Phone: (800) 489-3863
Web: transplants.org
Supports transplant patients through patient fundraising and general transplant information.

National Marrow Donor Program: Be the Match
Location: Minneapolis, MN
Phone: (888) 999-6743
Web: bethematch.org
Supports the largest marrow registry in the world and offers support to patients throughout the transplant process. This organization offers access to finding a bone marrow or cord blood transplant match in addition to working to help patients who struggle to afford treatment through their financial aid program.

OrganDonor.gov
Web: organdonor.gov
Offers facts about donation and transplantation, stories about transplants, and information regarding the organ matching process.

United Network for Organ Sharing
Location: Richmond, VA
Phone: (804) 782-4800
Web: unos.org
Maintains, updates, and provides transplantation and donation information to patients, family members, friends, potential donors, and medical professionals. This website has detailed information regarding factors in organ allocation and the ways that patients are prioritized for transplantation, as well as supporting the Organ Center that assists in placing donated organs, assisting in organ transportation, and providing additional resources.
Aid and Assistance

Cancer often imposes heavy burdens on families. Many need help with jobs, insurance policies, legal issues, air travel, ground transportation, prescriptions, and even financial aid for continuing education. This section offers resources that may help with a variety of needs and unique situations.
Camps and Vacation Retreats

These organizations provide access to camps or vacations that can relieve some of the stress related to having a pediatric cancer diagnosis. It is recommended that you speak specifically with your child’s medical team when considering a camp. Camps and retreats vary in the services they offer, activities, length of stay, medical assistance, and location. Most camps are free-of-charge and some may provide additional travel cost assistance for out-of-town campers.

**American Childhood Cancer Organization**

- Location: Kensington, MD
- Phone: (800) 366-2223
- Web: acco.org

Provides a comprehensive list of camps organized by state.

**B.A.S.E. Camp**

- Location: Winter Park, FL
- Phone: (407) 673-5060
- Web: basecamp.org

Provides a year-round base of support for children and parents facing the challenge of living with cancer and other life-threatening hematology diseases. B.A.S.E. Camp offers a one-night monthly camp for the whole family.

**Camp Good Days**

- Location: Mendon, NY
- Phone: (800) 785-2135
- Web: campgooddays.org

Campers have a chance to experience all the traditional camping activities such as hiking, sailing, fishing, and arts and crafts at the Keuka Lake facility. Camp also features a ropes course, a handicapped accessible swimming pool, miniature golf course, and areas for music, nature, and computers. This camp is available to children from all 50 states.

**Camp Mak-A-Dream Children’s Oncology Camp Foundation**

- Location: Missoula, MT
- Phone: (406) 549-5987
- Web: campdream.org

Cost-free camp program for children and young adults with cancer. Offers the opportunity to participate in a variety of fun-filled camp activities, learn new skills, form positive peer relationships, and develop greater independence and self-esteem. The camp is available on a priority basis to children and young adults with cancer and their families. Located in Gold Creek, Montana, this camp supports families throughout the U.S.

**Camp One Step**

- Location: Chicago, IL
- Phone: (312) 924-4220
- Web: camponestep.org

Offers multiple camp experiences and other educational and excursion programs throughout the year that allow children with cancer to just be kids. Support for siblings and parents as well.

**Camp Quality USA**

- Location: Stow, OH
- Phone: (530) 671-0167
- Web: campqualityusa.org

Fourteen free summer camps located throughout the country for children diagnosed with cancer. Each camper is matched one-on-one with their own volunteer adult companion for the entire week. The companion provides a helping hand and a listening ear for children who are dealing with the physical and emotional effects of cancer. All camp activities are designed to allow all campers to participate, regardless of stamina level or secondary physical handicap.

**Camp Simcha**

- Location: New York, NY
- Phone: (877) 242-4543
- Web: campsimcha.org

Camp offered to children ages 6 and older with chronic illnesses who are in treatment and post treatment. Specially trained staff are paired one-on-one with campers. Camp Simcha is available to children dependent on wheelchairs, walkers, respirators, gastric tubes, and other medical equipment.

**Epic Experience**

- Location: Arvada, CO
- Phone: 855-650-9907
- Web: epicexperience.org

Offers free week-long outdoor experiences to individuals who have been diagnosed with cancer. Experiences are based upon outdoor adventure activities such as white water adventures, snowshoeing, and cross country skiing.

**First Descents**

- Location: Denver, CO
- Phone: 303-945-2490
- Web: firstdescents.org

A multi-day adventure program for young adult cancer survivors centered around whitewater kayaking, rock climbing, or surfing. This free outdoor experience empowers campers to defy their cancer and connect with others doing the same.

**National Sports Center for the Disabled**

- Location: Denver, CO
- Phone: (303) 293-5711
- Web: nscd.org

Each year, thousands of children and adults with disabilities take to the ski slopes, mountain trails, and golf links to learn more about sports and themselves. With specially trained staff and its own adaptive equipment lab, participants with almost any medical or physical disability are taught a variety of summer and winter sports.

**Professional Association of Therapeutic Horsemanship International**

- Location: Denver, CO
- Phone: (800) 369-7433
- Web: pathintl.org

Promotes the benefit of horses for individuals with physical, emotional, and learning disabilities. For individuals with disabilities, equine-assisted activities have been shown to improve muscle tone, balance, posture, coordination, motor development, and emotional well-being.

**Project Koru**

- Location: Maui, HI; Hood River, OR
- Phone: 415-617-5678
- Web: projectkoru.org

Free adventure-based experiences such as surfing, outrigger canoeing, standup paddling, skiing, and snowboarding serve as channels of healing and renewal to treat the mind, body, and soul. Programs aim to help young adult cancer survivors thrive in all aspects of life.
SeriousFun
Children's Network
Web: seriousfunnetwork.org
Global network of thirty camps and programs serving children living with serious illnesses and their families. Camps feature a diverse range of inclusive programs such as universally accessible high ropes courses and adaptive winter sports, as well as traditional camp activities like swimming, boating, and campfires. All camps are offered free of charge.

SeriousFun Camps in the US:
- Camp Boggy Creek, Eustis, FL
- Double H Ranch, Lake Luzerne, NY
- Camp Korey, Mount Vernon, WA
- Flying Horse Farm, Mt. Gilead, OH
- The Hole in the Wall Gang Camp, Ashford, CT
- North Star Reach, Pinckney, MI
- The Painted Turtle, Lake Hughes, CA
- Roundup River Ranch, Avon, CO
- Victory Junction, Randleman, NC

Special Love
Location: Winchester, VA
Phone: (888) 930-2707
Web: speciallove.org
Provides a network of support, including various camps for patients/survivors, siblings, and families.

Community Forums and Friends
These forums connect kids with cancer with other kids, parents with parents, and siblings of kids with cancer with others who understand their unique situations. Online forums, pen-pal programs, and groups are listed here.

Child/Teen Support & Community Forums

13 Thirty
Location: Rochester, NY
Phone: (585) 563-221
Web: teenslivingwithcancer.org
Provides a face-to-face and virtual network for teens and young adults living with cancer.

Ability OnLine
Location: Etobicoke, Ontario, Canada
Phone: (866) 650-6207
Web: abilityonline.org
Free Internet community where youth with disabilities or illness and their parents can meet others like them, make friends from all over the world, share their hopes and fears, find role models and mentors, and feel like they belong.

Cancer Con
Location: Denver, CO
Phone: 877-735-4673
Website: www.cancercon.org
Annual convention welcomes hundreds of young adult cancer patients and survivors, along with their caregivers and family members, for three and a half days of transformational workshops, educational programs, group discussions, networking, and social activities.

Famous Fone Friends
Location: Los Angeles, CA
Phone: (310) 204-5683
Web: famousfonefriends.org
Provides encouragement and friendship to children who are hospitalized or homebound due to illness or injury. Actors, athletes, and musicians call children to help lift their spirits.

Gilda's Club® Worldwide
Location: New York, NY
Phone: (888) 445-3248
Web: gildasclubnyc.org
Provides meeting places where men, women, and children living with cancer, along with their families and friends, can join with others to build a personal network of social and emotional support as an integral part of cancer treatment.

Group Loop
Location: Washington, D.C.
Phone: (202) 659-9709
Web: grouploop.org
A safe place for teens touched by cancer to connect and find support, as well as education and hope, while dealing with a cancer diagnosis.

Imerman Angels
Location: Chicago, IL
Phone: (312) 274-5529
Web: imermanangels.org
Provides one-on-one cancer support; connecting cancer fighters, survivors, and caregivers with empathetic and understanding mentors.

