

# Beyond Diagnosis

Information for families dealing with Childhood Cancer and Blood Disorders

Compiled by Texas Children's Cancer and Hematology Center

Texas Children's Cancer and Hematology Center has put together this handbook of local, national and online resources that are available to patients and families who are facing a cancer or blood disorder diagnosis. There are two types of resources listed in this handbook: educational materials and information about support organizations.

We know how important it is to understand your child's diagnosis, procedures, and anything related to the treatment process. This handbook will direct you to useful sources of educational materials.

There are many support organizations to help you in this journey. The handbook has identified many organizations that provide emotional support, aid with basic needs, and various programs such as camps and school reentry.

Some of the organizations need an application or a referral in order to access their services. Visit with your social worker if you need help with the application process, or if you have any questions about this handbook.

If a website does not open when you click a link, please copy and paste the link into your web browser.

For more Texas Children's Hospital-specific resources, please visit <u>texaschildrens.org/cancer</u>.



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# Texas Children's Hospital\*

# Hematology



#### **Bone Marrow Failure**

Aplastic Anemia and MDS International Foundation	aamds.org	Comprehensive resource for families dealing with aplastic anemia, bone marrow failure, etc. Provides education, publications, and support.  I-800-747-2820  aamds.org/patients/parents Information on bone marrow failure for parents of pediatric patients.  aamds.org/sites/default/files/2014SupportingStudentsWithBone MarrowWeb.pdf  A guide for parents and school personnel regarding school reentry after treatment for aplastic anemia or another bone marrow failure.  aamds.org/bone-marrow-garden Explanation of bone marrow failure, treatments, side effects, and activity restrictions, plus a video and slide presentation created especially for children.  aamds.org/sites/default/files/BoneMarrowGardenActivityPages.pdf Activity sheet and word puzzle  aamds.org/patients/parents/resources A national network of volunteers, including patients and family members, willing to listen and offer comfort and support.
Diamond Blackfan Anemia Foundation	dbafoundation.org	Education, research and resources regarding Diamond Blackfan anemia. 716-674-2818
Dyskeratosis Congenital Outreach	mightycause.com	Support for patients and families dealing with dyskeratosis and a registry.
Fanconi Anemia Research Fund	fanconi.org	A resource for patients and caregivers for education and support. Many free publications available in several languages.  1-800-326-2664

Shwachman- Diamond Syndrome Foundation	shwachman- diamond.org	A resource for providers/clinicians and registry that provides educational services and emotional support to SDS families. Information is available in several languages.  An organizational guide for SDS patient care is available <a href="mailto:shwachman-diamond.org/guide-for-sds-patient-care/">shwachman-diamond.org/guide-for-sds-patient-care/</a>
Severe Chronic Neutropenia International Registry	scnir-neutropenia. uw.edu	Provides research and guidelines for management of severe neutropenia and a registry.  206-543-9749

#### **General Hematology**

		Education on monitoring anticoagulation medications
Alere	alerecoag.com	I-866-408-1205
American Society of Hematology	hematology.org	A resource for families dealing with disorders affecting blood and bone marrow. Publications, research, resources  202-776-0544
Clotcare	clotcare.com	Provides patients and healthcare providers with information on optimal use of antithrombotic and anticoagulant therapy.  210-860-0487
Coaguchek	coaguchek-usa.com	Education on monitoring anticoagulation medications I-800-428-5074
Cooley's Anemia Foundation	thalassemia.org	Information, education, support, and scholarships 212-279-8090
Fanconi Anemia Research Fund	fanconi.org	A resource for clinicians and patients regarding Fanconi anemia. Publications, research, etc.  541-687-4658
Foundation for Women and Girls with Blood Disorders	fwgbd.org	Provides education, resources and support to women with bleeding disorders.
G6PD Deficiency	g6pd.org	A resource for clinicians and patients, list of safe vs. non safe drugs and foods.
Immune Deficiency Foundation	primaryimmune.org	A resource for clinicians and patients regarding primary immunodeficiency diseases. Many pamphlets exist, including: School Guide for Students with Primary Immunodeficiency Diseases primaryimmune.org/wp-content/uploads/2015/01/IDF-School-Guide-3rd-Edition-2015-FINAL.pdf
National Blood Clot Alliance	stoptheclot.org	Dedicated to advancing the prevention, early diagnosis and successful treatment of life-threatening blood clots such as deep vein thrombosis, pulmonary embolism, and clot-provoked stroke.  703-935-8845

National Institute of Health	cc.nih.gov	Provides patients and clinicians with information on clinical research studies. Information for patients available in Spanish 301-496-4000
National Organization of Rare Disorders	rarediseases.org	Provides medication assistance, networking, a resource guide, a library of links, and news and information, including a database of diseases, organizations and subscriptions.  Available is a pdf version of 'The Power of Patients: Informing Our Understanding of Rare Disease.' The book amplifies the experience of individuals living with rare disease. rarediseases.org/iamrare-registry-program  203-744-0100
National Neutropenia Network	neutropenianet.org	Information and education about neutropenia.
Neutropenia Support Association	neutropenia.ca	Articles about neutropenia organized into different categories. An information library is available to answer questions from patients, their families, and the medical community.  1-800-326-7117
National Lymphedema Network	<u>lymphnet.org</u>	Information on the prevention, management and supportive care of primary and secondary lymphedema to patients and healthcare professionals.  1-800-541-3259
North American Thrombosis Forum	natfonline.org	Education, support and other resources for health care providers and patients.  617-730-4120
Platelet Disorder Support Association	pdsa.org	A resource for patients with ITP that offers many publications.
PTINR	ptinr.com	Provides education on the anticoagulation medication called warfarin. Offers a full menu of services, like lifestyle and safety tips, and other educational resources.  1-800-504-4032

Von Hippel Lindau Family Alliance	<u>vhl.org</u>	Information and support to families with the rare familial disorder, Von Hippel Lindau Syndrome. Includes a reference handbook for people with VHL, their families and support personnel.
Family Alliance	TIMOTS	personnel.

# Hemophilia

American Association of Blood Banks	aabb.org	Provides information for patients and donors about all aspects of blood banks, transfusion medicines, hemopoietic stem cells, cell and gene therapies, and tissue transplants.  301-907-6977
American Society of Hematology	hematology.org/ patients/	Rresources to educate the public about the importance of healthy blood and to raise the awareness of common blood diseases, including bleeding disorders.  202-776-0544
Camp Ailihpomeh - Texas Hemophilia Summer Camp	www.camp- ailihpomeh.org	Camp for boys ages 7-17 with hemophilia. \$45, 6-day camp held at Camp John Marc in Bosque County. Scholarships available  713-704-1984
Centers for Disease Control and Prevention (CDC)	cdc.gov/ncbddd/hem ophilia	Information about hemophilia and bleeding disorders.
Hemophilia Federation of America	hemophiliafed.org	Provides help and support to the blood clotting disorders community. Also has a link of website for helping hands program which provides information on how to obtain items and services.  202-675-6984
Local chapter of the National Hemophilia Foundation	lonestar hemophilia.org	Dedicated to the treatment and the cure of hemophilia related bleeding disorders through the support of research, advocacy, education, and other services.  713-686-6100
Medline Plus	nlm.nih.gov/medlinepl us/hemophilia.html	A vast amount of information from the National Institutes of Health and other reliable sources on hemophilia and other diseases and conditions (available in Spanish).
National Hemophilia Foundation	hemophilia.org	A resource for clinicians and patients regarding hemophilia. Publications, research, scholarships, etc.  See also, <a href="https://hemophilia.org/Community-Resources/Scholarships">hemophilia.org/Community-Resources/Scholarships</a> for a list of scholarships. Prospective candidates must check with the sponsor or administrator of each scholarship for eligibility criteria and submission procedures.  212-328-3700

#### **Sickle Cell Disease**

EDUCATION		
Hand in Hand  A HANDBOOK ON SICKLE CELL DISEASE FOR THE CHILD AND FAMILY  Texas: How	texaschildrens.org/ sicklecellhandbook	Handbook on sickle cell disease from Texas Children's Hospital  Español
National Heart, Lung and Blood Institute	nhlbi.nih.gov/health- pro/guidelines/sickle- cell-disease-guidelines	Sickle cell disease management guidelines for health care professionals and patients, recommended care plans, education, news, and resources.  1-877-645-2448
Centers for Disease Control and Prevention	cdc.gov/ncbddd/sickle cell	Education, publications, medical statistics and resources about sickle cell disease and sickle cell trait.  Information available in Spanish  1-800-232-4636

SUPPORT ORGANIZATIONS		
As One Foundation	asonefoundation.org	Mission is to educate and increase awareness of sickle cell trait while encouraging youth to achieve their dreams in the face of life's challenges.  832-308-9984
Comfort Ability	thecomfortability .com	Information about coping strategies and skills to manage chronic pain. List of resources, coping stories and guided exercises.  617-355-8297
International Association of Sickle Cell Nurses and Physician Assistants	iascnapa.org	Offers a college scholarship program to assist individuals living with sickle cell disease who will be attending an institution of higher learning in the United States.

The Periwinkle Foundation	periwinkle foundation.org	The Periwinkle Foundation provides camping opportunities for patients of Texas Children's Hospital including Camp YOLO (teen camp), and Periwinkle Day Camp.  713-807-0191
The Pin Cushion Gang	thepincushiongang .org	Organizes fundraisers, special events for the sickle cell community, blood drives, meal for inpatient families, and volunteers at the bedside.  832-845-0466
Self-Improvement Thru Riding Education	sire-htec.org	Free therapeutic horseback riding center with locations in Hockley, Spring and Fort Bend.  281-356-7588
Sickle Cell Disease Association of America	sicklecelldisease.org	Offers scholarship opportunities to students living with sickle cell disease and inspires graduates to consider dedicating their careers to sickle cell research and treatment.  410-528-1555
Sickle Cell Information Center (Emory Libraries and Information Technology)	scinfo.org	Comprehensive resource for families dealing with sickle cell disease. Many resources, such as: Parents Handbook for Sickle Cell Disease, list of camps, and Medicaid care coordination for families.  Handouts and guides available in Spanish 404-727-7857
Sickle Cell Association of Houston	sicklecellhouston.org	Resource for those living with sickle cell disease. Main focus is education, programming and research.  832-252-9293
Sickle Cell Association of Texas	sicklecelltx.org	Provides education, research awareness, outreach, support group meetings, assistance and numerous other services.  Hosts Camp Cell-A-Bration, a week-long camp for sickle cell patients between the ages of 6-14.  1-844-994-HOPE
Your Genes Your Health	yourgenesyourhealth. org/sickle/ whatisit.htm	Facts, treatment, testing and screening

SUPPORT GROUPS FOR SICKLE CELL		
Above The Crisis	facebook.com/Above TheCrisis	Adult sickle cell support group
Supporting our Sicklers	sosparentgroup.wix.c om/gr8trhstn facebook.com/groups /SOSSupportGroup	Parent and guardian support group

SCHOLARSHIPS FOR SICKLE CELL		
The Kermit B. Nash Academic Scholarship	sicklecelldisease.org	Scholarship provides recipient \$20,000 over the course of four years, split up into payments of \$2,500 per semester. Applicant must have sickle cell disease, (not the trait), a 3.0 GPA or higher and intend to pursue a 4-year college/university education.
Candice's Sickle Cell Fund	candicessicklecell fund.org	This sickle cell awareness organization awards three scholarships every year to rising college students with SCD. Each recipient gets \$1,500 for college tuition.
The International Association of Sickle Cell Nurse and Physicians Assistants Scholarship	scancainc.org/iascnap a-scholarships/	To apply for one of these \$500 scholarships, a student must have SCD and must either be enrolled in—or been accepted to—an institution of higher learning (four-year university, a trade school, etc.)
The Sickle Cell Thalassemia Patients Network	<u>sctpn.net</u>	Education, advocacy, referral services, and support for individuals and families living with sickle cell disease, thalassemia (Cooley's Anemia), and other inherited blood disorders. SCTPN awards children and young adults living with sickle cell/and or thalassemia, for their scholastic achievements. The Undergraduate Scholarship Program affords individuals entering college or already in college an opportunity to apply for our annual scholarship.

