



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.

#### LEGAL DISCLAIMER

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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.

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# How to Use This Resource Guide



Resources marked with this symbol have been identified as good places to begin you 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

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 Comprehensive clinical trial information center for patients, health professionals, and the public. Information on understanding trials, deciding whether to participate in trials, finding specific trials, research news, and other resources.

### **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 3

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.

#### Childhood Brain Tumor Foundation

Location: Germantown, MD Phone: (301) 515-2900 Web: childhoodbraintumor.org

Volunteer-run organization to raise funds and awareness about pediatric brain tumors. This site includes information, additional resources, and support for families and patients.

#### 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

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-todate 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.

#### **Pancreatica**

Location: Pacific Grove, CA Phone: (831) 658-0600 Web: pancreatica.org

Offers information regarding medical treatments, surgical options, diagnosis, and a 'speak with a survivor' service at 1-800-433-0464.

#### **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: cncfhope.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.

# 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.

#### Support for People with Oral, Head and Neck Cancer \*

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.

# 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.

#### Melanoma Research **Foundation**

Location: Washington, D.C. Phone: 800-673-1290

Web: melanoma.org/understandmelanoma/pediatric-melanoma

Provides information about Melanomas, discusses treatment options, and provides opportunities for community support and financial assistance.

#### **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.

#### Sarcoma Foundation of America

Location: Damascus, MD Phone: (301) 253-8687 Web: curesarcoma.org

Provides patient resources including general information about sarcoma, potential treatments for sarcoma, clinical trials, and infographics.

# **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.

# National Cancer Institute -**Ovarian Germ Cell Cancers**

Web: cancer.gov/ovarian

Provides information on ovarian germ cell cancer, diagnosis, treatment, and more.

#### **Urology Health**

Web: urologyhealth.org

Provides a wide range of services, including publications and education opportunities. The website offers a searchable database for information on pediatric urology and a specialist search.

# Other Hematology/ **Immune Deficiency** Syndromes & **Conditions**

#### **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, myclodysplastic 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/childhoodcancers/patient/unusual-cancerschildhood-pdg

Provides information on unusual cancers in children.

#### **National Organization for** Rare Disorders S

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.

#### **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.

# Americans with Disabilities Act 🖤 🗈

Location: Washington, D.C. Phone: (800) 541-0301 TTY: (800) 541-0383

Web: ada.gov

Offers resources related to the American Disabilities Act, guidelines, housing, employment, transportation, updates on ongoing investigations, and an information line at (800) 514-0301.

#### American Society for Deaf Children

Location: Washington, D.C. Phone: (800) 942-2732 Web: deafchildren.org

Offers support, encouragement, and information to families with hearingimpaired 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.

#### **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.

#### **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 agespecific information, ways to connect with other parents, and hearing systems.

### **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.

#### **Genetic Alliance**

Location: Washington, D.C. Phone: (202) 966-5557 Web: geneticalliance.org

Offers information on genetic counseling and genetic conditions, and organizes a network of more than 1,200 diseasespecific 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 also 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.

#### **National Rehabilitation** Information Center S

Location: Landover, MD Phone: (800) 346-2742 TTY: (301) 495-5989 Web: naric.com

Provides an information center focusing on disability and rehabilitation issues and research. This website offers references and referral services as well as custom database searches related to topics that include: aging, education, family, financial aid, general health resources, government resources, resources for specific disabilities, and mental health. NRIC also offers online chat support.

### 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 S

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: kidshealth.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.

#### **National Cancer** Institute 🖤 🖼

Location: Bethesda, MD Phone: (800) 422-6237 TTY: (800) 332-8615 Web: cancer.gov

Extensive and comprehensive information related to different types of cancer, new research, and clinical trials. This website offers a live chat and helpline in Spanish.

#### **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

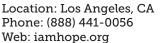
Dedicated to improving the health of racial and ethnic minority populations through resources, programs, campaigns, and initiatives.

# **Parent Advocacy Coalition** for Educational Rights (PACER) Center ♥ <sup>®</sup>

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



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 pain.

#### **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, treatmentrelated 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/medtermsmedical-dictionary/aritcle.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, internetbased 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/familyresources.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: cancerkn.com

Offers information and support for children, young adults, parents, and caregivers related to cancer treatment, creative and integrative therapies, end-oflife 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 ♥ <sup>®</sup>

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**

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-tounderstand 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 Bone Marrow** Transplant Link 🖼

Location: Southfield, MI Phone: (800) 546-5268 Web: nbmtlink.org

Delivers resources to help patients, caregivers, and families cope with the social and emotional challenges of bone marrow/stem cell transplant from diagnosis through survivorship by providing vital information and personalized support services.

# **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 **V**

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 lifethreatening 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: (330) 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 meidcal 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**

all aspects of life.