Look Good...Feel Better
Phone: (800) 395-5665
Web: lookgoodfeelbetter.org
Teaches beauty techniques related to skin and nail care, cosmetics, wigs, styling, and more, to help people with cancer find some sort of normalcy.

The Ulman Cancer Fund for Young Adults
Location: Baltimore, MD
Phone: (888) 393-3863
Web: ulmanfund.org
Provides support programs, education, and resources, free of charge to young adults, their families and friends, who are affected by cancer.

Parent Support & Community Forums

Day By Day
Web: health.groups.yahoo.com/group/DayByDay
Designed to be a forum and support group for parents who have lost a child to cancer or whose child has exhausted treatment options.
Momcology
Web: momcology.org
Offers a network for primary caregivers of children with cancer. Provides support groups, access to retreats, and more.

Pediatric Oncology Resource Center
Web: ped-onc.org
Designed for parents, friends, and families of children who have or had childhood cancer. This organization supports a resource center with information about treatment, survivorship, grief, and more.

Sibling Support & Community Forums
Sibling Support Project
Location: Seattle, WA
Phone: (206) 297-6368
Web: siblingsupport.org
Seeks to increase the peer support and information opportunities for siblings of people with special needs and to increase parents’ and providers’ understanding of sibling issues. Offers workshops, online support groups, and written materials.

SuperSibs!
Location: Bala Cynwyd, PA
Phone: (866) 333-1213
Web: supersibs.org
Works to ensure that siblings will feel valued, validated, heard, and supported. Also offers sibling scholarship program, bereavement care, and parent support.

Sesame Street Tool Kits
Web: sesamestreet.org/toolkits
Provides tool-kits to parents and families to help support and educate children experiencing difficult situations including grief, resilience, support after an emergency, and more.

Educational Financial Aid
The following organizations may offer financial assistance and scholarships to parents or children whose lives have been impacted by cancer.

Andre Sobel Award
Location: Los Angeles, CA
Phone: (310) 276-7111
Web: andreriveroflife.org
A juried essay competition for young survivors of a life-threatening illness. First place winner receives $5,000.

Beyond the Cure Scholarship
Location: St, Louis, MO
Phone: (314) 241-1600
Web: thenccs.org/scholarship
Awards college scholarships to childhood cancer survivors who have demonstrated the ability to overcome the difficult challenges of cancer with determination and motivation. Multiple winners each year.

Cancer for College
Location: Temecula, CA
Phone: (760) 599-5096
Web: cancerforcollege.org
Provides hope and inspiration to those who have battled cancer by awarding college scholarships to cancer survivors or amputees.

Cancer Survivor’s Fund
Location: Missouri City, TX
Phone: (281) 437-7142
Web: cancersurvivorsfund.org
Provides college scholarships and financial help for prosthesis for young adults diagnosed with cancer, receiving treatment for cancer, or in remission.

National Collegiate Cancer Foundation
Location: Bethesda, MD
Phone: (240) 515-6262
Web: collegiatecancer.org
Provides need-based financial support to young adult survivors pursuing higher education throughout their treatment and beyond.

Pediatric Brain Tumor Foundation
Location: Asheville, NC
Phone: (800) 253-6530
Web: pbtfus.org/survivors/education/scholarships
Scholarship program for students who have survived a central nervous system tumor. Scholarships are available to high school seniors or high school graduates starting college.

The Samfund
Location: Boston, MA
Phone: (617) 938-3484
Web: thesamfund.org
Provides various grants and scholarships to young adult survivors to help supplement the money that they and their families lose during treatment and pay for specific transitional issues, such as education, living, job search, lingering medical expenses, and fertility.

The Ulman Cancer Fund for Young Adults
Location: Baltimore, MD
Phone: (888) 393-3863
Web: ulmanfund.org
Offers scholarships to support the financial needs of individuals between 15 and 39 who are battling or have overcome cancer and who demonstrate financial need. Provides support programs, education, and resources free of charge to benefit young adults, their families, and friends who are affected by cancer.
Employment and Legal Assistance

For a variety of reasons, families may need to consult legal counsel or seek support from employment agencies during or after a child’s battle with cancer. These resources can help you find the support you need.

Cancer and Careers 😊
Location: New York, NY
Phone: (646) 929-8032
Web: cancerandcareers.org
Empowers and educates people with cancer and their families to thrive in their workplace by providing advice, tools, and events. Additional support includes assistance in finding a job, résumé review services, and advice from career coaches.

Equal Employment Opportunity Commission
Phone: (800) 669-4000
TTY: (800) 669-6820
Web: eeoc.gov
Enforces employment laws and provides oversight and coordination of all federal equal employment opportunity regulations, practices, and policies. Available in multiple languages.

Job Accommodation Network (JAN)
Location: Morgantown, WV
Phone: (800) 526-7234
TTY: (877) 781-9403
Web: askjan.org
Facilitates the employment and retention of workers with disabilities by providing employers, people with disabilities, their family members, and other interested parties with information on job accommodations, self-employment, and small business opportunities.

National Cancer Legal Services Network ❤️
Web: nclsn.org
Promotes legal services for people living with cancer, their families, and caregivers. The website serves as a comprehensive guide to existing cancer legal services that educates visitors about these services and will help them locate currently available programs.

Patient Advocate Foundation 💖️
Location: Hampton, VA
Phone: (800) 532-5274
Web: patientadvocate.org
This nonprofit organization can connect you with an attorney or case manager who can help you try to resolve cancer-related job-retention issues.

U.S. Department of Labor
Location: Washington D.C.
Phone: (866) 487-2365
TTY: (877) 889-5627
Web: dol.gov
Administers a variety of federal labor laws including those that guarantee workers’ rights to safe and healthful working conditions; a minimum hourly wage and overtime pay; freedom from employment discrimination; unemployment insurance; and other income support. Available in multiple languages.
Financial and Aid Assistance

Financial difficulties are hard, especially during times of crisis. These national organizations and resources offer financial or general aid assistance. Check with your local support organizations, churches, or social service organizations as many have financial funds for local individuals in need. Families should discuss any concerns regarding healthcare costs with their physician, medical social worker, or the business office at your hospital or clinic. Depending on your circumstances, hospitals may be able to reduce bills or set up payment plans.

**American Cancer Society**
Location: Atlanta, GA  
Phone: (800) 227-2345  
Web: cancer.org

Provides information about how to manage costs, understand financial and insurance issues, and how to find support programs and services in your area.

**American Kidney Fund**
Location: Rockville, MD  
Phone: (800) 765-3226  
Web: kidneyfund.org

Delivers direct financial aid to kidney patients in need as well as information on organ donations and kidney related diseases. Some of the services provided include: patient grants, patient emergency funds, children’s camp grants, pharmacy programs, and equipment.

**The Andrew McDonough B+ Foundation**
Location: Wilmington, DE  
Phone: (302) 563-8389  
Web: bepositive.org

Delivers financial support to families of critically ill children and funds medical research for pediatric cancers.

**Association of Maternal and Child Health Programs**
Location: Washington, D.C.  
Phone: (202) 775-0436  
Web: amchp.org

Provides financial grants to states for direct medical and related services for children with disabilities, including chronic and terminal illnesses. Every state has its own plan. You can contact this organization for information on your child’s eligibility for services as well as information on state specific programs.

**Bone Marrow Foundation**
Location: New York, NY  
Phone: (212) 838-3029  
Web: bonemarrow.org

Offers financial assistance to patients who need support related to transplant costs, as well as one-to-one funds for specific patients or procedures, and scholarship grants.

**Cancer Care, Inc.**
Location: New York, NY  
Phone: (800) 813-4673  
Web: cancercare.org/financial

Offers financial assistance related to transportation and childcare. On-call oncology social workers can help find additional resources.

**Catholic Charities, USA**
Location: Alexandria, VA  
Phone: (703) 549-1390  
Web: catholiccharitiesusa.org

Offers information related to finding resources in every state. Contact the Catholic Charities nearest you to see what kind of assistance they can provide.

**Children’s Liver Association for Support Services**
Location: Monica, PA  
Phone: (724) 888-2568  
Web: classkids.org

Provides financial aid for families of pediatric liver patients. Typical types of financial assistance include a parent’s food assistance during their child’s hospitalization, telephone service for a child awaiting transplant, or transportation expenses for a clinic visit.

**Elks USA**
Location: Chicago, IL  
Phone: (773) 755-4700  
Web: elks.org

May provide help to children with chronic illnesses or disabilities. Contact your local Elks lodge for more information.

**First Hand Foundation**
Location: Kansas City, MO  
Phone: (816) 201-1569  
Web: firsthandfoundation.org

Assists individual children with health-related needs when insurance and other financial resources have been exhausted.