**TEXAS CHILDREN'S CANCER AND HEMATOLOGY CENTERS** 

# Oncology





# **Bone Marrow / Stem Cell Transplant**

EDUCATION		
American Bone Marrow Donor Registry, Search Coordination Center	<u>dkms.org</u>	The Be The Match Registry® is the national bone marrow donor registry in the United States, operated by the National Marrow Donor Program (NMDP). Delete Blood Cancer DKMS is a bone marrow donor center officially affiliated with the NMDP, so every person we register is listed on the Be The Match Registry®.  212-209-6700
National Bone Marrow Transplant Link	nbmtlink.org	Publications on graft vs. host disease, survivorship, informative resource. Hotline, library, clearinghouse, suggestions for financial assistance.  1-800-LINK-BMT
Center for International Blood and Marrow Transplant Research	cibmtr.org	Publications about transplant outcomes, best practice in follow-up care, and more. See their 'Reference Center' for a list of over 1,000 publications, many with data and statistics.
Gift of Life	giftoflife.org	BMT registry, facts and stats on registry, etc.  I-800-9MARROW
National Bone Marrow Donor Program	bethematch.org	Manages the largest and most diverse marrow registry in the world and has educational information on BMT, core blood, donor registry, etc. Also provides educational materials specifically for the child. They have a video called Super Sam versus the Marrow Monsters, which is an animated video on what to expect throughout the transplant process.  Their Peer Connect Program allows you to talk with a transplant recipient or caregiver and share experiences  A great e-book explaining the entire BMT process in a kid friendly manner is available at bridges4kids.org/Disabilities/meandmymarrow.pdf

#### SUPPORT ORGANIZATIONS FOR BMT

Bone Marrow Foundation	bonemarrow.org	Publications and financial assistance, support and services to BMT. One on one support link system.  1-800-365-1336
Bone Marrow Transplant Information Network	bmtinfonet.org	Everything BMT resources, cord blood, monthly newsletter, online support, etc.  1-888-597-7674
Candlelighters Childhood Cancer Foundation	acco.org	Publications on BMT, support network, support groups at times  1-855-858-2226
Children's Organ Transplant Organization	cota.org	Support for bone marrow transplant or any organ transplant issue provides fundraising and public relations help to people organizing bone marrow transplant drives  1-800-366-2682
Cryobanks International	cryobank.com	A leader in the collection, processing and banking of umbilical cord blood stem cells.  1-866-927-9622
Dec My Room	decmyroom.org	Creates a healing place for kids who are in the hospital for extended period (BMT).  832-538-1201
Health Resource and Services Administration	bloodcell.transplant.hrsa .gov	Provides support to patients who need bone marrow transplant or core blood transplant.
HelpHopeLive	helphopelive.org	Fundraising for people with unmet medical expenses due to cell and organ transplants or catastrophic injuries and illnesses.  1-800-642-8399
His Grace Foundation	hisgracefoundation.org	Provides physical, emotional and financial support for the patients and families on the Bone Marrow Transplant Unit of Texas Children's Hospital.  281-620-4511

Icla Silva Foundation	icla.org	Provide emotional, logistical, and financial support to remove barriers to treatment for those receiving a bone marrow or stem cell transplant.  For patients who demonstrate a financial need, our IclaCares program can provide financial assistance as they work through their bone marrow, cord blood, or stem cell transplant and treatment.  There are five grant opportunities for bone marrow and cord blood transplant patients: caregiver expenses, housing, travel assistance, meals and HLA testing.  Priority for grants is given to patients who meet the eligibility guidelines and demonstrate the greatest financial need.  The maximum grant allocated per patient is \$1000
Leukemia & Lymphoma Society	lls.org	Bone marrow transplant — leukemia diagnosis. Publications on BMT, disease information  1-800-955-4572
National Foundation for Transplants	transplants.org	Financial assistance nationwide for bone marrow, stem cell, and cord blood patients for transplant-related care  1-800-489-3863
TRIO Scholarship Program	trioweb.org/resources/t rio-scholarships.html	Scholarships given to deserving students who are bone marrow transplant candidates, recipients, donors or their family members 813-800-8746
Viacord	viacord.com/cord- banking/sibling- connection	Cord blood collection and storage.  1-866-861-8435

#### **Brain Tumor**

EDUCATION		
American Brain Tumor Association	abta.org	Provides a free brain tumor dictionary and printable information on brain tumors.  Listing of support groups, pen-pal program, information on treatment facilities, sponsors regional town hall meetings, social worker on staff, symposium offered twice/year and a tri-annual newsletter: The Message Line.  See also, the pamphlets: and Returning to School  1-800-886-2282
Brain Surgery Information Center	brain-surgery.com	Educational information regarding brain tumor and neurosurgery
Cancer Net	cancernet.nci.nih.gov	Provides educational information about survivorship, research, cancer care and many other topics.  I-800-422-6237
Central Brain Tumor Registry of the United States	cbtrus.org	A registry of brain tumors in the United States. There are many publications, a glossary and fact sheets with statistics and incidences of brain tumors in the United States.
Lash and Associates Publishing	lapublishing.com	Primary focus is the neurological, psychological, communicative, psychosocial and educational impact of brain injuries among children youth and young adults. Provides practical, informative, and affordable materials for families, survivors, health care providers  919-556-0300

National Brain Tumor Society	braintumor.org	Publications about brain tumors, including: facts about symptoms, treatments, and clinical trials, and helpful resources and tools for patients and caregivers. Also provides a quarterly newsletter, information hotline, a resource guide for pediatric patients and a list of support groups.  blog.braintumor.org has information on brain tumors, such as fact sheets, what does metabolism have to do with tumors, etc.
Pediatric Brain Tumor Consortium	pbtc.org	Provides summaries for patients and families on all the current clinical trials as well as contact information for institutions. Provides a financial emergency assistance fund, called The Butterfly Fund.
Understanding the Journey, A Parent's Guide to DIPG	acco.org/books	A 368-page comprehensive book that guides the family whose child has been diagnosed with a diffuse intrinsic pontine glioma through this difficult diagnosis. Chapters are written by pediatric neuro-oncology experts and cover all aspects of treating a child with a DIPG, including: diagnosis, imaging, pontine function and anatomy, steroid treatment, radiation therapy, radio sensitizers, surgery, chemotherapy and biologics.

SUPPORT ORGANIZATIONS FOR BRAIN TUMOR		
A Kids Brain Tumor Cure	akidsbraintumorcure.org	A comprehensive resource regarding childhood brain tumors, including: publications, support and more.
Addi's Faith Foundation	addisfaithfoundation.org	Provides assistance with financial needs, college scholarships (for brain tumor) and grief support. Application process for financial help.  281-785-4098
Brain Tumor Foundation of Canada	<u>braintumour.ca</u>	A dedicated team of volunteers, patients, survivors, family members, health care professionals and staff, determined to make the journey with a brain tumor one full of hope and support.  519-642-7755

Children's Brain Tumor Foundation	cbtf.org	The free publication, A Resource Guide for Parents of Children with Brain and Spinal Cord Tumors is full of practical information regarding topics like medical procedures, interruptions to school and social life, and uncertainty about the future. In addition, provides Moving Forward Grants to young adults in need and scholarships for college.  1-866-228-4673
Childhood Brain Tumor Foundation	childhoodbraintumor.org	Raises funds for research and increases brain tumor awareness.
Cory's Crusaders	coryscrusaders.org	Financial assistance to families with child fighting brain cancer. Will assist if funds allow (focus on DIPG)
The Cure Starts Now Foundation	thecurestartsnow.org	Provides fundraising for brain stem glioma research and offers support and education materials to families dealing with brain tumors.  513-772-4888
Foundation Think Again!	thinkagain.org	Provides rehabilitation therapies to pediatric cancer and brain tumor survivors who continue to suffer due to the neurocognitive late-effects of cancer and cancer treatment. Funding for these costly, yet needed therapies, has either been denied by the child's medical insurance company, or insufficiently covered.  1-888-385-7057
International Radiosurgery Support Association	isrsy.org	Provides emotional support, education and referrals for treatment to patients worldwide. Quarterly Newsletter: Another Perspective.  717-260-9808
Making Headway Foundation	makingheadway.org	Provides care and comfort for families dealing with childhood brain and spinal tumors while funding medical research geared at discovering better treatments and a cure. Many services offered, including: counseling, education, scholarships, and medical research grants.  914-238-8384

The Matthew Larson Foundation for Pediatric Brain Tumors	<u>ironmatt.org</u>	Provides direct financial assistance to families, regardless of socio-economic status, brain tumor type (malignant or benign), or progress of the disease.  201-410-2751
Matthew Renk Foundation	matthewrenk foundation.org	Provides emotional and financial support to individuals and families facing pediatric brain cancer
Mission 4 Maureen	mission4maureen.org	Provides financial assistance to families who are burdened with the cost of brain cancer treatment 440-840-6497
Musella Foundation	virtualtrials.com	Dedicated to helping brain tumor patients with emotional and financial support, education, advocacy and funding for brain tumor research. Great publication for newly diagnosed brain tumor and includes a free brain tumor guide.  1-888-295-4740
Payton Wright Foundation	paytonwright.org	Financial assistance for families battling brain and spinal cord malignancies. Assistance includes, but is not limited to: mortgages/rent, utilities, travel expenses, phone bills, etc. It EXCLUDES hospital/doctor bills, medications and trial protocols.
Pediatric Brian Tumor Foundation	curethekids.org	Resource for families dealing with childhood brain tumors that provides education, support, college scholarships, etc. See also: <a href="mailto:curethekids.org/assets/documents/family-support/question_web.pdf">curethekids.org/assets/documents/family-support/question_web.pdf</a> I-800-253-6530
Smiles for Sophie Forever	smilesforsophieforever.o	Offers family grants with a child who has been diagnosed with brain cancer 1-17 years the opportunity to apply for \$1000 in grants to assist with financial hardships. Contact for application
Self- Improvement Thru Riding Education	sire-htec.org	Therapeutic horseback riding center that provides physical, emotional, educational and recreational benefits. Locations in Hockley, Fort Bend and Spring, Texas.  281-356-7588

Southeastern Brain Tumor Foundation	sbtf.org	Information, education, support for brain tumor patients and their families 786-505-7283
T.H.E. Brain Trust	braintrust.org	Provides support to people affected by brain tumors and related conditions.  I-877-252-8480
Team Buddy Forever	teambuddyforeverfounda tion.org	Supporting families of children battling pediatric brain cancer and Diffuse Intrinsic Pontine Glioma (DIPG).  Grants available.  (810) 397-8867
The Evan Foundation	theevanfoundation.org	Support neuroblastoma research bring joy to young cancer patients, and provide scholarships.
Team Luke Hope For Minds	teamlukehopeforminds.o	Supportive resources and financial assistance to any family with a child with any brain injury (includes strokes)
Tug McGraw Foundation	tugmcgraw.org	Provides support and resources for caregivers affected by brain tumors and brain-related trauma.  707-947-7124
Voices Against Brain Cancer	voicesagainstbraincancer. org	Focuses on research, support and education for those affected by brain tumors.  212-340-1340
Yuvaan Tiwari Foundation	www.ytfoundation.org	Assist children/families diagnosed with DMG/DIPG or any other type of fatal brain cancer. Provide financial assistance to help offset medical expenses, including travel, accommodation, and treatments. Also cover expenses for a special gift or experience for child. Any family with a child diagnosed prior to the child's 18th birthday is eligible for consideration. Child may be newly diagnosed, under treatment or in progression. Applicant and child must reside in the United States.

# **Genetic Predisposition**

A-T Children's Project	atcp.org	Raises funds to support research projects and scientific conferences aimed at finding life improving therapies and a cure for Ataxia-Telangiectasia.  954-481-6611
Children's Tumor Foundation	ctf.org	Provides education, resources and promotes research for Neurofibromatosis (NFI/NF2/Schwannomatosis).
Li-Fraumeni Syndrome Association	Ifsassociation.org	Provides education, community events, awareness, and webinars regarding LFSA.  1-855-239-5372
Neurofibromatosis Network	nfnetwork.org	Provides education, support and networking for those affected by neurofibromatosis.
PTEN Hamartoma Tumor Syndrome Foundation	ptenfoundation.org	Provides education, financial support, and supports research for PTEN harmartoma tumor syndrome.  1-800-942-6825
Texas Neurofibromatosis Foundation	texasnf.org	Provides education, support, advocacy and funds research for neurofibromatosis (NFI/NF2).  972-739-6086
Tuberous Sclerosis Alliance	tsalliance.org	Provides education, support and research regarding tuberous sclerosis.
Von Hippel-Lindau Alliance	<u>vhl.org</u>	Information and support to families with the rare familial disorder, Von Hippel Lindau Syndrome. Includes a reference handbook for people with VHL, their families and support personnel.

# Histiocytosis

Histiocytosis Foundation	histio.org	Dedicated to addressing the unique needs of patients dealing with histiocytosis. Publications, research, resources and general information regarding Langerhans cell histiocytosis.  856-589-6606
Liam's Way	liamslighthouse foundation.org	Provides financial assistance to defray treatment-related expenses for families affected by histiocytosis including ground transportation, air travel, and lodging related expenses

# Leukemia and Lymphoma

EDUCATION		
Childhood Leukemia Foundation	clf4kids.org	Publications, support and patient resources (wish basket, iPad, etc.)  1-888-253-7109
Children's Leukemia Research Association	childrensleukemia.org	Funds research efforts toward finding causes and cures for leukemia. On the website, you can find articles on childhood leukemia and a patient aid application.  516-222-1944
International Myeloma Foundation	myeloma.org	Provides information about myeloma, including research and treatment advances, as well as information about IMF, upcoming events, research, education and support.  818-487-7455
Leukemia and Lymphoma Society	<u>lls.org</u>	Publications such as: Sibs and Talk about Cancer and Juvenile Chronic Myelomonocytic Leukemia. They also have printable resources for teachers, parents and kids.  A weekly online chat that provides an open forum for young adults dealing with cancer and cancer survivorship  LLS Community, which features a group specifically devoted to the young adult cancer community  Webcasts that feature experts and young adults discussing topics such as the physical, emotional and financial challenges faced by young adults with cancer  Financial assistance for drugs used in care, treatment, and/or control of disease.
Lymphoma Research Foundation	lymphoma.org	Resource for families dealing with lymphoma. Offers publications, research and financial assistance.