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

#### 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 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 prostheses 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

# 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.

#### Centers for Medicare & **Medicaid Services**

Location: Baltimore, MD Phone: (877) 267-2323 TTY: (866) 226-1819 Web: cms.gov

Provides information on Medicare and Medicaid benefits.

#### Chai Lifeline

Location: New York, NY Phone: (212) 465-0949 Web: chailifeline.org

Offers a large network of free health support services that provide psychological, emotional, and financial assistance for seriously ill children and

their families.

# 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 healthrelated 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.

#### 

Location: Hampton, VA Phone: (800) 532-5274 Web: patientadvocate.org

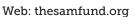
Provides a national financial resource directory that is searchable by state, age range, diagnosis, and resource type. Additional information includes insurance assistance details, patient support programs from drug manufacturers, and more.

# 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



This organization provides assistance to young adult cancer survivors including direct financial support and education regardless of diagnosis and location.

#### 

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.

#### Special Love

Location: Winchester, VA Phone: (888) 930-2707 Web: speciallove.org

Offers college scholarships for kids with cancer, camp opportunities, and emergency funds for families in need.

### 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 \(\bigsire\)

Web: youcaring.com

Offers resources to conduct peerto-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 S



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.

#### .org

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

Provides resources and information for families and children during and after treatment. Post-treatment information includes the first few months to a year after treatment as well as long-term follow-up care.

#### 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 S

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 vear until age 21.

#### Gabe's Chemo Duck Program Heavenly Hats

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: graciesgowns.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 nonprofit 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.

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 organizations 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: peachsneetfeet.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

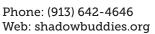
Donates handmade security blankets, quilts, and afghans to children undergoing difficult medical situations.

## 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



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.

#### Wias 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**

## Air Care Alliance National Patient Air Transport Helpline

Location: Lindrith, NM Phone: (888) 260-9707 Web: aircareall.org

Nationwide league of humanitarian flying organizations dedicated to community service. Links you to nationwide listings of organizations that provide transportation for patients and sometimes family members needing to get to treatment.

#### **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.

#### **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.

## 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.

#### 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.

## 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 lowincome 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/supportprograms-and-services/road-torecovery

The Road to Recovery program assists in finding local rides for cancer patients traveling to appointments.

#### The Angel Wheels to Healing

Phone: (800) 768-0238 Web: angelwheels.org

Provides non-emergency, long-distance ground transportation to patients in need. This organization offers assistance for bus, train, and gas cards.

## Lodging

## **American Cancer Society** Hope Lodge 😉

Location: Atlanta, GA Phone: (800) 227-2345

Web: cancer.org/treatment/supportprograms-and-services/patientlodging/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.

## 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 lifethreatening illnesses.

## Catch-A-Dream

Location: Starkvill, 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: littlestar.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 lifethreatening 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: martylyonsfoundation.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) 396-4770 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 lifethreatening 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 Hospice Net

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.

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: (961) 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 stepby-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

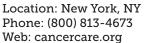
Provides information with multiple resources available on various end of life issues including death of a child, coping with the loss of a sibling, how to help someone who is grieving, and more.

#### **Bereaved Parents** of the USA

Location: Poughkeepsie, NY Phone: (501) 847-4102 Web: bereavedparentsusa.org

Educates 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.



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 nonprofit 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 emotinally 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

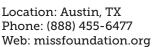
A support group in print and complete grief resource center. The stories, articles and poems in the magazine come from bereaved individuals. Regular articles in the magazine are written by professionals who are in the field of grief intervention. Their articles address physical and mental health issues, the psychology of mourning, ecumenical faith and crosscultural perspectives, the grief of children, and even humor.

#### Mental Health Network

Phone: (888) 993-3112 Web: mentalhelp.net

Extensive guide to mental health, psychology, and psychiatry online resources, currently listing over 7,000 individual resources for depression, suicide, eating and sleeping problems, loss, and bereavement.

## M.I.S.S. Foundation



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.



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

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## **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.

Organization Submission (1)		Organization Sub	mission (2)		
ORGANIZATION NAME		ORGANIZATION NAME			
ADDRESS		ADDRESS			
CITY, STATE, ZIP		CITY, STATE, ZIP			
PHONE	FAX	PHONE		FAX	
ORGANIZATION WEBSITE		ORGANIZATION WEBS	ITE		
DESCRIPTION OF SERVICES:		DESCRIPTION OF SERV	VICES:		
Please detach and return t	this form to: Children's C	Cancer Association, 1200 NV	/ Naito Pkwy #14	40, Portland,	OR 97209
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Questions? Call (503) 244-3141. Please make checks payable to Children's Cancer Association. Return this form to: Children's Cancer Association, 1200 NW Naito Pkwy #140, Portland, OR 97209 or give online at www.JoyRx.org.











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