**Family Reach**
Location: Parsippany, NJ; Boston, MA  
Phone: (973) 394-1411; (857) 233-2764  
Web: familyreach.org

Works with hospitals and cancer centers nationwide to alleviate the financial burden of cancer. Provides families with immediate financial assistance, education and awareness, and financial coaching.
General Grand Chapter, Order of the Eastern Star
Location: Washington, D.C.
Phone: (202) 667-4737
Web: easternstar.org
State or local chapters can assist in setting up a fund to provide for medical equipment, supplies, prescription medications, and/or medical transportation for children with chronic illnesses or disabilities.

Glenn Garcelon Foundation
Location: Coppell, TX
Phone: (503) 969-7651
Web: glenngarcelonfoundation.org
Dedicated to helping those afflicted by brain tumors connect with the tools they need to get by day-to-day. Specifically works to provide patients with medical equipment they need but cannot afford.

Leukemia & Lymphoma Society
Location: White Plains, NY
Phone: (941) 949-5213
Web: lls.org
Offers financial aid to people who have leukemia, non-Hodgkin’s lymphoma, Hodgkin’s disease, or multiple myeloma by aiding through co-pay assistance programs, travel assistance, prescription drug costs, and transplantation costs.

The National Children’s Cancer Society
Location: St. Louis MO
Phone: (800) 532-6459
Web: thenccs.org
Helps children with cancer and their families by providing financial and fundraising assistance related to emergency assistance and transportation assistance. Provides a scholarship program as well as additional resources during and after treatment.

Pinky Swear Foundation
Location: Bloomington, MN
Phone: (952) 974-9600
Web: pinkyswear.org
Supports families’ quality-of-life with direct financial aid for basic needs, and through experiences that create emotional support, including: home payments, transportation costs, groceries, family getaways, and more.

Partnership for Prescription Assistance
Web: pparx.org
Provides a single point of access to more than 475 patient assistance programs, including nearly 200 offered by biopharmaceutical companies. Helps individuals get prescription drugs for free or at very low-cost.

Patient Advocate Foundation
Location: Hampton, VA
Phone: (800) 532-5274
Web: patientadvocate.org
Provides a national financial resource directory that is searchable by state, age range, diagnosis, and resource type. Additional information includes insurance assistance details, patient support programs from drug manufacturers, and more.

Salvation Army National Headquarters
Location: Alexandria, VA
Phone: (703) 684-5500
Web: salvationarmyusa.org
Local units can offer emergency financial assistance to families.

The Samfund
Web: thesamfund.org
This organization provides assistance to young adult cancer survivors including direct financial support and education regardless of diagnosis and location.

Social Security Administration
Phone: (800) 772-1213
TTY: (800) 325-0778
Web: ssa.gov
Provides monthly income for eligible individuals. Some states acknowledge cancer needs. Information on Medicare is available by calling your local office for details and availability. Available in multiple languages.

St. Jude Children’s Research Hospital
Location: Memphis, TN
Phone: (866) 278-5833
TTY: (901) 595-1040
Web: stjude.org
Offers free treatment, travel, and lodging for eligible children diagnosed with cancer. Parents wishing to have their child treated at St, Jude Hospital must have the child’s treating oncologist contact a St, Jude Hospital physician. Final acceptance occurs when the patient is deemed eligible and is enrolled in a specific protocol. Available in multiple languages.

Traveler’s Aid International
Location: Beltsville, MD
Phone: (202) 546-0599
Web: travelersaid.org
Local agencies help individuals and families who are traveling with unforeseen problems or with anticipated travel-related challenges.

United Healthcare Children’s Foundation
Location: Minneapolis, MN
Phone: (855) 698-4223
Web: uhccf.org
Provides grants for financial assistance for families when their medical insurance does not cover, or fully cover, their medical needs. Applications can be submitted online.

United Methodist Association of Health and Welfare Ministries
Location: Germantown, MD
Phone: (662) 269-2955
Web: ouruma.org
Member organizations may provide services or financial assistance. Additionally, provides assistance in using prescription savings cards.

Wigs for Kids
Location: Westlake, OH
Phone: (440) 333-4433
Web: wigsforkids.org
Supplies wigs to children under 18 who cannot afford hairpieces and are experiencing hair loss from chemotherapy, radiation, burns, alopecia, or other medical conditions. Information about qualifications and application instructions are online.
Fundraising and Social Networking

Fundraising is another option to consider when working to cover costs. Some families find that friends, family, and even strangers are willing to contribute financially to a fundraising effort if they are aware of a difficult situation.

CaringBridge
Location: Eagan, MN
Phone: (651) 452-7940
Web: caringbridge.org
An online space where you can connect, share news, and receive support. Make your own personal site to keep others informed throughout your journey.

Children’s Organ Transplant Association ❤
Location: Bloomington, IN
Phone: (800) 366-2682
Web: cota.org
Provides guidance to families and communities with transplant-needy individuals to raise the necessary funds for transplants. This organization will offer up to $5,000 as a challenge grant, as well as assistance in planning successful events, working with local media, using online resources, and organizing and training volunteers.

First Hand Foundation ❤
Location: Kansas City, MO
Phone: (816) 201-1569
Web: firsthandfoundation.org
Helps children with health issues address financial needs. Request funding online.

Giveforward
Web: giveforward.com
Provides free online fundraising pages to allow friends and family to raise money directly for a loved one when they need it the most. Create a fundraising page to raise funds for transportation, house cleaning, childcare, educational and medical expenses, and more. Giveforward will keep 5% of the total amount raised to cover operating costs.

GoFundMe.com
Web: gofundme.com
Offers a platform to fundraise for medical expenses using social media platforms.

Help, Hope, Live
Phone: (800) 642-8399
Web: helphopelive.org
Helps patients and their families organize, launch, and sustain grassroots fundraising campaigns, providing fiscal accountability for the funds raised and weekly disbursements for life-saving and life-sustaining medical care.

My Lifeline
Location: Denver, CO
Phone: (720) 883-8715
Web: mylifeline.org
Encourages cancer patients and caregivers to create free, customized websites, empowering patients to build an online support community of family and friends to foster connection, inspiration, and healing.

YouCaring ❤
Web: youcaring.com
Offers resources to conduct peer-to-peer fundraising through social media. This site also provides additional information about best practices for fundraising. There are no fees.
Insurance and Medical Assistance
The following organizations offer assistance and information about insurance issues and aid related directly to treatment needs.

Centers for Medicare & Medicaid Services
Phone: (877) 267-2323
TTY: (866) 226-1819
Web: cms.hhs.gov
Provides information on Medicare, Medicaid, the Children’s Health Insurance Program, and the Health Insurance Marketplace.

Dept. of Health and Human Services Fraud Hotline
Location: Washington, D.C.
Phone: (800) 447-8477
TTY: (800) 377-4950
Web: oig.hhs.gov/fraud/hotline
U.S. government hotline for complaints regarding Medicare or Medicaid; provides assistance with issues of entitlements, benefits, insurance, and community resources.

Insure Kids Now
Phone: (877) 543-7669
Web: insurekidsnow.gov
National campaign to link uninsured children – from birth to age 18 – to free and low-cost health insurance. Puts families in direct contact with their own state’s children’s health insurance program through this website.

National Association of Insurance Commissioners
Location: Kansas City, MO
Phone: (816) 842-3600
Web: naic.org
Offers help with situations in which you feel you or your family are not being treated fairly by your insurance carrier. Includes information related to consumer protection, healthcare reform, and cyber security.

National Patient Advocate Foundation
Location: Washington, DC
Phone: (202) 347-8009
Web: npaf.org
Provides legal consulting and referral services for patients confronting denial of insurance coverage, employment discrimination, and/or a need for negotiating support with public assistance programs through both state and federal agencies through their National Legal Resource Network.
Life After Cancer

This section addresses the comprehensive needs of survivors and the long-term effects of cancer treatments. Many survivors and their families continue to confront complex and life-long issues. This section offers information and services to help cope with these issues.

American Cancer Society
Phone: (800) 227-2345
Web: cancer.org

A nationwide, community-based voluntary health organization. This website has cancer survivor information such as: special needs and interests, tools to develop healthy habits after treatment, connect with other survivors, and find opportunities to volunteer and donate.

American Childhood Cancer Organization
Location: Kensington, MD
Phone: (800) 366-2223
Web: acco.org

Helps families cope with the emotional stresses of their experiences.

American Institute for Cancer Research
Location: Washington, DC
Phone: (800) 843-8114
Web: aicr.org/patients-survivors

Provides information for cancer patients and survivors including nutritional information, physical activity guidelines, support groups, frequently asked questions, and additional tools and resources.