#### **Solid Tumors**

BONE CANCER		
EDUCATION		
American Childhood Cancer Organization	acco.org/types-of- childhood- cancer/bone-cancer	Group that provides education and support to families affected by childhood cancer. Publications on all types of cancer, including bone cancer.  1-855-858-2226
Lady Shriver Sarcoma Initiative	sarcomahelp.org/ osteosarcoma.html sarcomahelp.org/ ewings-sarcoma.html	Fact sheets about osteosarcoma and Ewing's sarcoma
Northwest Sarcoma Foundation	nwsarcoma.org	Supports and educates those living with sarcoma and other rare bone tumor diseases. Provides resources related to education, support, financial assistance and support groups.  206-257-7215
Sarcoma Alliance	sarcomaalliance.org	Strives to improve the lives of people affected by sarcoma through accurate diagnosis, improved access to care, guidance, education, and support. Financial assistance for those securing a second opinion.
		415-381-7236
SUPPORT ORGANIZ	ZATIONS	
Sarcoma Foundation of America	curesarcoma.org	Advocates for sarcoma patients by funding research and increasing awareness about the disease. Raises money to privately fund grants for sarcoma researchers and conducts education and advocacy efforts on behalf of sarcoma patients.
		301-253-8687
AMPUTATION		
Amputee Coalition of America	amputee- coalition.org	Provides education, support, advocacy, and promotes limb loss prevention. Bi-monthly magazine <i>inMotion</i> . Provides a summer camp for kids with limb loss/limb difference, ages 10–17, free of charge.
		L-888-267-5669

AMPower	https://hangerclinic.co m/patients/emotional -support/	<ul> <li>AMPOWER peer mentors can connect with you and your loved ones in person, over the phone, or online. They can help:</li> <li>Answers basic questions about the recovery process, using a prosthesis, and the concerns of daily living</li> <li>Provide emotional support, with a firsthand understanding of the grieving process</li> <li>Share information and resources</li> </ul>
Challenged Athletes Foundation	challenged athletes.org	Seeks to provide opportunities and support to people with physical challenges, so they can pursue active lifestyles through physical fitness and competitive athletics.  858-866-0959
City of Houston Adaptive Sports and Recreation	houstontx.gov/parks/ adaptivesports.html	Check out the sports available for youth and adults with mobility constraints. They offer adaptive yoga, wheelchair basketball, adaptive aquatics and more.  832-395-7333
Disabled Sports USA	disabledsportsusa.org	Provides national leadership and opportunities for individuals with disabilities to develop independence, confidence, and fitness by participating in community sports, recreation and education.  301-217-0960
I-CAN Children's Amputee Network	child-amputee.net	Promotes education, support, information, and empowerment. Extensive mentor program available.
ITT/Hartford Ski Spectacular	moveunitedsport.org	One of the nation's largest winter sports festivals for people with disabilities.  301-217-0960
Cancer Survivors Fund	cancersurvivors fund.org	Provides college scholarships and prosthetics for the benefit of persons diagnosed with cancer, receiving treatment for cancer or in remission.  281-437-7142

Limbs for Life	limbsforlife.org	Payment assistance for lower limb prosthetic care to amputees who have no other means to pay, including Medicare, insurance coverage or state assistance.  I-888-235-5462  tmarchisio@mpihouston.com admin@LimbsForLife.org
Making it Better Agents	mibagents.org	A national organization dedicated to Making It Better for kids with osteosarcoma. Education, support, and gaming for families touched by osteosarcoma  518-524-3890
MPI Muilenburg Prosthetics	mpihouston.com	Helps those with limb loss achieve an improved quality of life with the most appropriate functional prosthesis. New amputees are invited for a pre-surgical visit to learn more about the practice, meet practitioners, and see the prosthetic technology available for each individual's varied needs.
National Amputation Foundation	amputationfoundatio n.org	Pamphlets about recreational activities for amputees. Listings of support groups, resources, referrals. \$25 membership includes bimonthly newsletter, <i>The Amp</i> . Check out the sports available for youth and adults with mobility constraints. They offer adaptive yoga, wheelchair basketball, adaptive aquatics and more.  516-887-3600
National Sports Center for Disabilities	nscd.org	Winter and summer programs in Winterpark, CO. Reservations required, prices vary. <a href="mailto:info@nscd.org">info@nscd.org</a>
Self- Improvement Thru Riding Education	sire-htec.org	Therapeutic riding center that provides physical activities, emotional support, education and recreation to people with disabilities. Prices vary. Locations in Spring and Fort Bend.  281-356-7588
Texas Elks Children's Service Prosthetic Grant Program	texaselks.org	Coverage for limbs, hearing aids, telephonic equipment, bracing devices, adaptive/assistive devices for health such as seating, positioning, mobility, and integration equipment. Physician must fill out part of application. Call to locate nearest Elk Lodge to you.

LIVER TUMOR		
Children's Liver Association for Support Services	<u>classkids.org</u>	Information about pediatric liver disease, a newsletter, resource links, medical articles, and a parent matching system that links families for friendship and support.  724-581-5527
Hepatoblastoma Resource Network	hepatoblastoma.org	Support, research, clinical trials, and community conferences led by hepatoblastoma professionals

NEUROBLASTOMA		
Children's Neuroblastoma Cancer Foundation	cncfhope.org	Educational information, a forum for patients and family member, information about treatment, palliative care, hospice services, bereavement groups and emotional support. Handbook includes topics such as: surviving neutropenia, hearing loss, clinical trial information, etc.  1-866-671-2623
Neuroblastoma Children's Cancer Society	neuroblastoma cancer.org	Dedicated to fundraising, support, research, and advocacy for children with neuroblastoma and their families. Parent-to-parent online network and a newsletter are available.  1-800-532-5162
Neuroblastoma Research Consortiums	www.nbparentsymposium.com/video-library	First link is for a global conference that is free and great educational resource for families. The second link is for the recorded videos from the last symposium.

RETINOBLASTOMA		
American Association for Pediatric Ophthalmology and Strabismus	aapos.org	Provides doctor search, information about childhood eye disorders and additional information. Available in Spanish and Chinese.
Eye Cancer Network	eyecancer.com	Information about the diagnosis and treatment of ocular tumors, eye cancer, and orbital diseases for patients, their families, and their health professionals.
National Retinoblastoma Research Support	eyecancermd.org	Disseminates information and resources to families dealing with emotional pain and anxieties related to having a child with retinoblastoma.  305-487-7470

ORAL, HEAD AND NECK		
AboutFace	aboutface.ca	Supports individuals touched by facial differences with peer connections, information, emotional support and opportunities to enhance their life circumstances.  1-800-665-3223
American Head and Neck Society	ahns.info	Focuses on prevention, diagnosis, treatment and rehabilitation of diseases of the head and neck.  310-437-0559
Head and Neck Cancer Alliance	headandneck.org	Provides support, education and research regarding head and neck cancers.  1-866-792-4622
Support for People with Oral, Head and Neck Cancer	spohnc.org	Information on cancers affecting the mouth, head, and neck. Addresses the broad emotional, physical and humanistic needs of these patients.  I-800-377-0928

# **Books for Oncology**

PRESCHOOL/ELEMENTARY AGE		
American Childhood Cancer Organization	acco.org/books	Chemo, Craziness and Comfort, My Book about Childhood Cancer Practical advice for children diagnosed with cancer between ages 6-12. Warm and funny illustrations and easy to read text that helps the child make sense of cancer and its treatment.  Cozy Cares Journal  A fun keepsake for children to document their treatment journey. It is also a treasure for family and friends to experience the cancer journey through the words of a child. Can order a Port-A-Cat to go along with this journal.  La Fantistica Hannah: Miren todo lo que puedo hacer! For Spanish-speaking children diagnosed between 1-5 years old. Through real life photos, children identify with Hannah's hospital stay, special friends, tests, treatment, and germ care.  Life Me Up A coloring book of inspirational pictures for 3-10 year-olds with cancer.  Marvelous Marleigh Through real life photos, preschool children are able to identify with Marleigh's treatments and hospital stays.  Medical Play Kit One of the strongest types of fear is that of the unknown— by giving children the opportunity to better understand and mentally prepare for upcoming tests or treatments, the Medical Play Kit helps to familiarize children with procedures to ease their anxiety and fear.  1-855-858-2226

Be The Boss of Your Pain: Self Care for Kids	amazon.com	Timothy Culbert & Rebecca Kajander (2007). Helps your child to be in control of their pain and anxiety and explains how pain happens in the nervous system and things they can do anywhere to calm anxiety and lessen the pain. It teaches breathing and focus.
Chemo to the Rescue: A Children's Book About Leukemia	chemotothe rescue.com	Created by a 5-year-old and her family to help her come to terms with her illness and accept the treatments.
I am Leah Strong	iamleahstrong.com	Book by Devon and Leah Still about a child battling cancer.
Jacob Has Cancer His Friends Want to Help	acs.bookstore.ipgbook.com/jacob-has-cancer-products-9781604430127.php	Coloring book by the American Cancer Society. \$3.50
Little Tree: A Story for Children with Serious Medical Problems	amazon.com	This children's book is a story of hope and inspiration for children with serious illness or injury.
I Still Dream Big: Stories of Teens Living with Chronic Illness	amazon.com	A celebration of life and a reminder to hold onto our own dreams for the future, and to remember to dream big.
It's Okay to be Different	amazon.com	Targeted to young children learning to read, this book will inspire kids to celebrate their individuality through acceptance of others and self-confidence. This book is in a child-friendly format that features Todd Parr's trademark—bold, bright colors and silly scenes.
Life Isn't Always a Day at the Beach	copingforkids.com	Two books for children battling cancer. Life Isn't Always a Day at the Beach is meant for school-age kids and Life Isn't Always a Breeze is for teens/young adults.
Mookey the Monkey Gets Over Being Teased	amazon.com	Helpful ideas for children dealing with teasing, and to help them realize their own strengths.
My Cancer Days	amazon.com	Helping children with cancer cope with their illness, this illustrated book approaches emotions from diagnosis-through-treatment in a way that they can easily understand and can help describe what they are feeling.
My Doctor and Me ABC	amazon.com	Alphabetic journey of the sights and sounds of the doctor's office. Prepares a child for doctor visit. By Dr. Stephanie Cox

Notes Left Behind	notesleftbehind.com	Compiled by the founders of the Cure Starts, the book is a compilation of notes their daughter left for them for after she died. She hid the notes in various places around the house for them to find. Also contains some of her diary entries.
Oncology Stupology	amazon.com	Book for children battling cancer. Takes you through the emotional frustrations from being in the hospital. By Marilyn Hershey
Taking Cancer To School	amazon.com	Book that describes and simplifies some childhood conditions. Attempts to help children empathize with cancer and the circumstances for the family. Includes a quiz and tips for teachers for additional facts and ideas. By Cynthia Henry
The Lemonade Club	amazon.com	Patricia Polacco (2007). A young girl with cancer discovers her class at school supports her. Together, they turn lemons into lemonade.
The Long and Short of It: A Tale about Hair	amazon.com	Barbara Meyers, Lydia Criss Mays & Shennen Bersani (2011). A story about a young cancer patient and her hair loss journey.
Why Charlie Brown, Why?	amazon.com	A story about what happens when a friend is very ill. By Charles Schulz

BOOKS FOR TEENS		
Between Two Kingdoms	amazon.com	Suleika Jaouad (2021). A searing, deeply moving memoir of illness and recovery that traces a young woman's journey from diagnosis to remission to re-entry into 'normal' life—from the author of the Life, Interrupted column in The New York Times
Dance In The Rain	acco.org/books	A teen journal that allows adolescents a place to write out their feeling and thoughts throughout their cancer journey. This book is accompanied by a wooden pen and pencil set.  1-855-858-2226
It's Not About the Bike	amazon.com	Lance Armstrong (2000). The story of Armstrong's journey from inauspicious beginnings through triumph, tragedy, transformation, and transcendence

Our New Normal	store.tsehai publishers.com	A collection of personal stories of teens with cancer. It is a resource for teens diagnosed with cancer—and their loved ones—to learn what it feels like to have chemo, how to remain mentally strong throughout this process, and what positives can be gleaned from facing cancer.
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BOOKS FOR PARENTS			
American Childhood Cancer Organization	acco.org/books	Along the Way, Documenting My Child's Cancer Journey A logbook that provides a way to document medical treatments, hospital contact information, treatment expenditures, and local resources. It also contains information about clinical trials, treatment procedures, blood counts, side effects, a journal section, and a place to take notes.  A Parent's Guide to Clinical Trials A concise reference guide which explains the process and structure of clinical trials in easy to understand language  A Parent's Guide to Enhancing the Quality of Life in Children with Cancer A 261-page book written about childhood cancer from the parents and clinicians point of view.  Educating the Child with Cancer: A Resource for Parents and Teachers An essential resource for families who have faced childhood cancer. Written by researchers in the field, and balanced with parents' personal experiences, this 334-page book focuses on educational issues for children treated for cancer.  Understanding the Journey, A Parent's Guide to DIPG A 368-page comprehensive book that guides the family whose child has been diagnosed with a diffuse intrinsic pontine glioma through this difficult diagnosis. Chapters are written by pediatric neuro-oncology experts and cover all aspects of treating a child with a DIPG, including: diagnosis, imaging, pontine function and anatomy, steroid treatment, radiation therapy, radio sensitizers, surgery, chemotherapy and biologics.	
Childhood Cancer Guides	childhoodcancergui des.org	This group has published books for families of kids with cancer and survivors of childhood cancer. Books are a mix of medical information and books for parents and children.  1-866-333-1213	

BOOKS FOR SIBLINGS		
Oliver's Story	acco.org/books	A 40-page illustrated book for the 3-8 year old siblings of a child diagnosed with cancer. Offered in Spanish as well.  1-855-858-2226
Hi, My Name is Jack	amazon.com	A children's book specifically for the healthy siblings of chronically ill, disabled or dying children. This book addresses and focuses upon some of the feelings that may be experienced by healthy siblings. This book is unique in that it is not illness specific and does not focus on the illness itself. It is appropriate for a variety of illnesses and medical situations
What About Me? When Brother's and Sister's Get Sick	amazon.com	When a child is seriously ill, siblings experience mixed emotions and hurt feelings. This book is written by a confused young girl and her experience at the hospital with her brother.

OTHER BOOKS		
The Association for Pediatric Oncology Nursing	aphon.org	Extensive bookstore I-855-202-9760

## **Camps for Oncology**

Camp for All	campforall.org	Camp For All hosts campers with cancer, autism, muscular dystrophy, epilepsy, autism, severe burns, sickle cell, cerebral palsy, cognitive challenges, cardiac issues, spinal cord injuries, PKU, neurofibromatosis, HIV, dermatological issues and more.  979-289-3752 or 713-686-5666
Camp C.L.I.F.F.	candle.org/family- events/camp-cliff	For a child diagnosed with cancer and family members. Held every October. Free. 713-270-4700
Camp Hole in the Wall Gang	holeinthewallgang.org	Seriously ill children and their siblings, ages 7-15. Free, located in Connecticut 203-772-0522
Camp Mak-A- Dream	campdream.org	Free camp for kids with cancer (ages 6-14), teen camp and young adult camp as well. Some travel scholarships available (camp is located in Montana)  406-549-5987
Camp Simcha	campsimcha.org	Children age 6-20 with cancer or blood disorders. Free and kosher  1-800-343-2527
Camp Sunshine	campsunshine.org	Camp for children with life threatening illnesses. Camp is free but family must pay for transportation. Located in Maine.  207-655-3800
Children's Oncology Camping Association	<u>cocai.org</u>	Information on many camps offered for children and families affected by cancer 803-434-3533
Children's Oncology Services	onestepcamp.org	Offers camps and other educational and excursion programs throughout the year.  312-924-4220

Comfort Zone Camp	comfortzonecamp.org	Child who has lost an immediate family member (parent, sibling or close friend). Free. Located in Richmond, VA.  I-866-488-5679
Dream Street Foundation	dreamstreet foundation.org	Nationwide camping programs for children and young adults with cancer, chronic and life threatening illnesses. Children are given the opportunity to enjoy activities they would normally be restricted from due to their illness, while Dream Street supports their medical needs. Free and will fly kids in from all over the world to participate.  424-333-1371
Epic Experience 2017	epicexperience.org	A free, week-long outdoor camp for adults who have been diagnosed with cancer at any time in their lives. Experiences are based upon outdoor adventure activities, such as white water kayaking, and during the winter months snowshoeing and cross-country skiing. Participants are encouraged to recognize that cancer is a part of their story, but it no longer defines them. Connections with other individuals who share a similar story will create a community that lasts long after their Epic Experience has ended.
First Descents	firstdescents.org	Young adult cancer fighters and survivors (ages 18–39). Free. Some travel scholarships are available.  303-945-2490
Happiness Is Camping	happinessiscamping.org	Children with cancer (6-15) and their families. Free. In Hardwick, NJ 908-362-6733
Hunt with A Heart	huntwithaheart.org	Provides a respite in the Texas Outdoors to children with life threatening illnesses. Activities include archery, fishing, guided hunts etc.
Lighthouse Family Retreat	lighthousefamily retreat.org	Child with cancer and immediate family members. Free. 678-290-2955

The Periwinkle Foundation	periwinklefoundation.org	The Periwinkle Foundation develops and provides several camping opportunities for patients of Texas Children's Hospital including Camp Periwinkle, Camp YOLO, Family Camp, Long Term Survivor Retreat, and Periwinkle Day Camp.  713-807-0191
True North Treks	truenorthtreks.org	Offers outdoor adventures for teen and young adult cancer survivors. They have caregiver hikes, and survivor only hikes, and then together hikes. The participants pledge to raise \$1200 to attend.
Special Love Camps	specialove.org	Camp for kids with cancer. Free 540-667-3774
Self- Improvement Thru Riding Education	sire-htec.org	Therapeutic horseback riding center. Free. Locations in Hockley, Spring and Fort Bend. 281-356-7588
Trent's Retreat	trentsretreat.org	This retreat provides an opportunity for kids to run and play and laugh and for parents to relax and for families to make memories.  325-718-9340
Tyler's Grace Foundation	tylersgracefoundation.org	Offers programs for camping and retreats. The group is based in California. The Retreat is open year-round to one family at a time. It is a place for families to enjoy spending time relaxing and making memories together.

#### **Cancer Survivorship**

EDUCATION		
Passport for Care®	cancersurvivor. passportforcare.org	Texas Children's Cancer and Hematology Center's innovative health care initiative to provide survivors of childhood cancer increased access to medical information and healthcare follow up guidelines. Survivorship guidelines
Cancer Survivors Network	csn.cancer.org	Focuses on cancer survivorship. Provides information, free publications, and support.  1-800-227-2345
Children's Oncology Group Guidelines	survivorship guidelines.org	Long-term follow-up guidelines for survivors of childhood cancer. Information also available in Spanish and Chinese.
National Coalition for Cancer Survivorship	canceradvocacy.org	Focuses on cancer survivorship, advocacy, publications and support.
National Children's Cancer Society	thenccs.org/support- after-treatment	Focuses on cancer survivorship. Provides information, free publications and support.  314-241-1600
Triage Cancer	triagecancer.org	Works to address cancer-related health disparities through the delivery of cancer survivorship education, particularly information related to accessing care. Information is tailored to specific cancer community audiences, including childhood cancer survivors and their parents, adolescents and young adults, seniors, newly diagnosed patients, individuals who have completed treatment, individuals with advanced disease, caregivers, advocates, and healthcare professionals.

## **Counseling for Oncology**

American Psychosocial Oncology Society	apos-society.org	Toll-free hot line for cancer patients or patient advocacy organizations to obtain referrals for local counseling and support services throughout the U.S. The referral program aims to connect patients to psychiatrists, psychologists, nurses, and social workers skilled in the management of cancer-related distress.
Cancer Care	cancercare.org	One to one counseling, medical care information and telephone support groups; Spanish speaking available. Also offers financial help.  1-800-813-4673
Candlelighters Childhood Cancer Foundation	candle.org	Provides groups, parent-to-parent counseling, practical and emotional support. Also offers meal passes and grocery certificates (limited supply). Spanish speaking available  713-270-4700
Childhood Cancer Guides	childhoodcancer guides.org	Provides clear explanations of the various types of childhood cancer and treatments, emotional support for every member of the family, and access to helpful resources.  1-866-333-1213
The HOPE Line	hopeandhealingcent er.org	Offer clinical, medication and case management for mental health needs. Free service  Clinical:  CBT - 6 - 12 month wait list  DBT- 13 plus month wait list  Screening is completed to assess which services fit best  Serve ages 18 plus. All services free, no insurance billed etc.  Have support groups and helpline which have no wait time and can be initiated immediately  Most services in person but some are virtual.  346-335-8625

## Financial Assistance for Oncology

A Small Miracle Foundation	childcareforcancer patients.org	Provides childcare assistance for children/families undergoing cancer treatment. Free, in-home childcare for families in the Houston/Dallas/Fort Worth areas. Provides 60 hours of care at no cost during treatment. May reapply for 60 additional hours of childcare.
Adam's Angels Ministries	adamsangelsministry.org	Assists families touched by cancer in helping with living expenses, meals, transportation, and parking fees.  979-836-0955
Addi's Faith Foundation	addisfaithfoundation.org	Provides assistance with financial needs, college scholarships (for brain tumor) and grief support.  Application process for financial help.  281-785-4098
Alex's Lemonade Stand Foundation	alexslemonade.org	The Travel for Care program assists eligible families with travel expenses related to active treatment. Covers oncologic diagnoses and cancer predispositions, including LCH. For criteria, visit alexslemonade.org/travel-for-care
American Children's Cancer Benevolence Fund	accbf.org	Provides financial support to families whose child has cancer and to cancer survivors within 4 years of remission.  813-550-8999
Andrew McDonough Be Positive (B+) Foundation	bepositive.org	Provides financial assistance, funds cancer research and helps spread positivity. Funds for utility, phone, car payment, car insurance and rent are considered. Must have hospital social worker involved.  302-563-8389
American Children's Cancer Foundation	accf4cure.org	Provides support to families touched by cancer in the form of education, financial assistance and family support.  Application for financial assistance (online)
Arms Wide Open	awoccf.org	Provides monthly grants to families suffering hardship due to their child's cancer diagnosis. Application on website. Social work referral.

Cancer Financial Assistance Coalition	cancerfac.org	Resource directory. They help cancer patients and their families manage their financial challenges.
Cheyanna's Champions 4 Children	cc4c.org	Assists families with child battling rare or undiagnosed conditions. Will reimburse for prescription and many items that insurance won't cover including lodging. Eligibility is rare diagnosis and ages 0 – 19. No financial requirements. Up to \$6000 a year per family. Application is on the website. Only in English (FYI). Can re-apply if get one item and then in need of another item to be reimbursed.
Children's Cancer Recovery Foundation	childrenscancerrecovery.o	Provides emergency bridge payments directly to the utility companies and landlords 717-688-7940
Chronic Disease Fund, Inc.	gooddaysfromcdf.org	Helps patients with chronic disease, cancer and other life-threatening conditions obtain the life-saving medications they need. Also provides travel assistance.
Clayton Dabney Foundation	claytondabney.org	Assists families who have children in the last stages of terminal cancer, to create everlasting memories.  713-488-4096
Compassion Can't Wait	compassioncantwait.org	Assists families with urgent financial needs for children with any catastrophic illness. Assist with needs such as ballet shoes for a sibling to rent assistance.  310-276-7111
Correa Foundation	correafamily foundation.org	Provides transformative experiences to improve the emotional status and well-being of kids with cancer and their families, and to offer financial support supplying grants to assist with indirect and non-medical expenses. Social work referral required.
Family Reach	familyreach.org	Working with more than 200 hospitals and cancer centers nationwide, they provide immediate financial assistance, education and navigation to families before they hit critical breaking points.  973-394-1411

Friends of Danielle	friendsofdanielle.org	Provides financial assistance to pediatric cancer families undergoing cancer treatment (ages 21 and under). 914-699-9775
Food Assistance	sph.uth.edu/research/cent ers/dell/houston-area- food-access-analysis-tool	An interactive map of the various food access-related services in Houston/Harris County. Data was collected pre-hurricane Harvey in 2016-2017
Gianna Nicole	giannanicoles heartofhope.org	Provides financial assistance to pediatric cancer families undergoing cancer treatment (ages 21 and under).  718-644-4431
Health Well Foundation	healthwellfoundation.org	Assistance with coinsurance, copayments, deductibles and health insurance premiums.
Heroes For Children	heroesforchildren.org	Provides financial assistance to families with a child battling cancer. Social worker will need to make a referral and assist with the process. Group also has social programs, including: valentine dinner, movie day, etc.
National Pediatric Cancer Foundation	nationalpcf.org/research/sa fety-net	Provides financial assistance for travel, insurance co- payments, medication and equipment.
The Invincible Foundation	beinvinceable.org	Help families of children with cancer to navigate, cope and overcome this devastating disease. Provide financial assistance up to \$5000 (which includes a college fund donation).
The Isaiah Alonso Foundation	isaiahalonsofoundation.org	Provides financial assistance to families of kids with cancer. Financial assistance application online  270-300-5329

Jadyn Fred Foundation	jadynfred.org	Provides financial support directly to the patient and their families, including: motel, food, gas, CAT scans, ultrasounds, etc. not covered by insurance.  406-370-2159
Jay Ross Foundation	thejayrossfoundation.org	Provides assistance to families who must travel long distances for treatment of childhood cancer.  571-305-2711
Jenna's Rainbows	<u>jennasrainbow.org</u>	JRF gives grants to meet specific financial challenges facing families undergoing treatment and supporting end of life care, to fill the gaps where other organizations could not step in. Grant amounts have varied depending on need and specific circumstances. Referrals are made by a professional team to indicate need.
Jennifer Ireland Foundation	jif4families.com	Provides direct support to families. With a thorough but streamlined application process they are able to provide quick aid in paying those financial obligations that tend to stack up quickly during the toughest of times for families dealing with cancer.
Joey's Wings	<u>joeywings.org</u>	Funds research that focuses on kidney cancer affecting children and young adults. Financial assistance 18 years or younger, diagnosed with pediatric renal cancer or renal cell carcinoma.  352-538-2155
Kasie Helpz Kids	khkidz.org	Assists families with up to \$500 per year in reimbursements for co-pays, medications, and counseling services during their child's battle with cancer.  Application on website. 0–19 years  850-449-2892
Lazarex Cancer Foundation	lazarex.org	Assists with costs related to clinical trial treatment, including transportation, lodging and some uncovered medical expenses. Application can be accessed through social worker.  1-877-866-9523