Cancer Hope Network
Location: Chester, NJ
Phone: (908) 879-6518
Web: cancerhopenetwork.org

Free, confidential, one-on-one support to people with cancer and their families. Matches patients with trained volunteers who have undergone a similar experience. Provides support and hope to help patients and families look beyond the diagnosis, cope with treatment, and start living life to its fullest once again.

Cancer Survivor’s Toolkit
Location: Silver Spring MD
Phone: (888) 622-7937
Web: canceradvocacy.org/toolbox

Free downloadable information from leading cancer organizations to help people develop skills to better meet and understand the challenges of their illness. The program offers help navigating a diagnosis and other key issues faced by people who have been treated for cancer.

Center for Parent Information and Resources
Location: Newark, NJ
Web: parentcenterhub.org

Information to assist parents, educators, caregivers, advocates, and teachers in helping children and youth with disabilities participate as fully as possible at school, at home, and in their community.

Childhood Cancer Guides
Location: Bellingham, WA
Web: childhoodcancerguides.org

Creates, publishes, and updates books that help families of children with cancer and survivors of childhood cancer.

Life After Cancer Care
Phone: (855) 245-6150
Web: mdanderson.org

Provides information for those who have finished cancer treatment including social and emotional changes, survivor groups, and ways to connect with other past cancer patients.

LiveStrong Foundation
Location: Austin, TX
Phone: (855) 220-7777
Web: livestrong.org

Provides practical information and tools for people who have completed treatment. This includes emotional support and fertility information.

Lucy’s Love Bus
Location: Boston, MA
Phone: (857) 277-1984
Web: lucyslovebus.org

Delivers comfort to children with cancer by paying for any therapy that helps to balance traditional cancer care and improves the quality of life for the child. Offers grants up to $1,000 for any child in the Northeastern US between the ages of birth and 21 years old who is coping with a cancer diagnosis or late effects of cancer treatment.

National Cancer Survivors Day Foundation
Location: Franklin, TN
Phone: (615) 794-3006
Web: ncsdf.org

Organizes Survivors Day, an annual, nationwide celebration of life for cancer survivors, their loved ones, and health care professionals. It is celebrated on the first Sunday in June.

The National Children’s Cancer Society
Location: St. Louis, MO
Phone: (314) 241-1600
Web: thenccs.org

Provides information pertaining to all areas of the survivor’s life. The Late Effects After Treatment Tool allows you to build an assessment of late effects specific to your diagnosis and treatment. Additional information relates to school, relationships, emotions, healthy living, and more.

National Rehabilitation Information Center
Location: Landover, MD
Phone: (800) 346-2742
TTY: (301) 459-5984
Web: naric.com

Information center focusing on disability and rehabilitation issues and research. Provides reference and referral services, as well as custom database searches of the REHABDATA bibliographic database. Provides information on prosthetics, equipment, and supplies.
Odds and Ends

From hats, to dolls, to humor, this list includes helpful, unique, and fun resources that did not fit neatly into any one category.

American Massage Therapy Association
Location: Evanston, IL
Phone: (877) 905-0577
Web: amtamassage.org

Helps locate massage therapists who can help reduce stress, relieve postoperative pain, chronic pain, and more. AMTA also offers specific information for massage professionals about pediatric massages for children with cancer.

BeauBeau: Beautiful Scarves for Beautiful Heads
Web: 4women.com

A fun, fashionable, and comfortable alternative to wearing a wig made from beautiful and unusual fabrics. This is not a non-profit organization.

Cancer Nutrition Center
Phone: (310) 766-8597
Web: cancernutrition.com

Offers information related to nutrition and cancer treatment. There are links to numerous lectures and resources related to specific nutrition and cancer topics, and questions that can be asked of a nutritionist.

Casey Cares Foundation
Location: Baltimore, MD
Phone: (443) 568-0064
Web: caseycares.org

Helps keep families’ spirits high by arranging events for families throughout the Mid-Atlantic region and portions of the Midwest. These events range from sporting events, movies, local attractions, surprise birthday deliveries, weekend getaways, themed pajama parties, grocery bills assistance, family group support, and more.

Children with Hair Loss ♥
Location: South Rockwood, MI
Phone: (734) 379-4400
Web: childrenwithhairloss.us

Provides hair to children and young adults who are experiencing hair loss. Human hair replacements are provided at no cost to qualifying recipients every year until age 21.

Gabe’s Chemo Duck Program
Location: Spring Hill, TN
Web: chemoduck.org

A unique educational program for children with cancer. Provides a soft, cuddly companion that provides hope and alleviates fear and anxiety. Developed with child life specialists and medical professionals, helps introduce children and families to their new life and encourages healing through play therapy.

Got Transition
Location: Washington, D.C.
Phone: (202) 429-3957
Web: gottransition.org

A resource for young people who are leaving their pediatric care and moving toward the adult health system and doing things they have never done before. Dedicated to improving this process by supporting health providers, young adults, and their families with resources and information.

Gracie’s Gowns
Location: Spotsylvania, VA
Phone: (540) 287-0143
Web: graciegowns.org

Makes hospital gowns for chronically ill children throughout the US and internationally as well. They are personalized with the child’s name and match the fabric/gown to what the child likes or is interested in the most.

Hats, Scarves and More
Location: Spokane, WA
Phone: (509) 484-2095
Web: hatsscarvesandmore.com

Quality head coverings for women, men, teens, and children with hair loss due to cancer, chemotherapy and other medical conditions. This is not a non-profit organization.

Headcovers Unlimited
Location: League City, TX
Phone: (800) 264-4287
Web: headcovers.com

Wigs, hats, and cosmetics for cancer patients. This is not a non-profit organization.

Heavenly Hats
Location: Green Bay, WI
Phone: (920) 362-2668
Web: heavenlyhats.org

Collects and distributes brand new hats of all kinds to those who have lost their hair due to the treatment of cancer or the many other medical conditions which may cause hair loss.

Hopecam, Inc.
Location: Reston, VA
Phone: (703) 364-5609
Web: hopecam.org

Uses technology to connect children undergoing treatment with their friends at school in order to alleviate social isolation. Provides equipment, IT support, and works with the school to secure and facilitate their participation.

Icing Smiles, Inc.
Location: Ellicott City, MD
Phone: (443) 420-7096
Web: icingsmiles.org

Provides custom celebration cakes and other treats to families impacted by the critical illness of a child.

Linus Pauling Institute of Science and Medicine
Location: Corvallis, OR
Phone: (541) 737-5075
Web: lpi.oregonstate.edu

Extensive research on the use of micronutrients in the complementary treatment and prevention of cancer and degenerative diseases. Publishes a quarterly newsletter and an extensive array of research reports.

LiveStrong Fertility
Location: Austin, TX
Phone: (866) 673-7205
Web: livestrong.org/we-can-help/livestrong-fertility

Includes educational information and access to resources related to fertility preservation, and to learn about the fertility-related risks for common cancer treatments.
Locks of Love
Location: West Palm Beach, FL
Phone: (561) 833-7332
Web: locksoflove.org
Provides hairpieces to financially disadvantaged children in the United States and Canada under age 18 suffering from long-term medical hair loss from any diagnosis.

Look Good...Feel Better
Location: Washington, D.C.
Phone: (202) 331-1770
Web: lookgoodfeelbetter.org
A free national public service program dedicated to teaching young and adult cancer patients beauty techniques to help foster self-confidence and self-image during chemotherapy and radiation treatment. Offers group or individual sessions conducted by trained and certified cosmetologists, complimentary makeup kits for patients participating in a group program, and free materials such as video tapes and pamphlets.

Luke’s Fastbreaks
Location: Dallas, TX
Phone: (855) 585-3732
Web: lukesfastbreaks.org
This organization donates medical t-shirts to hospitals and Ronald McDonald Houses across the nation. These colorful shirts are fashioned with snaps to make practical and kid-friendly replacements for hospital gowns.

Monkey in My Chair
Location: Cincinnati, OH
Phone: (513) 772-4888
Web: monkeyinmychair.org
A beneficial program to help cancer patients stay connected to their classmates. Each child receives a monkey with a backpack to take their place in the classroom while they are in treatment as well as a teacher guide.

National Center for Complementary and Integrative Health
Location: Bethesda, MD
Phone: (888) 644-6226
TTY: (866) 464-3615
Web: nccih.nih.gov/health/cancer
Provides information on alternative medicine, including cancer treatments and comfort management. It supports basic and applied research and training, and disseminates information on complementary and alternative medicine to practitioners and the public.

Peach’s Neet Feet
Location: Farmington, NM
Web: peachesneetfeet.com
Provides custom, hand-painted shoes to children living with disabilities and fighting serious illnesses. Additionally, PNF provides care packages and outreach parties to communities across the US.