Leukemia and Lymphoma Society: Co-Pay Assistance Program	lls.org/support/financial- support/co-pay-assistance- program	Assistance with insurance premiums and co-pay obligations.
Liam's Way	liamslighthousefoundation. org	Provides financial assistance to defray treatment-related expenses for families affected by Histiocytosis including ground transportation, air travel, and lodging related expenses.
Live Like Bella Foundation	<u>livelikebella.org</u>	Assists families with emotional and financial assistance. Also assists with memorial services. 786-505-3914
Luke Neuhedel Foundation	www.lukefund.org	Dedicated to improving the quality of life for children currently undergoing and who have undergone treatment for pediatric cancer. Since 2002 LNF has provided gifts, toys, support, grants, entertainment.
The Mattie Miracle Foundation	www.mattiemiracle.com	Dedicated to increasing childhood cancer awareness, education, advocacy, research and psychosocial support services to children, their families, and medical personnel. Offer several grants for mental health assistance and family fun trip (\$1000 each)
Max Cure Foundation	maxcurefoundation.org	Funds research and provides financially assistance to low-income, military and first responder families battling childhood cancer  201-569-5595
National Children's Cancer Society	thenccs.org	Services include an online support network for parents of children with cancer, educational materials, and financial assistance for treatment-related expenses. Printable publications. They also partner with Agility, a national provider of discount prescription drug cards.  314-241-1600
Patches of Light	patchesoflight.org	Provides financial assistance to families affected by catastrophic illness.
Pinkie Swear	pinkyswear.org	Helps with financial and emotional support for children with cancer and their families. Application required. 952-974-9600

Still Strong Foundation	stillstrongfoundation.org	SSF will pay non-medical expenses including: rent, mortgage, utilities, travel expenses, car payments, insurance, etc. Payments are made directly to the vendor/service provider.
Team Luke Hope For Minds	teamlukehope forminds.org	Supportive resources and financial assistance to any family with a child with any brain injury (includes strokes)

## **Getting through School while on Treatment**

American Brain Tumor Association	abta.org	Publications: Educating Children and Teenagers and Returning to School  773-577-8750
Alex's Lemonade Stand Foundation	alexslemonade.org	Publishes a school reentry guide for families and teachers.
American Childhood Cancer Organization	acco.org/books	Many free publications regarding childhood cancer. One book called "Educating the Child With Cancer" is available - order online.  1-855-858-2226
Chris Lantos Foundation	chrislantos foundation.org	Provides an iPad to any child fighting cancer so they can stay connected with friends during treatment.
Cure Search for Children's Cancer	curesearch.org	Guidance for School Personnel  curesearch.org/Guidance-for-School-Personnel  Guidance for Parents  curesearch.org/Guidance-for-Parents  Learning Problems During or After Treatment  curesearch.org/Learning-Problems-During-or-After-Treatment  1-800-458-6223
Hopecam	hopecam.org	Hope cam provides the child with cancer a tablet computer equipped with a webcam, Internet access in the home if the child is without, and works with the child's school to provide them a web cam so the child can participate in classroom activities, and see and talk with their friends.  703-364-5609
Homeschool Foundation	homeschool foundation.org	Mission is to make homeschooling possible during hard times. 540-338-8688

Keep Kids Connected	keepkids connected.org	Provides a notebook/tablet computer to kids with cancer or other life-threatening illnesses to help them stay connected with friends and school while undergoing treatment.  Application process.
Leukemia and Lymphoma Society	lls.org/sites/default/ files/file_assets/childh oodleukemialympho ma.pdf	Provides a variety of publications including Learning and Living With Cancer. LLS also provides the Trish Greene Back to School Program.  Videos for school personnel:  Ils.org/professional-education-webcasts/videos-school-personnel  For Parents and Educators: Ils.org/article/resources-families
Livestrong	livestrong.org/ school	Lessons and activities to teach students about cancer using age-appropriate lessons. Resources created to generate meaningful discussions about cancer, cancer treatment and how to support those living with cancer.
Mikey's Way Foundation	mikeysway.org	They strive to create connection and diversion to help children face the emotional and physical hardships of long term, debilitating treatment. Provides computers, iPads and other electronic devices for children with cancer.
Monkey In My Chair	monkeyinmychair.org	This monkey and school reentry backpack is for pre-school and elementary aged children who are away from school because of a cancer diagnosis. This program helps to educate the classmates regarding the child's medical diagnosis and to keep the child connected with the class.
National Children's Cancer Society	thenccs.org/ publications	Provides a variety of publications, including 'An Educational Guide for Friends of Teens with Cancer' 314-241-1600

#### **Kindness Kits**

Amanda Hope Rainbow Angels	amandahope.org	Provides a free comfy cozy shirt to any child receiving chemo. Shirts are designed for easy access to ports or central lines. See social worker for referral code for a free shirt.
A Moment of Magic	amomentofmagic.org	A community partner that has traditionally provided character visits to kids in hospitals. They teamed up with other non-profits to bring their services to kids, families, and hospitals all over the world via their digital platform. The programming is on demand and can be filtered by: language, favorite superheroes, arts and craft activities with a princess, and unique collaborations with celebrities and athletes across the country.
Brennan's Buddies	brennansbuddies.org	Provides care packages and delivers holiday toys 832-390-1299
CeCi Cares Foundation	cecicares.org	Provides toys, art supplies, personal items to children undergoing medical care in the local Houston area. <a href="mailto:information@cecicares.org">information@cecicares.org</a>
Chemo Duck	chemoduck.org	Chemo Duck is a soft, cuddly companion that provides huggable hope and alleviates fear and anxiety. Developed with the help of child life specialists and medical professionals, Chemo Duck introduces children and families to their new life and encourages healing through the power of play therapy.  615-830-0126
Childhood Cancer Research Fund	childrenscancer.org	Free bear to any child fighting cancer  I-888-422-7348
Cure Search	curesearch.org/ella- barbie	Through a partnership with Mattel, Curesearch provides every young cancer fighter an Ella doll. Ella dolls can be requested online for the patient or sibling.  1-800-458-6223
Feel Better Friends	fbfdolls.org	Handmade dolls filled with love and well wishes. Made for kids with matching eye and hair color. For children battling cancer and other illnesses. Request a doll online.

Flashes of Hope	flashesofhope.org	Provides photography for child with cancer. Raises funds to accelerate a cure for children's cancer.  440-442-9700
Gracie's Gowns	graciesgowns.org	Makes hospital gowns for chronically ill children. Gown is personalized with child's name and match the fabric to child's interests.
Jamie's Hope	jamieshope.org	Through their program called 'Bald is Beautiful', Jamie's Hope offers a free photo shoot for cancer patient, family, before and after loss of hair.  346-335-3099
Jessie Rees Foundation	negu.org	Provides awareness, encouragement, and connection to other families in similar situations. Also gives joypacks to kids and siblings to foster hope and encouragement. Sign up online  1-888-648-6348
Joe Joe Bear Foundation	joejoebear.org	Free bear to any child fighting a life-threatening illness 281-398-4522
Julia's Grace Foundation	juliasgrace foundation.org	Offers opportunities for special moments (a.k.a., 'hugs') to children with cancer and their families. 4 kits are available to children. They also grant financial assistance (a.k.a., 'graces') to families experiencing financial hardship due to their child's cancer treatment and care costs.
Kelsey's Dream	kelseysdream.org	Hopper the Cancer Crusher is a therapy toy for children undergoing treatment for cancer. Hopper is equipped with a mediport similar to the ones used to deliver chemotherapy Hopper is not only there to keep children company through medical procedures, but in many ways, takes the journey with them.
Icing Smiles	icingsmiles.org	Provides a custom cake for the ill child or sibling to help create a positive memory during a difficult time.  443-420-7096

Lightz Of Hope	lightzofhope.org	Mission is to spread hope with the gift of light to children suffering from a severe illness or disability. Also provides financial assistance to families in need. Up to \$1000 per family to assist with utilities, gas assistance, medication, eyeglasses.
Luke's Fast Breaks	lukesfastbreaks.org	Makes colorful medical shirts for children fighting cancer who are staying in the hospital for long periods of time. The shirts have snap tape up and down each side to replace traditional hospital gowns as a way to help kids feel normal and helping with the mental fight these children face.
Marlee's Smile	marleessmile.org	Provides a personalized Build-a-Bear to children battling cancer and their siblings.  210-683-3370
Oliver Patch Project	www.oliverpatchproj ect.org	Open to any child in the United States in active treatment for cancer. Warriors are provided a secret "patch code" that takes them to their own portal. Within the Warrior Login Portal, they will create their account and then the fun begins! The child then picks out a jacket or tote and twenty (20) patches. Group sews these patches on each garment and mail to them to the home. Caregivers are sent a box of thirteen (13) milestone patches so that they can support and empower their warriors along their cancer journey (patches are made to be given at certain timeframes like bone marrow biopsy, blood products given, MRI and each patch has a QR code that takes child to a video). Program is completely free of charge. All OPP members receive an awesome patch, croc charms and more each month for the next year reminding them that they are not alone.  Siblings can access a patch as well on website via the national patch day icon on the website. Sibling may choose from 5 patches.
Operation Snowstorm	operation snowstorm.org	Offers sick children the opportunity to experience snow in Texas.
Packages of Hope	packagesofhope.com	Sends packages of gifts and toys to children of all ages across the United States who are battling cancer.
Peaches Neet Feet	peachsneetfeet.com	Provides personalized shoes to kids experiencing hardship due to cancer or blood disorder. Ages I-18 qualify. Apply online.

Project Linus	projectlinus.org	Donates handmade security blankets, quilts and afghans to children undergoing difficult medical situations.  309-585-0686
Riley's Cause	rileyscause.org	Provides assistance to families with a child receiving cancer treatment to make a child smile. Might be a sporting event, movie passes, travel or a restaurant certificate. Apply online.
Sara's Smiles Foundation	saras-smiles.org	Sara's Smiles "Inspiration Kits" contain items in a durable, portable box that will help families stay organized, connect to others, and explore creative ways to encourage smiles.  267-287-8244
Shadow Buddies	shadowbuddies.org	Soft doll friends for kids and resource packets for medical caretakers. 21 illnesses have their own symptom and treatment specific buddies – oncology and sickle cell are two of them. Request through Child Life.
The Stuff the Sleigh	thesleigh.org	Helps provide the spirit of Christmas year-round for kids affected by cancer and hematology conditions. Funeral assistance, iPad program, financial assistance and scholarships.
Superfly Kids	superflykids.com	Provides free superhero cape to any child facing life threatening illness.  313-454-1492
Tubie Friends	tubiefriends.com	Makes a stuffed friend with medical equipment mirroring the child's feeding tube, G tube, etc. A stuffed animal with similar medical equipment can make the process less frightening.
Ween Dream	weendream.org	Free Halloween costume to child with medical or special needs. Apply online.

## **Major Organizations for Oncology**

EDUCATION		
Cancer Net	<u>cancer.net</u>	Cancer information from the American Society of Clinical Oncology. Has an entire section on coping with cancer, along with childhood cancer facts, stats, side effects, research, etc.  1-888-651-3038
Children's Neuroblastoma Cancer Foundation	cncfhope.org	Their handbook on neuroblastoma includes topics such as: surviving neutropenia, hearing loss, information about clinical trials, etc.  1-866-671-2623
Children's Oncology Group	childrensoncology group.org	The Children's Oncology Group Family Handbook is a free e-book that's available in English, Spanish, and French. This is a valuable resource for families as they navigate their child's cancer journey. It provides reliable information about treatment, support and follow-up care.
Coalition Against Childhood Cancer (CAC2)	cac2.org	A collaborative network of nonprofits, corporations, and individuals from 36 states and five countries, supporting and serving the childhood cancer community. CAC2 members effectively advance a variety of childhood cancer causes by unifying their efforts.
CureSearch	curesearch.org	Provides up-to-date information about childhood cancer from pediatric cancer experts. Has sections for patients, families, and friends to help guide them on how to support a child with cancer. Also has long-term follow-up guidelines for young cancer survivors at <a href="survivorshipguidelines.org">survivorshipguidelines.org</a> . These guidelines provide recommendations for screening and managing late effects that may result from pediatric cancer treatments. This group also has developed a mobile app that allows you to organize treatment dates, track side effects, view reports, see trends, etc.  1-800-458-6223
Leukemia and Lymphoma Society	lls.org	Free educational programs for parents and teachers such as Staying Connected: Facilitating the Learning Experience During and After Cancer. Also has the Trish Greene Back to School Program, which includes publications, DVDs, videos and programs that can help you discuss a cancer diagnosis with teachers and classmates.  Staying Connected: Facilitating Link to participate:

		https://www.lls.org/professional-education-webcasts/staying-connectedr-facilitating-learning-experience-during-after  Videos are available for school personnel and families: https://www.lls.org/professional-education-webcasts/videos-school-personnel For Parents: https://www.lls.org/article/resources-families  I-800-955-4572
OncoLife	oncolife.oncolink.org	Publications and presentations— not just for childhood cancer
National Cancer Institute	cancer.gov	Publications like Young People with Cancer and a dictionary of cancer terminology  I-800-4-CANCER
National Children's Cancer Society	thenccs.org	Services include: online support network for parents of children with cancer, educational materials, publications and financial assistance for treatment-related expenses. They also partner with Agility, a national provider of discount prescription drug cards.  I-800-5-FAMILY
National Pediatric Cancer Foundation	nationalpcf.org	Goal is to fund research for pediatric cancer. Other programs include a health navigator to help families identify resources and educational materials. 813-269-0955
The HOPE Portal	searchhope.chla.org	A searchable database, made possible by a generous grant from the Ronald McDonald Children's Charities. The HOPE Portal was developed as a key resource for families to access trustworthy information and find assistance.

## **Scholarships for Cancer Patients**

American Cancer Society	cancer.org	Offers scholarships for undergraduate college, trade or vocational schools to cancer survivors who were diagnosed under the age of 25
Andre Sobel River of Life Foundation Award	andreriveroflife.org	Provides scholarships for cancer patients and survivors to attend college.  310-276-7111
APON Scholarship (Gulf Coast)	Visit our social work office	This scholarship provides funding for college/vocational education to pediatric hematology/oncology patients, on or off therapy.  832-465-8992
Ashley Tamburri Scholarship	theashley foundation.org	Provides scholarships for cancer patients and survivors to attend college.
B.I.G. Love Cancer Care	biglovecancercare .org	Eligibility Requirements: graduating high school seniors, community college and/or four-year university students. Must be enrolled in courses that fulfill nursing school required courses. Applicants must have battled childhood cancer, be a sibling or a parent of a childhood cancer patient  1-888-522-7339
Beat Cancer	beatcancertoday. storenvy.com/ scholarships	College scholarships for survivors and siblings of individuals who have been diagnosed with pediatric cancer. The scholarships help qualified applicants pursue post-secondary education from accredited educational institutions.  515-639-0006
Candlelighters	candle.org	Scholarship for college education and or vocational training. 713-270-4700
Cancer for College	cancerforcollege.org	Must be a US resident enrolled in a university or community college located in the United States.  760-599-5096

Children's Cause for Cancer Advocacy	childrenscause.org	Annual opportunity for two childhood cancer survivors to receive a \$2,000 college scholarship.  202-552-7392
FinAid!	finaid.org	A smart guide to financial aid. Can search for scholarships for cancer patients, survivors, children of a cancer patient, children who have lost a parent or sibling to cancer, and students pursuing careers in cancer treatment.
Friends of Scott	friendsofscott.org	College scholarship will be awarded to a cancer patient or cancer survivor based on financial need and personal hardship. 619-993-2917
Hydrocephalus Association	hydroassoc.org/how- to-apply/	The Scholarship Program provides financial assistance to capable and promising young adults who live with the ongoing challenges and complexities of hydrocephalus.  888-598-378
The Izzy Foundation	theizzyfoundation.org	Offers academic scholarships to children with cancer (survivors or current treatment) and siblings. 401-331-4999
Jack's Ride Scholarship Program	<u>jacksride.org</u>	Scholarships will be awarded as a one-time disbursement to each recipient. Fund will be paid by Jack's Ride to the school of the recipient's choice for university, 2-year community college or trade or vocational school.  832-498-5096
Jeremy Cares	jeremycares.org	Scholarships for cancer patients, survivors and siblings.
National Children's Cancer Society	thenccs.org	Promotes children's health through financial assistance, advocacy, support services, education and scholarships.  1-800-532-6459
National Collegiate Cancer Foundation	collegiatecancer.org	Provides scholarships to young adults whose lives have been impacted by cancer.  240-515-6262

National Grace Foundation	graceamerica.org	Provides free college admission and financial aid consulting services for pediatric cancer survivors and families. Provides free services to assist with college admission and financial aid process, essay and personal statement writing.  401-793-6337
Nicki Leach Foundation	nickileach.org	College scholarship to young people impacted by cancer. Apply online.  904-716-5394
Northwestern Mutual Childhood Cancer Survivor Scholarship Program	learnmore.scholarsap ply.org/nmsurvivors/	Twenty-five, \$5,000 undergraduate awards will be given for the upcoming academic year for children impacted by cancer.
Patient Advocate Foundation	patientadvocate.org	Provides support to patients seeking to initiate or complete a course of study that has been interrupted or delayed by a diagnosis of cancer or other life-threatening disease.  1-800-532-5274
The Simon Cancer Foundation Scholarship Program	thescf.org	Awards scholarships and makes charitable donations to camps and educational programs. Scholarship eligibility information is available on their website.
Snowdrop Foundation	snowdrop foundation.org	The Snowdrop Foundation is based in Houston and fundraises for cancer research and scholarships for cancer survivors. Scholarship monies are paid directly to the school the recipient has enrolled in.  713-232-9051
Super Sibs Scholarship Program	supersibs.org	For brothers and sisters of children with cancer. Must apply during final year of high school.  1-866-333-1213
The Pediatric Brain Tumor Foundation	curethekids.org	The world's largest nonprofit funder of childhood brain tumor research. Provides free educational information about brain tumors, college scholarships, and more.  1-800-253-6530

The SAMFund for Young Adult Survivors of Cancer	thesamfund.org	Supports young adult cancer survivors in the United States as they recover from the financial impact of cancer treatment. Through direct financial assistance and free online support and education, The SAMfund helps young adults move forward towards their personal, professional, and academic goals.
The Ulman Cancer Fund for Young Adults	ulmanfund.org	A leading voice in the young adult cancer movement, working at a grassroots level to support, educate, connect and empower young adult cancer survivors  410-964-0202
College Scholarship Search Engines		scholarships.com/financial-aid/college-scholarships/scholarships-by-type/cancer-scholarships/ ped-onc.org/scholarships/index.html  cancer.org/content/cancer/en/about-us/local/resources-list.detail.html/120668.html  lls.org/support/other-helpful-organizations/financial-resources/scholarships-education

## Siblings and Cancer

EDUCATION		
Alex's Lemonade Stand	alexslemonade.org/ campaign/supersibs	Super sibs program is available through Alex's Lemonade Stand.
Leukemia Society	<u>lls.org</u>	Publication for siblings: Sibs & Talk about Cancer  1-888-557-7177
National Cancer Institute	cancer.gov/Publications/patient-education/sibling-has-cancer	The NCI has many publications dealing with childhood cancer, one specifically for siblings is called When Your Brother or Sister Has Cancer.  1-800-4-CANCER

SUPPORT ORGANIZATIONS		
American Cancer Society	cancer.org	ACS has lots to offer including: support groups, literature on a large variety of topics, summer camps for children with cancer, research and educational programs. Search for "siblings"  I-800-ACS-2345
American Childhood Cancer Organization	acco.org	Free services include: an annual bibliography and resource guide, quarterly newsletter, and handbooks to help families of children with cancer. Search for "siblings"  1-855-858-2226
Sibling Support Project	siblingsupport.org	Seeks to increase peer support and information for siblings of people with special needs and to increase parents' and providers' understanding of sibling issues. Trains local providers how to create community-based peer support programs for young siblings; hosting workshops, listservs, and websites; and increasing parents' and providers' awareness of siblings' unique, life-long, and ever-changing concerns

## **Social Support for Cancer Patients and Families**

GENERAL SOCIAL SUPPORT		
Alex's Lemonade Stand Foundation	alexslemonade.org	Fact sheets on childhood cancer, journal that can be printed or ordered.  1-866-333-1213
American Childhood Cancer Organization	acco.org	Books, publications, medical kits; all free to patients and teachers, etc.  1-855-858-2226
Big Love	biglovecancer care.org	Provides basic necessities and personalized care for patients in an inpatient setting (parking, meals, weekly toys, etc.).  1-888-522-7339
Candlelighters	candle.org	Provides emotional, educational and practical support (parking, meals etc.) for families with childhood cancer diagnosis. This is the local chapter.  713-270-4700
Chance For Hope	chanceforhope foundation.org	Free temporary housing, meal delivery inpatient, gift cards for back to school supplies and research
Chemo Angels	chemoangels.com	Provides support through a "buddy" system; the buddy provides encouragement and support.
Chemotherapy Cheerleader	facebook.com/pages/ category/Community /Chemotherapy- Cheerleader- 463022633790211/	Great source of information for new patients and caregivers about how families can help, from a doctor who underwent cancer treatment.
Children's Cancer Association	joyrx.org	Focuses on the belief that joy changes lives. They provide programs (music, friendship, play, and resources to create transformative moments of joy for 20,000 children, teens, and their family members each year. This group gathers information and resources in a free book.  503-244-3141

Coach Art	<u>coachart.org</u>	Free I:I arts and athletics coaching to any child who has a chronic physical illness and/or their siblings between the ages of 5-18. Also offer group programs called "clubs" where kids can connect with their peers in a safe learning environment and learn fun arts and athletics activities. The lessons are all virtual using zoom. Ship all the needed materials free of charge (musical instruments, art supplies, cooking ingredients, sports equipment, etc) to the family.
Connecting Champions	connecting champions.org	Mentorship program for children and youth affect by cancer, ages 3 – 21.
Kids Kicking Cancer	kidskickingcancer.org	Their mission is to ease the pain of very sick children while empowering them to heal physically, spiritually and emotionally. Provides super power kit  248-864-8238
Life Extra	liveextra.org	This group developed a platform to highlight a family journey showcasing their situation through blog, video, etc. Features include: journaling capability, ability to upload pictures and videos, calendar/scheduling capability so friends/family can schedule times to assist with everyday chores (mowing the lawn, food delivery, babysitting,) Easily links to social media platforms so families don't have to rewrite their journals Stories can be shared publicly or kept private.  Plumfund is a similar platform where you can fundraise without fees.
L3 Foundation	l3foundation.com	This group's mission is to work hand in hand with children to raise awareness, support, and funding focused on finding the cure to childhood soft tissue cancer.
Lotsa Helping Hands	lotsahelping hands.com	Online calendar. Post requests for support like meals, rides to appointments, etc.
Momcology	momcology.org	Provides peer support, research and advocacy services surrounding childhood cancer.
Pablove Shutterbugs	pablove.org	A photography program for kids 6–18 with cancer. 323-657-5557

The Periwinkle Foundation	periwinkle foundation.org	The Periwinkle Foundation develops and provides programs that positively change the lives of children, young adults and families who are challenged by cancer and other lifethreatening illnesses and are cared for at Texas Children's Hospital.
The Snowdrop Foundation	snowdrop foundation.org	Raises money toward research. Also has a bling for bravery (nominate online) program.  713-232-9051

PEER-TO-PEER		
Cancer Care	cancercare.org	Provides telephone, online and support groups.  1-800-813-HOPE
Imerman Angels	imermanangels.org	Online peer support program for patients of any age.
National Children's Cancer Society	thenccs.org	This mentoring program partners children ages 10-17, who are undergoing treatment, with childhood cancer survivors who are now young adults.  314-241-1600
Zach's Bridge	www.zachsbridge.org	Peer to peer connection for advanced pediatric cancer. Program is completely virtual.

#### Teens/ Young Adults with Cancer

EDUCATION		
13 Thirty Cancer Connect	13thirty.org	Provides educational information about cancer and tools for coping and healthy living. Many fact sheets on topics like mouth sores, fatigue, and chemo brain.
Allyson Whitney Foundation	allysonwhitney.org	Awards 'Life Interrupted Grants' to young adult patients aged 15-36 undergoing treatment or finished protocol within 6 months. Grant applications are accepted 2-3 times a year, depending on funds. Grants cover a wide range of needs, including, but not limited to: medical bills, rent, car and health insurance premiums, IVF treatments, integrative therapies, travel expenses, phone, etc. The maximum amount awarded is \$1,500.
American Cancer Society	cancer.org	Online groups for childhood and young adult survivors.  1-800-227-2345
Bite Me Cancer	bitemecancer.org	Provides teen support bags to teens fighting cancer. Bag is full of teen items including a hat, coupon to design their own t-shirt, a mug and more.
Cactus Cancer Society	cactuscancer.org	Provides online support and programs for creative coping to young adult cancer patients, survivors, and caregivers. Provides virtual programming including a monthly hang out, book club, yoga program, creative writing workshop, survivor series, guy's discussion group, journaling and more.
Cancer and Careers	www.cancerandcaree rs.org/en	Cancer and Careers empowers and educates people with cancer to thrive in their workplace, by providing expert advice, interactive tools and educational events. Free publications and more.
Cancer Care	cancercare.org	Online counseling, support groups, education and financial assistance. No peer to peer.

Cassie Hines Shoe Foundation	cassiehinesshoescanc er.org	Mission to support young adults with cancer from the beginning of their battle to life beyond cancer. Support programs, peer support, survivorship programs, and more. Interactive website designed for AYA (ages 18 – 40); Base 2 Summit adventure in Northern Michigan; Financial support for AYA to travel to camps listed on website.
Coach Art	<u>coachart.org</u>	Free I:I arts and athletics coaching to any child who has a chron physical illness and/or their siblings between the ages of 5-18. Also offer group prograr "clubs" where kids can connect with their peers in a safe environment and lear arts and athletics activities. The lessons are all virtual. sports equipment, etc) to the family.
Connecting Champions	connecting champions.org	Mentorship program for children and youth affect by cancer, ages 3 – 21.
Critical Mass: The Young Adult Cancer Alliance	criticalmass.org	The full-time federal advocacy arm of the entire adolescent and young adult cancer community.
Elephants and Tea	elephantsandtea.com	Media company for adolescent and young adult (AYA) cancer patients and survivors, written by AYA cancer patients and survivors who tell their story in their own words. Through stories & artwork, their goal is to help AYA patients and survivors experience relief through self-expression, inspire others during their cancer journey and connect with support organizations across the nation.
Group Loop	cancersupportcomm unity.org/group-loop www.grouploop.org	A safe place for teens to connect, to find support, education and hope while dealing with a cancer diagnosis.  1-888-793-9355
Hope Lab	hopelab.org	Video games that give teens chance to blast their cancer in a video game. re-mission.net. Computer game. Free 3D shooter video game designed for teens. All related to side effects, bacterial infections, etc.