Project Linus
Location: Bloomington, IL
Phone: (309) 454-1764
Web: projectlinus.org
Donates handmade security blankets, quilts, and afghans to children undergoing difficult medical situations.

Save My Fertility
Location: Chevy Chase, MD
Phone: (866) 708-3378
Web: savemyfertility.org
Delivers information and resources for families and cancer patients who are interested in preservation options for cancer patients.

Shadow Buddies
Phone: (913) 642-4646
Web: shadowbuddies.org
Provides soft doll friends for kids and resource packets for medical caretakers. Twenty-one illnesses have their own symptom and treatment specific buddies – oncology being one of them.

Songs of Love Foundation
Location: Forest Hills NY
Phone: (718) 441-4588
Web: songsoflove.com
Create personalized one-of-a-kind songs for children and teens facing medical, physical, or emotional challenges. Produces intimate musical portraits (which are never duplicated) for thousands of children and teens.

Starlight Children’s Foundation
Location: Los Angeles, CA
Phone: (310) 479-1212
Web: starlight.org
Dedicated to brightening the lives of seriously ill children (ages 4-18) through numerous resources and educational programs.

Stupid Cancer
Location: New York, NY
Phone: (877) 735-4673
Web: stupidcancer.org
Empowers young adults (ages 15 – 39) affected by cancer through innovative and award-winning programs and services. As the nation’s premier patient advocate for this underserved population, their charter is to ensure that no one goes unaware of the age-appropriate support resources they are entitled to so they can get busy living. Numerous resources available.

TeamIMPACT
Location: Quincy, MA
Phone: (617) 801-0248
Web: goteamimpact.org
Harnesses the power of teamwork by matching kids battling serious illness with college athletic teams. Team IMPACT children are drafted onto local college athletic teams and, to the greatest extent possible, become an official member of the team for the duration of their treatment and beyond.

Wigs for Kids
Location: Westlake, OH
Phone: (440) 333-4433
Web: wigsforkids.org
Provides wigs to children 18 and younger who are experiencing hair loss as a result of medical treatment.
**Prescription Assistance**

The cost of paying for medication can be difficult. This section includes resources and programs that may help pay for prescription drugs. Check with your oncologist for a listing for your child’s medication. You may be able to contact the manufacturers of each medication for additional help.

**NeedyMeds, Inc.**
Location: Gloucester, MA  
Phone: (800) 503-6897  
Web: needymeds.org

Provides information about patient assistance programs that provide no-cost prescription medications to eligible participants.

**Pharmaceutical Research and Manufacturers of America (PhRMA)**
Location: Washington D.C.  
Phone: (202) 835-3400  
Web: phrma.org

Brings together America’s pharmaceutical companies, doctors, other health care providers, patient advocacy organizations, and community groups to help qualifying patients who lack prescription coverage get the medicines they need through the public or private program that’s right for them. Offers a single point of access to hundreds of public and private patient assistance programs, including over 200 programs offered by pharmaceutical companies.

**RxAssist**
Web: rxassist.org

A nationally recognized, web-based medication assistance resource center. RxAssist gives providers, advocates, patient, and caregivers comprehensive, up-to-date information in an easy to use format.

**Medical Security Card Company (MSC), LLC**
Location: Tucson, AZ  
Phone: (800) 347-5985  
Web: medicalsecuritycard.com

Offers a discount card for numerous participating pharmacies through membership to individuals without considerations of income.

**Travel and Lodging Assistance**

These organizations can help you arrange for air transportation, ground transportation, lodging and more to help ease the financial burden associated with getting to and from important treatment.

**Air Transport**

**Angel Flight West**  
Location: Santa Monica, CA  
Phone: (888) 426-2643  
Web: angelflightwest.org

Flights serve a wide variety of needs. All are intended for situations in which the passenger cannot afford to purchase commercial airline tickets, or when it is a physical hardship to travel by land or commercial airline. Other situations include, but are not limited to, a compromised immune system or living in a remote area without access to commercial transportation. There are different Angel Flight programs by region.

**Children’s Flight of Hope**  
Location: Morrisville, NC  
Phone: (919) 466-8593  
Web: childrensflightofhope.org

Provides free, private air transport to and from medical facilities for critically ill or injured children (with their families or guardians) who, due to medical, financial, or logistical reasons, are unable to travel to their destinations by any other mode. Highly qualified volunteer pilots operate aircraft to transport children and their families to and from medical facilities throughout the eastern U.S.

**Angel Flight, Inc.**  
Location: Tulsa, OK  
Phone: (918) 749-8992  
Web: angelflight.com

Provides non-emergency transportation to medical treatment for patients who cannot afford it, or cannot fly on public transportation for health reasons, or for those who do not have access to public transportation in their area.

**Air Charity Network**  
Location: Virginia Beach, VA  
Phone: (877) 621-7177  
Web: aircharitynetwork.org

Air Charity Network provides free air transportation to specialized health care facilities or distant destinations due to family, community, or national crisis.
Corporate Angel Network Program  
Location: White Plains, NY  
Phone: (866) 328-1313  
Web: corpangelnetwork.org  
Finds available space on corporate jets for cancer patients in need of transportation for treatment, consultations, or checkups. The service is free for the patient and one attendant or family member.

Lifeline Pilots  
Web: lifelinepilots.org  
Volunteer pilots who fly people in need of medical care, or other compelling need, to distant care centers or locations. There is no charge for the pilot’s services. Requirements: patients must be ambulatory; patients must be unable to use other transportation; patients must have verifiable financial need; requests must be submitted by an agency, social worker, doctor, medical personnel, or other similarly qualified individual.

Mercy Medical Angels  
Location: Virginia Beach, VA  
Phone: (800) 296-1217  
Web: mercymedical.org  
Provides access to distant medical appointments, diagnosis, or treatment through air travel, and ground transportation.

Miracle Flights for Kids  
Location: Las Vegas, NV  
Phone: (800) 359-1711  
Web: miracleflights.org  
Provides financial assistance to low-income children for commercial care to obtain special medical care.

National Patient Air Transport  
Location: Virginia Beach, VA  
Phone: (800) 296-1217  
Web: patienttravel.org  
Provides listings of discounted and free air travel options. Referrals are made to all known appropriate charitable, charitably assisted, and special patient discount commercial services, based on an evaluation of the patient’s medical conditions, type of transport required, and departure/destination locations.

PALS: Patient Airlift Services  
Web: palservices.org  
Arranges free air transportation for individuals needing medical diagnosis or treatment in the Northeastern United States.

Volunteer Pilots Association  
Location: Bridgeville, PA  
Phone: (412) 221-1374  
Web: volunteerpilots.org  
Provides air transportation to individuals needing assistance due to verifiable financial need, generally via a social work referral. This organization provides assistance within the Northeastern United States but partners with other organization in other regions.

Ground Transport  
Note: Many organizations offer free ground transportation in most cities for cancer patients through medical institutions, local transit authorities, social service agencies, religious organizations, and cancer organizations. The social worker at your treatment facility may be able to help you find phone numbers for any of these businesses or assist you with information. Ground transport services may be offered or mileage reimbursed through your state or local Department of Social Services. These national organizations may also offer help.

American Cancer Society  
Location: Atlanta, GA  
Phone: (800) 227-2345  
Web: cancer.org/treatment/support-programs-and-services/patient-lodging/hope-lodge  
Free, temporary housing facilities for cancer patients who are undergoing treatment and their families. Hope Lodges provide guests with private rooms, kitchen facilities, and, in some locations, transportation to treatments. Accommodations and eligibility requirements may vary by location.

Believe in Tomorrow  
Location: Baltimore, MD  
Phone: (800) 933-5470  
Web: believeintomorrow.org  
Offers overnight accommodations for families receiving treatment at Johns Hopkins Children’s Center as well as at multiple respite locations in other areas.

Joe’s House  
Phone: (877) 563-7468  
Web: joeshouse.org  
Provides a nationwide online service that helps cancer patients and their families find lodging near treatment centers, often for reduced rates.

National Association of Hospital Hospitality Houses  
Location: Gresham, OR  
Phone: (800) 542-9730  
Web: nahhh.org  
Information on lodging and support available for families receiving medical care away from home. Services vary from facility to facility and are offered at little or no cost to the guests.

Ronald McDonald House Charities  
Location: Oak Brook, IL  
Phone: (630) 623-7048  
Web: rmhc.com  
Provides lodging for families of seriously ill children being treated away from home. Lodging is generally close to treatment centers.