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Hope Cam	hopecam.org	Provides computer, ipad, playstation etc. for young people undergoing cancer treatment.
Hope for Young Adults with Cancer	Hope4yawc.org	Provides resources and funds for young adults $(18-40)$ with everyday expenses (on treatment or up to 5 years post cancer treatment).
I Had Cancer	<u>ihadcancer.com</u>	Online resources for people affected by cancer, including topics about survivorship, relationship, fertility, school and work, finances, emotional support, awareness and education.
I'm Too Young For This / Stupid Cancer	stupidcancer.org	Founded by a young adult brain cancer survivor. Research, support, outreach, mobile awareness for teens with cancer. Also provides a free Instapeer app for you to connect with other survivors and find programs and meetups in your town.
Lacuna Loft	lacunaloft.org	A support network for young adults with cancer. They have articles on cancer life hacks, exercise, chemo brain, etc. They provide chemo care kits, activity kits and articles for the patient and caregivers.
National Bone Marrow Program/Be The Match	network.nmdp.org	Peer Connect Program connects patients/caregivers by phone or email with someone who's been through transplant.  Network of trained Peer Connect volunteers share their experiences, provide support and answer questions. When a connection is requested, we identify a volunteer who most closely matches the patient's or caregiver's situation. Patients and caregivers can request a connection by visiting: <a href="https://bethematch.org/patients-and-families/support-for-you-and-your-family/peer-connect-program/">https://bethematch.org/patients-and-families/support-for-you-and-your-family/peer-connect-program/</a>
National Children's Cancer Society	thenccs.org	Teen guide, parent guide to surviving childhood cancer and other educational materials  1-800-532-6459
National Collegiate Cancer Foundation	collegiatecancer.org	Services and support to young adults diagnosed with cancer. NCCF is committed to providing need-based financial support to young adult survivors who are pursuing higher education throughout their treatment and beyond.
Nicki Leach Foundation	nickileach.org	Provides modest financial assistance to young adults (18-30) afflicted with cancer. 904-716-5394

Noah's Gift	noahsgift.org	Application for adventure seeking teens. Will fund up to \$2500 of a travel style request. Must apply. Ages 13-19 years.
Stupid Cancer	stupidcancer.org	The Stupid Cancer App connects you to a network of peers who understand what you're going through. They've been there, too. You have a right to know they exist and #sayhello
Team Impact	goteamimpact.org	Works at improving quality of life for children facing life threatening and chronic illnesses through the power of team. They do this by drafting courageous kids with a local college athletic team.
Teen Cancer America	teencanceramerica.or	Partners with hospitals throughout the United States to develop specialized facilities and services for teens and young adults with cancer. Develop standards for age-targeted care, improve collaboration between pediatric and adult specialists and enable dedicated research to improve outcomes and survival for our young people. Provides an AYA newsletter and more.
The SAMFund for Young Adult Survivors of Cancer	thesamfund.org	Supports young adult cancer survivors in the United States as they recover from the financial impact of cancer treatment. Through direct financial assistance and free online support and education, the SAMfund helps young adults move forward towards their personal, professional, and academic goals.  617-938-3484
The Ulman Foundation	ulmanfoundation.org/	Provides community of support for young adults and their loved ones touched by cancer. Publishes an amazing book called "No Way" written for AYA regarding cancer. Download on the website.
Young Survival Coalition	youngsurvival.org	YSC is dedicated to the critical issues unique to young women who are diagnosed with breast cancer. YSC offers resources, connections and outreach so women feel supported, empowered and hopeful.  1-877-972-1011
Young Adult Cancer Connection	yacancer connection.org	Resources and support for young adults with cancer.

We Believe webelievefour net	Assistance, Awareness and Advocacy are the pillars of this organization and how they make a difference. Assistance takes many forms: providing financial hardship grants, lost part-time wage grants, Pink Hearts of Hope grants.
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#### SUPPORT ORGANIZATIONS FOR TEENS WITH CANCER

## Wish Organizations

		Wish Kids must meet these simple criteria:
A Wish With Wings	awww.org	<ul> <li>Have a medical diagnosis of a life-threatening medical condition.</li> <li>Be between ages 3 and 19 years when the form is received. Wishes for children under age 3 must be approved by the board of directors.</li> <li>Have not previously received a wish from any wishgranting organization.</li> <li>Reside in or being treated in Texas.</li> </ul>
3 Little Birds 4 Life	3littlebirds4life.org	Dreams of a lifetime for persons ages 18–40 with any cancer, any stage in the Ohio and Illinois area. Special wishes provided on a case by case basis for those who have not had a wish (due to over age 18 or under age 3).
A Special Wish Foundation, Inc.	spwish.org	Dedicated to granting the wishes of children under the age of 21 and diagnosed as having a life-threatening disorder. Serves infants to age 20.  1-800-486-9474
Catch a Dream Foundation	catchadream.org	Grants once-in-a-lifetime hunting and fishing experiences to children 18 years old or younger who have a life-threatening illness.  662-324-5700
Children's Wish Foundation International	childrenswish.org	Fulfills wishes for children under 18yo diagnosed with a life-threatening illness. Depending on the child's medical condition, they try to wait until the child is old enough to fully enjoy and remember the experience of their wish.  800-323-WISH

Compassion Partners	no website	Provides free tickets to Partnering Theme Parks in the Central Florida area, for children and adults with life changing illnesses like cancer. The patient or caregiver writes a letter requesting the tickets and the doctor confirms the diagnosis. Compassion Partners obtains tickets for you.  407-396-5320
Do It for the Love	doitforthelove.org	Brings children with severe challenges, people living with life-threatening illnesses and children with severe challenges to live concerts. Provides up to 4 event tickets to the recipient and their family members, friends or caretakers.  844-484-3568
Dream Foundation	dreamfoundation.org	Serves terminally ill adults and their families by providing end of life dreams that offer inspiration, comfort, and closure.
Give Kids the World Village	jeanl@gktw.org	Offers a compassion program which assists families with park passes if their wish is not Disney. 407-396-5320
Go 4 the Goal	go4thegoal.org	Provides financial support, develops and implements unique hospital programs, funds innovative research, and grants personal wishes. Financial support is limited to availability of foundation funds.
Granted Wish	grantedwish.org	Wish granting organization that is dedicated to granting wishes exclusively in the sports genre. Available for ages 5–25.
Kids Wish Network	kidswishnetwork.org	Wish granting organization for children 3-18yo who are battling a life-threatening medical condition  888-918-9004
Make-A-Wish Foundation	wish.org	Grants wish to child, ages 2.5-18, with life threatening illness.
Sunshine Foundation	sunshinefoundation.o rg	Sunshine Foundation answers the dreams of children, ages three through eighteen, who have <b>severe or profound</b> physical/developmental/intellectual challenges or trauma from physical/sexual abuse, and whose families have limited income. Household income less than \$75,000.

# Texas Children's Hospital\*

# **Vascular Anomalies**



DISEASE AND TREATMENT		
Cloves Syndrome Community	clovessyndrome.org	Provides support, education and publications.
Cure Hereditary Hemorrhagic Telangiectasia Foundation	curehht.org	Provides education, research updates, links and a newsletter.
Klippel-Trenaunay Support Group	<u>k-t.org</u>	Provides factual information, resources and links
Lymphangiomatosis and Gorham Disease Alliance	<u>lgdalliance.org</u>	Provides education, disease fact sheets and more.
Lymphatic Education and Research Network	lymphatic network.org	Support organization that focuses on education, research and advocacy.
M-CM Network	m-cm.net	M-CM Network provides comprehensive medical information about M-CM (MCAP, M-CMTC) and develops programs to promote education and research.
National Lymphedema Network, Inc.	<u>lymphnet.org</u>	Support organization that provides education resources and an e-newsletter.
Sturge-Weber Syndrome Community	swscommunity.org	Support organization that provides informational resources, links, etc.
The Sturge-Weber Foundation	sturge-weber.org	Support organization that provides education, resources and research updates.

SUPPORT ORGANIZATIONS		
AboutFace USA	aboutface.ca	Support organization that provides education and publications.  1-800-665-3223
Angioma Alliance	www.alliancetocure.o	An organization by and for those affected by cavernous angiomas and their loved ones, health professionals, and researchers.
AVM Survivors	avmsurvivors.org	Support group for patients and families that have had an arteriovenous malformations (AVM).
Birth Defects Research for Children, Inc.	birthdefects.org	Publications, research information and resources for birth defects.
Blue Rubber Bleb Nevus Facebook Support Group	facebook.com/groups /bluerubberbleb	Provides a community for families coping with blue rubber bleb nevus syndrome
Camp Dermadillo	campforall.org	A camp for children, ages8-16, with dermatologic conditions that is held at Camp For All in Burton, TX. You must be nominated by a dermatologist to attend. Free.
CMTC OVM USA (Van Lohuizen Syndrome)	cmtcovm-us.org	Focuses on the well-being of people who suffer from vascular malformations, such as CMTC (Van Lohuizen syndrome), and to stimulate the scientific research of such conditions.
Department of State Health Services Children with Special Health Care Needs Services Program	dshs.state.tx.us/cshcn	Resources for home medical, parent/youth transition worksheets, brochures, etc.
Easter Seals — Houston	easterseals houston.org	Support, educate, empower; publications regarding individuals with disabilities 713-838-9098
Hereditary Hemorrhagic Telangiectasia (HHT) Foundation	hht.org	HHT provides advocacy and support. Includes factual information, research updates, helpful links, and a newsletter. 410-357-9932

Infantile Hemangioma	infantile hemangioma.com	Resource that provides education, publications, etc.
Kennedy's Cause	kennedyscause.com	Raises awareness of lymphatic malformations and to raise funds to support the research for a cure.  856-437-0605
National Organization for Rare Disorders	rarediseases.org	Resource which provides education, resources, awards grants and networking
Operation Smile	operationsmile.org	Provides free surgeries to kids who need them, teaches medical personnel.  I-888-OPSMILE
Parents Helping Parents (PHP)	php.com	PHP increases the quality of life for children with special needs by providing services, resources, and support for children, their families, and caregivers
PHACE Syndrome Community	phacesyndromecom munity.org	Works to raise awareness, promote peer support, fund research, finding a cause, and improving treatment 678-744-3971
Proteus Syndrome Foundation	proteus- syndrome.org	Dedicated improving the lives of Proteus patients by funding AKTI research. They focus on providing family support in the form of education and networking.
PTEN Hamartoma Tumor Syndrome Foundation	ptenfoundation.org	Offers education about PTEN syndromes, provides financial support to patients, supports research, and promotes awareness.
Vascular Birthmarks Foundation	birthmark.org	Factual information, parent networking, physician list, newsletter, transportation, insurance, and advocacy.
VHL Alliance	vhl.org	Dedicated to improving the diagnosis, treatment, and quality of life for VHL (Von Hippel-Lindau disease) patients and their families.

### **Books**

Buddy Booby's BirthMark		
Mookey The Monkey Gets Over Being Teased		This is a list of books that are written specifically for children with vascular anomalies and their families.
Little Tree: A Story for Children with Special Medical Problems It's OK To Be Different!	amazon.com	
Hi, My Name is Jack (A Book for the healthy siblings of chronically ill children)		
I Still Dream Big Stories of Teens with Chronic Illness		
100 Questions & Answers About Vascular Anomalies		

### **Craniofacial**

SUPPORT ORGANIZATIONS		
AboutFace International	aboutfacecorp.com	Networking, information and support
Children's Craniofacial Association	ccakids.com	Information networking, and support for families
Craniofacial Foundation of America	craniofacialfoundation.org	Networking, information and support, some financial assistance
FACES — National Craniofacial Association	faces-cranio.org	Serves patients with severe craniofacial deformities resulting from birth defects, injuries, or disease. Addresses three distinct areas: client travel, public awareness and understanding, and information and support.  1-800-3-FACES-3
Foundation for Faces of Children	facesofchildren.org	Dedicated to improving the lives of children with craniofacial differences, including: cleft lip, cleft palate, and other head and facial conditions.

General Resources for all Patients Arts in Medicine

CLINICAL TRIALS		
American Childhood Cancer Organization	acco.org	Support organization with many publications, including: A Parent's Guide to Clinical Trials.  1-855-858-2226
Children's Oncology Group	childrensoncology group.org	The Children's Oncology Family Handbook is available through the social workers in the cancer center or you can download a copy from their homepage. See also, What Is A Clinical Trial? at <a href="mailto:childrensoncologygroup.org/index.php/what-is-a-clinical-trial">childrensoncologygroup.org/index.php/what-is-a-clinical-trial</a>
National Cancer Institute	cancer.gov	Clinical trial information  Children with Cancer: a Guide for Parents cancer.gov/publications/patient-education/guide-for-parents  When your Brother or Sister has Cancer: a Guide for Teens cancer.gov/publications/patient-education/sibling-has-cancer  Taking Part in Cancer Treatment Research Studies cancer.gov/publications/patient-education/cancer-treatment-research-studies  I-800-4-CANCER
Center Watch Clinical Trials Listing Service	centerwatch.com	Leading source of news, directories, for clinical research. Publications for patients and professionals  1-866-219-3440
Coalition of Cancer Cooperative Groups	cancertrialshelp.org	Awareness of clinical trials, search database
National Institute of Health	clinicaltrials.gov	Information about clinical trials
More Moments More Memories Foundation	MoreMomentsMore Memories.org	Provides grants for travel expenses to help people access oncology clinical trials for potentially life-saving treatment. Eligible applicants have been referred to a cancer clinical trial by a physician and demonstrate financial need. Eligible expenses include gas mileage, airfare or bus fare, lodging, and meal allowance during travel and treatment.