Note: Many organizations offer free ground transportation in most cities for cancer patients through medical institutions, local transit authorities, social service agencies, religious organizations, and cancer organizations. The social worker at your treatment facility may be able to help you find phone numbers for any of these businesses or assist you with information. Ground transport services may be offered or mileage reimbursed through your state or local Department of Social Services. These national organizations may also offer help.
## Wish Fulfillment Organizations

These organizations grant a wide variety of wishes that are requested by children, teens, and young adults. Wishes are granted to children and teens with chronic, life-threatening, or terminal illnesses. Each organization has its own eligibility requirements and conditions for granting wishes.

### Benefit4Kids
- **Location:** Macomb, MI
- **Phone:** (877) 245-5430
- **Web:** benefit4kids.org

An all-volunteer organization that grants the outdoor wishes of children with life-threatening illnesses.

### Catch-A-Dream
- **Location:** Starkville, MS
- **Phone:** (662) 324-5700
- **Web:** catchadream.org

Grants once-in-a-lifetime hunting and fishing experiences to children 18 years old or younger who have a life-threatening illness.

### Challenge Air Love Field Airport
- **Location:** Dallas, TX
- **Phone:** (214) 351-3353
- **Web:** challengeair.com

Provides experiences for children and youth with special needs related to the experience of flying a plane.

### Children’s Wish Foundation International
- **Location:** Atlanta, GA
- **Phone:** (800) 323-9474
- **Web:** childrenswish.org

Grants wishes for children under the age of 18 with life-threatening illnesses, regardless of where the child lives or where he or she is undergoing treatment. Wish expenses are covered for the family including airline tickets, rental expenses, meals, spending money, and any salary potentially lost as a result of parents taking time off from their jobs to share their child’s wish.

### Clayton Dabney Foundation
- **Location:** Dallas, TX
- **Phone:** (214) 361-2600
- **Web:** claytondabney.org

Provides families of children in the last stages of terminal cancer with assistance in creating everlasting memories. The assistance is arranged through the parents and is unknown to the child.

### The Dream Factory
- **Location:** Louisville, KY
- **Phone:** (800) 456-7556
- **Web:** dreamfactoryinc.org

The Dream Factory is an all-volunteer organization that grants wishes to children with life-threatening or terminal diagnoses, as well as chronic illnesses and disorders.

### Kids Wish Network
- **Location:** Holiday, FL
- **Phone:** (888) 918-9004
- **Web:** kidswishnetwork.org

Kids Wish Network fulfills wishes of children with life-threatening illnesses, coordinating personalized, unique wishes for each child.

### Little Star Foundation
- **Location:** Santa Rosa Beach, FL
- **Phone:** (800) 543-6565
- **Web:** littlesstar.org

Founded by tennis pro Andrea Jaeger, Little Star provides a summer camp and grants wishes to children receiving treatment for illnesses.

### Make-A-Wish Foundation of America 🌈
- **Location:** Phoenix, AZ
- **Phone:** (602) 279-9474
- **Web:** wish.org

Grants wishes to children who have life-threatening medical conditions. Make-A-Wish operates within the United States as well as internationally, granting a wish on average every 35 minutes.

### The Marty Lyons Foundation
- **Location:** Commack, NY
- **Phone:** (631) 543-9474
- **Web:** martilyonsfoundation.org

Fulfills the special wishes of children ages three to seventeen years old, who have been diagnosed as having a terminal or life threatening illness by providing and arranging special wish requests.

### Special Wish Foundation
- **Location:** Columbus, OH
- **Phone:** (614) 258-3186
- **Web:** spwish.org

Grants wishes to children under age 21 who are diagnosed with life-threatening or terminal illness.

### Sunshine Foundation 🌞
- **Location:** Feasterville, PA
- **Phone:** (215) 356-4770
- **Web:** sunshinefoundation.org

Grants wishes to chronically ill, seriously ill, physically challenged, and abused children between the ages of three and eighteen. Child qualify if their families cannot fulfill their requests due to financial strain.

### Western Wishes Foundation
- **Location:** Weatherford, TX
- **Phone:** (817) 757-9216
- **Web:** westernwishes.org

Grants wishes to kids faced with adversity and who love the western way of life.
Wish Fulfillment Organizations for Young Adults
Wish fulfillment that grants the wishes of terminally ill young adults ages 18 and older.

3 Little Birds 4 Life
Location: Collinsville, IL
Web: 3littlebirds4life.org
Grants wishes to patients between the ages of 18 and 40 who are currently managing cancer diagnoses.

Dream Foundation
Location: Santa Barbara, CA
Phone: (888) 437-3267
Web: dreamfoundation.org
Grants wishes to people ages 18 to 65 with a life expectancy of one year or less.

The Nicki Leach Foundation
Location: Summit, NJ
Phone: (904) 716-5394
Web: nickileach.org
Provides individuals between the ages of 18-30 who have been diagnosed with cancer with the opportunity to enjoy normal or extraordinary activities they might otherwise not be able to afford.
Support for End of Life

Nothing in life prepares us for a terminal prognosis. Grief can be a long, painful, and difficult process. There are many ways to grieve, to honor the life of your child, and to support them in their final days. This section offers resources related to hospice and compassionate care, grief support, and assistance in memorializing the life of your child.
Compassionate Care Resources

This section includes information related to compassionate care, hospice, and palliative care, answering tough questions, and assisting on issues related to the end of life.

Association of Maternal and Child Health Programs
Location: Washington, D.C.
Phone: (202) 775-0436
Web: amchp.org
Provides financial grants to states for direct medical and related services for children with disabilities, including chronic and terminal illnesses. Every state has its own plan. You can contact this organization for information on your child’s eligibility for services as well as information on state specific programs.

Caregiver Action Network
Location: Washington, D.C.
Phone: (202) 454-3970
Web: caregiveraction.org
Education, support, respite care, and advocacy for caregivers. Their toll-free information line provides referrals to caregiver support groups and a resource guide. Distributes a newsletter with practical tips on caregiving.

Children’s Hospice International
Location: Alexandria, VA
Phone: (703) 684-0330
Web: chionline.org
Provides support to children with life-threatening conditions and their families through referral and information services. Promotes hospice support through pediatric care facilities to encourage the inclusion of children in existing and developing hospice/homecare programs and to include the hospice perspective in all areas of pediatric care.

Clayton Dabney Foundation
Location: Dallas, TX
Phone: (214) 361-2600
Web: claytondabney.org
Grants wishes and financial assistance to terminally ill children and their families across the United States.

CureSearch.org
Location: Bethesda, MD
Phone: (800) 458-6223
Web: curesearch.org/Palliative-Care
Provides information and resources to help with end of life decisions and how they might affect families. Resources include information about end of life, recent death, and months or years after death.

Hospice Foundation of America
Location: Washington, D.C.
Phone: (800) 854-3402
Web: hospicefoundation.org
Information on hospice care, philosophies, care standards, how to select a hospice team, and locations of a hospice near you. Many additional resources are available related to grief and end-of-life care.

Hospice Net
Location: Nashville, TN
Web: hospicenet.org
Information and links for families facing end of life decisions. This resource contains many sections including information for caregivers, pain management, bereavement, and helping children to understand and cope.

National Association for Home Care and Hospice
Location: Washington, D.C.
Phone: (202) 547-7424
Web: nahc.org
Information and links for families facing end of life decisions. This resource contains many sections including information for caregivers, pain management, bereavement, and helping children to understand and cope.

National Hospice and Palliative Care Organization
Location: Alexandria, VA
Phone: (703) 837-1500
Web: nhpco.org
Designed to promote and maintain hospice care and to encourage support for patients and family members. Information about hospice providers, end-of-life care resources, and grief and bereavement.
**Funeral and Memorial Services**

Funerals and memorial services are complex events that must balance many factors, including religious requirements, emotional needs, and financial resources. If you want additional information about how to make funeral arrangements and available options, you may want to talk with your hospital social worker or chaplain.

**Cremation Association of North America**
Location: Wheeling, IL  
Phone: (312) 245-1077  
Web: cremationassociation.org  

An association of crematories, cemeteries, and funeral homes that offer cremation and encourage the concept of memorialization.

**Funeral Consumers’ Alliance**
Location: South Burlington, VT  
Phone: (802) 865-8300  
Web: funerals.org  

Advises families of their rights, educates them regarding choices, and helps connect with lower priced options.

**National Funeral Directors’ Association**
Location: Brookfield, WI  
Phone: (800) 228-6332  
Web: nfda.org/consumer-resources/planning-a-funeral  

Offers information on funerals and memorial planning. Provides numerous links to resources associated with the passing of a loved one.

**Partnership for Parents**
Location: Sacramento, CA  
Phone: (916) 489-2222  
Web: partnershipforparents.net  

Designed for parents experiencing many stages of having a seriously ill child, including planning a funeral.

**Seven Ponds**
Location: Albany, CA  
Phone: (415) 431-3717  
Web: sevenponds.com  

Provides information and practical guides to planning a funeral and remembrance events. Helpful step-by-step guides ease the process by answering questions and assisting you in making informed decisions.

**Grief and Bereavement**

The following organizations focus on coping with grief and loss. They can provide support, information, and resources for parents and siblings who are experiencing loss.

**Association for Death Education and Counseling**
Location: Oakbrook Terrace, IL  
Phone: (847) 686-2240  
Web: adec.org  

Provides information with multiple resources available on various end of life issues including death of a child, coping with the loss of a sibling, how to help someone who is grieving, and more.

**Bereaved Parents of the USA**
Location: Poughkeepsie, NY  
Phone: (501) 847-4102  
Web: bereavedparentsusa.org  

Edcucates families about the grief process as it applies to the death of a child at any age and from any cause; aids and supports those who are suffering such a loss; creates connections with other bereaved parents, siblings, and grandparents who are able to offer support to other more newly bereaved families, and much more. Offers resources from national and local chapters.

**Cancer Care, Inc.**
Location: New York, NY  
Phone: (800) 813-4673  
Web: cancercare.org  

Service programs include group, individual, family, and bereavement counseling (in person, online, and via telephone). Information and referral to local community resources are also available.

**Centering Corporation**
Location: Omaha, NE  
Phone: (402) 553-1200  
Web: centering.org  

Provides guidance for families, children, and parents experiencing grief. Request a copy of their catalog describing many books, pamphlets, and videos that focus on healing. This is not a non-profit organization.

**The Compassionate Friends**
Location: Oak Brook, IL  
Phone: (877) 969-0010  
Web: compassionatefriends.org  

Offers friendship and understanding to families who are grieving the death of a child of any age, from any cause. It is a national network of support groups that focus on assisting parents who have lost a child. Parents can also find advice and support for helping surviving children cope with the loss of a sibling. Offers publications for parents and siblings.

**Compassion Books, Inc.**
Location: Burnsville, NC  
Phone: (800) 970-4220  
Web: compassionbooks.com  

Delivers carefully selected resources related to loss and grief for people of all ages. Over the past 20 years they have collected over 400 titles that have been reviewed by professionals. This is not a non-profit organization.
Dougy Center for Grieving Children  
Location: Portland, OR  
Phone: (503) 775-5683  
Web: dougy.org  
Provides children and teens a place to meet and be supported by peers and families who have experienced the death of a sibling, parent, or family member. Provides support and training locally, nationally, and internationally to individuals and organizations seeking to assist children and teens in grief. Also offers information and resources on the Web.

Elisabeth Kubler-Ross Foundation  
Location: Scottsdale, AZ  
Web: ekrfoundation.org  
Offers seminars, retreats, lectures, and an assortment of literature based on the work of Dr. Ross.

Emotions Anonymous  
Location: St, Paul, MN  
Phone: (651) 647-9712  
Web: emotionsanonymous.org  
Twelve-step organization composed of people who come together in weekly meetings for the purpose of working toward confronting emotional difficulties. EA members are from many walks of life and are of diverse ages, economic status, social, and educational backgrounds. The only requirement for membership is a desire to become emotionally well. Available in multiple languages.

Grief Recovery Method  
Location: Bend, OR  
Phone: (818) 334-7606  
Web: griefrecoverymethod.com  
Offers thousands of certified Grief Recovery specialists to help individuals through grief. This website can help you find one-on-one support, weekend workshops, and support groups in your area.

Healing Hearts for Bereaved Parents  
Location: Covington, WA  
Web: healingheart.net  
Offers understanding, suggestions for coping, support, friendship, and hope for grieving families. Specific sections for siblings, parents, and grandparents.

Hospice Net  
Location: Nashville, TN  
Web: hospicenet.org  
Information and links for families facing life-threatening illness. Sections for caregivers, bereavement, and helping kids understand and cope. Suggestions on talking to children about death.

Living with Loss Magazine  
Location: Eckert, CO  
Phone: (888) 604-4673  
Web: livingwithloss.com  
A support group in print and complete grief resource center. The stories, articles and poems in the magazine come from bereaved individuals. Regular articles in the magazine are written by professionals who are in the field of grief intervention. Their articles address physical and mental health issues, the psychology of mourning, ecumenical faith and cross-cultural perspectives, the grief of children, and even humor.

M.I.S.S. Foundation  
Location: Austin, TX  
Phone: (888) 455-6477  
Web: missfoundation.org  
Provides emergency support to families in crisis after the death of their child from any cause. They help families cope with the resultant feelings of overwhelming grief and loss.

Salt Water  
Web: findyourharbor.com  
Provides an online community where those grieving can find comfort, support, and tools to survive the death of a loved one. The website shares resources and articles, as well as invites guests to submit articles of their own.

Shiva Foundation  
Phone: (805) 541-3364  
Web: goodgrief.org  
Formed to open the dialogue around issues of grief and loss in such a way that honors loss in the cycle of life.
Index
Index

13 Thirty ................................................................. 26
3 Little Birds 4 Life .................................................. 39
Abilty OnLine .......................................................... 26
AbleData ............................................................... 12, 13
About Face ............................................................. 13
Air Care Alliance National Patient Air Transport Helpline .................................................. 36
Air Charity Network ................................................. 36
American Academy of Audiology ................................ 13
American Academy of Dermatology ......................... 10
American Association for Pediatric Ophthalmology and Strabismus .................................... 9
American Brain Tumor Association ............................. 7
American Cancer Society ........................................ 3, 18, 29, 33, 37
Hope Lodge ................................................................ 37
American Childhood Cancer Organization ................. 3, 18, 25, 33
American Chronic Pain Association ........................... 16
American Council of the Blind ................................... 13
American Counseling Association .............................. 18
American Family Therapy Academy ........................ 18
American Indian Cancer Foundation .......................... 15
American Institute for Cancer Research ....................... 33
American Kidney Fund .............................................. 21, 29
American Liver Foundation ........................................ 9, 21
American Lung Association ....................................... 9
American Massage Therapy Association .................... 34
American Medical Association - Doctor Finder ............ 17
American Pain Society .............................................. 17
American Pediatric Surgical Association ................... 17
Americans with Disabilities Act .................................. 13
American Society for Deaf Children ......................... 13
Amputee Coalition of America ................................... 13
Andre Sobel Award ................................................. 27
The Andrew McDonough B+ Foundation .................... 29
Angel Flight West ..................................................... 36
Angel Flight, Inc ....................................................... 36
The Angel Wheels to Healing ..................................... 37
Aplastic Anemia and MDS International Foundation .... 10
ARCH: National Respite Network .............................. 13
The Asian American Cancer Support Network .......... 15
Association for Death Education and Counseling ....... 44
Association of Cancer Online Resources (ACOR) .......... 18
Association of Maternal and Child Health Programs ................................................. 29, 43
Association of Pediatric Hematology/Oncology Nurses ......................... 19
Association of Pediatric Oncology Social Workers ....... 19
Bandaids & Blackboards .......................................... 19
B.A.S.E. Camp ......................................................... 25
BeauBeau: Beautiful Scarves for Beautiful Heads ........ 34
BEGINNINGS .......................................................... 13
Believe in Tomorrow ................................................ 37
Benefit4Kids .......................................................... 38
Bereaved Parents of the USA ...................................... 44
Best Doctors .......................................................... 17
Beyond the Cure Scholarship ..................................... 27
Blood & Marrow Transplant Information Network ....... 21
Bone Marrow Foundation ......................................... 29
Brain Trust .............................................................. 7
Brain Tumour Foundation of Canada .......................... 7
BreastCancer.org ..................................................... 8
Camp Good Days ..................................................... 25
Camp Mak-A-Dream Children’s Oncology ................. 25
Camp Foundation ..................................................... 25
Camp One Step ....................................................... 25
Camp Quality USA ................................................ 25
Camp Simcha .......................................................... 25
Cancer and Careers ............................................... 28
Cancer Con ............................................................ 26
Cancer Care, Inc. ...................................................... 12, 19, 29, 44
Cancer for College .................................................. 27
Cancer Hope Network ............................................... 19, 33
Cancer Knowledge Network ...................................... 19
Cancer.Net .............................................................. 3, 16, 17, 19
Cancer Nutrition Center ............................................ 34
CancerQuest ............................................................ 15
Cancer Support Hotline ............................................ 18
Cancer Survivor’s Fund ............................................ 27
Cancer Survivor’s Toolkit .......................................... 33
Carcinoid Cancer Foundation .................................... 8
Caregiver Action Network ....................................... 12, 43
Caregiver Survival Resources ................................... 12
CaringBridge .......................................................... 31
Casey Cares Foundation .......................................... 34
Castle Connolly ........................................................ 17
Catch-A-Dream ....................................................... 38
Catholic Charities, U.S.A. .......................................... 29
Center for Parent Information and Resources .......................................................... 13, 33
Centering Corporation .......................................................... 44
Centers for Medicare & Medicaid Services ........................................ 29, 32
Chai Lifeline .......................................................... 19, 29
Challenge Air Love Field Airport ........................................ 38
Childhood Brain Tumor Foundation .......................................................... 7
Childhood Cancer Guides .......................................................... 19, 33
Childhood Leukemia Foundation ........................................ 8, 19
Children’s Brain Tumor Foundation .......................................................... 7
Children’s Flight of Hope .......................................................... 36
Children’s Hospice International ........................................ 43
Children’s Leukemia Research Association ........................................ 9
Children’s Liver Association for Support Services ........................................ 9, 21, 29
Children’s Neuroblastoma Cancer Foundation ........................................ 9
Children’s Oncology Group .......................................................... 3
Children’s Organ Transplant Association ........................................ 21, 31
Children’s Tumor Foundation .......................................................... 9
Children’s Wish Foundation International ........................................ 38
Children with Hair Loss .......................................................... 34
Clayton Dabney Foundation .......................................................... 38, 43
The Coalition Against Pediatric Pain .................................................... 16
The Compassionate Friends .......................................................... 44
Compassion Books, Inc. .......................................................... 44
Corporate Angel Network Program .................................................... 37
Cremation Association of North America ........................................ 44
The Cure Our Children Foundation .................................................... 7
CureSearch.org .......................................................... 3, 16, 33, 43
Dana-Farber Cancer Institute
  Children’s Hospital Boston .......................................................... 7
Day By Day .......................................................... 26
Dept. of Health and Human Services
  Fraud Hotline .......................................................... 32
Disability Rights Education and Defense Fund ........................................ 13
Disabled Sports USA .......................................................... 13
Dougy Center for Grieving Children .................................................... 45
The Dream Factory .......................................................... 38
Dream Foundation .......................................................... 39
Elks USA .......................................................... 29
Emotions Anonymous .......................................................... 45
Epic Experience .......................................................... 25
Equal Employment Opportunity Commission ........................................ 28
Eye Cancer Network .......................................................... 10
Family Reach .......................................................... 29
Family Voices .......................................................... 19
Famous Fone Friends .......................................................... 30
Fanconi Anemia Research Fund .......................................................... 11
Federation for Children with Special Needs ........................................ 14
First Descents .......................................................... 25
First Hand Foundation .......................................................... 29, 31
Funeral Consumers’ Alliance .......................................................... 44
Gabe’s Chemo Duck Program .......................................................... 34
General Grand Chapter, Order of the Eastern Star .................................. 30
Genetic Alliance .......................................................... 14
Get Palliative Care .......................................................... 16
Gilda’s Club® Worldwide .......................................................... 26
Giveforward .......................................................... 31
Glenn Garcelon Foundation .......................................................... 30
GoFundMe.com .......................................................... 31
GoodTherapy.org .......................................................... 18
Got Transition .......................................................... 34
Gracie’s Gowns .......................................................... 34
Grief Recovery Method .......................................................... 45
Group Loop .......................................................... 26
Hats, Scarves and More .......................................................... 34
Head and Neck Cancer Alliance .......................................................... 10
Headcovers Unlimited .......................................................... 34
Healthgrades.com .......................................................... 17
Healing Hearts for Bereaved Parents .................................................... 45
HEATH Resource Center .......................................................... 14
Heavenly Hats .......................................................... 34
Help, Hope, Live .......................................................... 21, 31
Hirshberg Foundation for Pancreatic Cancer Research .................................. 8
Histocytosis Association of America .................................................... 11
Hopecam Inc. .......................................................... 34
Hospice Foundation of America .................................................... 43
Hospice Net .......................................................... 43, 45
Icing Smiles, Inc. .......................................................... 34
Imerman Angels .......................................................... 19, 26
Insure Kids Now .......................................................... 32
Intercultural Cancer Council .......................................................... 15
International Myeloma Foundation .................................................... 9
Job Accommodation Network (JAN) .................................................... 28
Joe’s House .......................................................... 37
Joint Commission on Accreditation of Healthcare Organizations ................. 17
KidsHealth.org .......................................................... 3, 15, 19
Kids Wish Network .......................................................... 38
Lab Tests Online .......................................................... 17
The Nicki Leach Foundation .......................................................... 39
Northwest Sarcoma Foundation .................................................. 10
Office of Minority Health .............................................................. 15
Oley Foundation ........................................................................... 12
Oncolink ....................................................................................... 3
OrganDonor.gov ........................................................................... 21
Padres Contra El Cancer ................................................................. 15, 20
PALS: Patient Airlift Services ........................................................ 37
Pancreatica ..................................................................................... 8
Pancreatic Cancer Action Network ................................................ 8
Parent Advocacy Coalition for Educational Rights (PACER) Center ..................................................................................... 15, 20
Parents Helping Parents ................................................................. 20
Partnership for Parents ................................................................. 44
Partnership for Prescription Assistance ........................................ 30
Patient Advocate Foundation ......................................................... 28, 30
Peach’s Neet Feet ........................................................................... 35
Pediatric Brain Tumor Foundation ................................................ 8, 27
Pediatric Oncology Resource Center ........................................... 20, 27
Bone Cancers ................................................................................ 7
Pediatric Services of America ....................................................... 12
Pharmaceutical Research and Manufacturers of America (PhRMA) ................................................................. 36
Pinky Swear Foundation ............................................................... 30
Pituitary Network Association ....................................................... 8
Professional Association of Therapeutic Horsemanship International ............................................................... 14, 25
Project Koru .................................................................................. 25
Project Linus .................................................................................. 35
Psych Central .................................................................................. 20
R.A. Bloch Cancer Foundation ....................................................... 20
Ronald McDonald House Charities .............................................. 37
RxAssist ......................................................................................... 36
RxList ............................................................................................. 17
Salt Water ....................................................................................... 45
Salvation Army National Headquarters .......................................... 30
The Samfund .................................................................................... 27, 30
The Sarcoma Alliance ..................................................................... 27, 30
Sarcoma Alliance of America ....................................................... 10
Sarcoma Foundation of America .................................................. 10
Save My Fertility ............................................................................ 35
SeriousFun Children’s Network .................................................... 26
Sesame Street Tool Kits ................................................................. 27
Seven Ponds ................................................................................... 44
Shadow Buddies ............................................................................. 35
Shiva Foundation ........................................................................... 45
Sibling Support Project ................................................................. 27
Social Security Administration ..................................................... 30
Songs of Love Foundation ............................................................ 35
Southeastern Brain Tumor Foundation ......................................... 8
Special Love ................................................................................... 20, 26, 30
Special Wish Foundation ............................................................... 38
Starlight Children’s Foundation .................................................... 30
St. Jude Children’s Research Hospital ......................................... 10
Osteosarcoma ................................................................................ 7
Stupid Cancer ................................................................................ 35
Sunshine Foundation ..................................................................... 38
SuperSibs! ....................................................................................... 27
Support for People with Oral, Head and Neck Cancer ......................... 10
Susan G. Komen for the Cure ......................................................... 8
Team IMPACT ............................................................................... 35
Traveler’s Aid International ............................................................ 30
The Ulman Cancer Fund for Young Adults ...................................... 20, 26, 27
United Healthcare Children’s Foundation ...................................... 30
United Methodist Association of Health and Welfare Ministries ............................................................... 30
United Network for Organ Sharing ................................................. 21
United Ostomy Association ............................................................ 14
Urology Health ................................................................................. 10
U.S. Department of Labor .............................................................. 28
U.S. Pain Foundation ....................................................................... 16
Visiting Nurse Association of America .......................................... 12
Vital Options International ............................................................ 20
Volunteer Pilots Association .......................................................... 37
Von Hippel Lindau Family Alliance ............................................... 11
WebMD – Physician Directory ....................................................... 17
Western Wishes Foundation ......................................................... 38
Wigs for Kids ................................................................................. 30, 35
Wheel to Walk Foundation ............................................................ 14
YouCaring ....................................................................................... 31

For the most up-to-date resource list, visit JoyRx.org/KCP

52 | Index
**Share Your Feedback**

The Kids’ Cancer Pages was created by the Children’s Cancer Association to provide resources and information to families across the U.S. We would appreciate your feedback. Please submit any comments, suggestions, or organization additions by using this form.

**Comments/Suggestions**

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**Organization Submission (1)**

<table>
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