COUNSELING		
Al-Anon Intergroup	houstonalanon.org	12 step self-help group for those impacted by another's alcohol use. Also has group for adult children of alcoholics. ALATEEN and PRE-ALATEEN. Information on group locations.  713-683-7227
Alcoholics Anonymous	aahouston.org	12-step self-help group for those abusing alcohol. Call 24-hour number for nearest group meeting.  713-686-6300
Association for the Advancement of Mexican Americans	aama.org	Family and individual counseling (drug and alcohol), gay violence for adolescence, GED program, HIV testing, and Spanish speaking available 713-967-6700
Catholic Charities of Galveston — Houston	catholiccharities.org/our- services/strengthening- families/counseling- services/	Provides individual counseling at multiple locations. Spanish speaking available.  713-874-6590
The Center for Creative Resources	therapyhouston.org	Provides counseling for all areas of support. 713-461-7599
Center for Family Consultation	<u>cfctexas.com</u>	Counseling for individuals, families, adolescents, and children 713-526-4751
Community Family Centers	communityfamilycenter s.org	Provides family and individual counseling and substance abuse counseling primarily for Spanish speaking clients, but accepts all. Also offers counseling for youth with drug abuse, truancy, delinquency and teen pregnancy problems. Spanish speaking available.  713-923-2316
Depelchin	depelchin.org	Provides individual, family and group counseling for adults and children on a medical outpatient basis. Spanish speaking available. Accepts a range of private insurances, plus Medicaid and Chip.  713-861-8136

The HOPE Line	hhci.org	Offer clinical, medication and case management for mental health needs. Free service  • Clinical:  • CBT - 6 - 12 month wait list  • DBT- 13 plus month wait list  • Screening is completed to assess which services fit best  • Serve ages 18 plus. All services free, no insurance billed etc.  • Have support groups and helpline which have no wait time and can be initiated immediately  • Most services in person but some are virtual.  346-335-8625
Houston Area Women's Center	hawc.org	Provides shelter and counseling services for battered women and their children. Spanish speaking available. 713-528-6798
Houston Center for Christian Counseling	christiancounseling houston.com	Provides counseling services for individuals, marriage, and family. Also offer groups, workshops, and seminars.  281-398-0022
Houston Galveston Institute	talkhgi.org	Provides individual counseling and therapy for individuals and groups (on occasion). Spanish speaking available. 713-526-8390
Interface Samaritan Counseling Center	houstonsamaritan.org	Provides family and individual Christian counseling and workshops.  713-626-7990
Jewish Family Services	jfshouston.org	Provides counseling related to family problems and psychiatric evaluation.  713-667-9336
National Suicide Prevention Hotline	suicideprevention lifeline.org	24/7, free and confidential support line for people in distress, prevention and crisis resources for you or your loved ones, and best practices for professionals.  I-800-273-TALK

United Way Referral	unitedwayhouston.org/	Provides referral service. Spanish, French, Vietnamese, Cantonese, and Mandarin speakers available.
Service	our-211-helpline	
		713-957-4357

# **S**cholarships

Federal Student Aid	www.usa.gov/fafsa	Free application for federal student aid
The Gates Millennium Scholars	gmsp.org	Promotes academic excellence and provides an opportunity for outstanding minority students (African American, American Indian, Alaskan Native, American Asian, Hispanic American) with significant financial need to reach their full potential
National 4-H Council	4-h.org/resource- library/grants-awards	Grants, awards, and scholarships. They have disability specific scholarships.
Patient Advocate Foundation	patientadvocate.org	Scholarships based on need
Ronald McDonald House Charities National Scholarship Program	rmhc.org	Scholarships to students in financial need who have demonstrated academic achievement, leadership and community involvement. Since 1985, more than \$56 million in scholarships have been awarded.
The Joshua O'Neill and Zeshan Tabani Enrichment Fund	ndss.org	Offers financial assistance to young adults with Down syndrome who wish to enrich their lives by enrolling in postsecondary programs or taking classes that will help them gain employment, independent living skills, life skills, or others
Fastweb	www.fastweb.com	Free scholarship search platform that connects students to college scholarships, trade school scholarships and financial aid tools.
Hispanic Scholarship Fund	www.hsf.net	Scholars are selected based on merit. Award amounts range from \$500 - \$5,000 based on relative need.

## **S**chool

American Disabilities Act — Disability and Business Technical Assistant Center	ada.gov	Counseling, self-esteem classes, social skills training classes I-800-949-4232
Association on Higher Education and Disability	ahead.org	Parents of children can join (membership fees vary). Bimonthly newsletter Alert. Jobs postings, publications such as How To Choose A College 704-947-7779
Avance Houston	avancehouston.org	GED adult education, literacy classes, and job skills training 713-812-0033
Bridging Apps	bridgingapps.org	This mobile app is provided through Easter Seals and helps to identify apps that are helpful to kids with special needs—particularly kids with Down syndrome.  One particularly interesting app is the Storybook Maker which allows users to write, illustrate and publish their own storybook using text, photos, graphics and audio recordings. There are many uses for this app, but one we have found especially useful for children is a method for discussing upcoming changes in a schedule due to holidays or some other event that is out of the ordinary routine.
Career and Recovery Resources	careerand recovery.org	Job placement services, resume writing, job counselors available 713-754-7000
The College Resource Center	thecollegeresource center.com	Scholarship, grants, loans 713-783-7575
Community Family Center	communityfamily centers.org	GED classes, free service referral by Social Worker 713-923-2316

Council for Exceptional Children	cec.sped.org	Information for parents of gifted or handicapped children, ERIC clearinghouse  1-888-232-7733
Depelchin Children's Center	depelchin.org	Social skills groups, educational testing. Accepts insurance and has a sliding scale for families with limited income 713-730-2335
Disability Rights Education Defense Fund	<u>dredf.org</u>	A national civil rights law and policy center directed by individuals with disabilities and parents who have children with disabilities. Also operate an information line.  510-644-2555
Disability Rights Texas	disabilityrightstx.org	Free services for persons with disabilities. Services are divided by region. Legal assistance to people with disabilities who are experiencing problems due to disability, enforcement of ADA requirements, special education laws  1-800-252-9108
Ed White Youth Center		Regular school job skill training, GED classes, ages 16-21 child care, teen group, sliding scale 281-474-2853
Employment and Training Center	etchouston.com	GED and job placement, financial aid for college and vocational programs. 713-439-7530
Equal Employment Opportunity Commission	eeoc.gov	Publications, fact sheets, posters and a resource directory for people with disabilities.  1-800-669-4000
GED Hotline	gedtest.org	GED applications with a learning disability. Information on local GED classes, testing services and accommodations guide  1-800-626-9433
Head Start	eclkc.ohs.acf.hhs.gov/ hslc	Early Head Start program ages 0-3 and pre-k program. Ages 3 and 4 only, must meet income guidelines  1-866-763-6481

Greater Houston Area Home Educators	g-hah.org	Parents who are interested in home schooling their child. Volunteer board, home school information available, support groups, newsletter
Heath Resource Center	https://www.navigatel ifetexas.org/en/	Clearinghouse on post-secondary education for individuals with disabilities. Great resource. Puts out a publication for guidance counselors for working with students with disabilities  1-800-544-3284
HISD	houstonisd.org	All questions related to HISD. 713-556-6005
Homebound School Services	houstonisd.org/ Domain/15044	Children who are unable to attend school due to illness may utilize the Homebound Services Program. The paperwork must be completed by school and physician; contact your social worker and she/he can help you set it up.  713-967-5285
Learning Disabilities Association of America	https://ldaamerica.org	LDA has provided support to people with learning disabilities, their parents, teachers and other professionals with cutting edge information on learning disabilities, practical solutions, and a comprehensive network of resources.  412-341-1515
Learning Disabilities Association of Texas	ldatx.org	Maintains a database of professional service providers. Provides advocacy, information and referrals, school programs.
Meyer Center for Developmental Pediatrics at Texas Children's Hospital	www.texaschildrens. org	Diagnoses and evaluates developmental learning disorders referral by doctor, nurse practitioner, or social worker.  832-822-3400
National Center for Learning Disabilities	ncld.org	Information and referral service, educational programs, public outreach. Also provides a list of scholarships for students with learning disabilities.
Neuhaus Education Center	neuhaus.org	Professional teacher development, parent reference center, adult literacy classes — programs all related to reading success.  713-664-7676

Partners Resource Network	partnerstx.org	Families with a child who has a disability often need information about the disability of their child, about early intervention (for babies and toddlers), school services (for school-aged children), therapy, local policies, transportation, and much more  281-969-5944
Speech, Language and Learning Clinic at Texas Children's Hospital	texaschildrens.org/	Neuro-psychological evaluation, social skills groups, parenting classes referral by doctor, PNP, or social worker.  832-822-3700
Texas Education Agency	tea.state.tx.us	Provides leadership, guidance and resources to help schools meet the educational needs of all students and prepare them for success in the global economy.  512-463-9734

# **Vocational Training**

VOCATIONAL TRAINING HOUSTON AREA		
Houston Community College Vocational Advancement and Social Skills Training	hccs.edu	Educational opportunities for individuals with developmental and learning disabilities. Courses offered include: Academic Skills, Career Vocational, Independent Living and Life Math Skills.  713-718-6000
Houston Center for Independent Living	<u>hcil.cc</u>	Provides information and referrals, peer support, and independent living skills training 713-974-4621
Texas Department of Assistance and Rehabilitation Services	www.sunset.texas.go v/reviews-and- reports/agencies/dep artment-assistive- and-rehabilitative- services	Provides services for persons with physical and mental disabilities. Programs include vocational rehabilitation, transition planning, employment, and Independent living 713-267-3470
Texas Workforce Commission	twc.state.tx.us/jobsee kers/career-schools- colleges-students	Career guidance, school and college information for all students. 512-936-3100
The Arc	thearc.org	Provides resources and advocacy for those with developmental disabilities as well as for their families and caretakers. Offers information, referral services, parent support groups and training, mentoring programs, social programs, advocacy, etc. They also provide weekend activities and summer camps.  713-957-1600

VOCATIONAL TRAINING NATIONAL		
American Civil Liberties Union	aclu.org	For almost 100 years, the ACLU has worked to defend and preserve the individual rights and liberties guaranteed by the Constitution and laws of the United States.  212-549-2500
Children's Brain Tumor Foundation	cbtf.org	Brings survivors together and to help survivors deal with the social challenges that brain tumor survivor's experience, including: career, employment, educational advocacy, cognitive challenges, health insurance problems and independent living issues.  1-866-228-4673
Job Corps	https://www.jobcorps .gov/	Free job training program for all young adults ages 16 – 24. Learn a career and earn a high school diploma or GED. Includes health insurance and living stipend.

Texas Children's Cancer and Hematology Center offers an annual memorial service for families of children that were treated at Texas Children's Hospital. 832-822-4564.

#### **Bereavement**

Organization	Website	Spanish Speaking	Service
Abby's Gift	abbysgift.org	No	Created to help other families with a critically or terminally ill child.  281-731-0713
American Hospice Foundation	americanhospice.org/working- through-grief	No	Brochures on hospice, what to ask, etc. 713-792-7184
Bo's Place	bosplace.org	Yes	Free grief support groups for children ages 3-18 and their families who have experienced the death of a child or adult in their immediate family.  713-942-8339
Cancercare	cancercare.org	Yes	Online support forums led by professional oncology social workers who offer support and guidance. Groups are held for 15 weeks and registration is required.  1-877-969-0010
Clayton Dabney Foundation	claytondabney.org	Yes	Assistance in creating everlasting memories to families with children in the last stages of terminal cancer.  713-488-4096
Comfort Ability	thecomfortability.com	Online	Information about coping strategies and skills to manage chronic pain. List of resources, coping stories and guided exercises

Compassionate Friends	compassionatefriends.org	Yes	Newsletter, information, support groups, resource catalog. Multiple locations. 713-730-2335
Courageous Parents Network	courageousparents network.org	Yes	To empower, support, and equip families and providers caring for children with serious illness.
Family 2 Family	cbtf.org	No	Connects bereaved parents and family members to bereaved mentors. 713-467-7423
Grief Recovery Center	griefrecoveryhouston.com	Yes	Grief counselors who provide individual therapy, family therapy, grief counseling and a full 70-week grief recovery course.  832-906-7250
Houston Hospice Butterfly Program	houstonhospice.org	Yes	Bereavement services for parents, siblings, and loved ones are offered through their Butterfly Program.  713-526-8390
Houston Galveston Institute	talkhgi.org	Yes	Offers individual and family counseling on a sliding scale. 713-944-6569
Kyssi Andrews Foundation for Pediatric Cancer	kyssiandrewsfoundation.org	No	Provides financial assistance, emotional support, grief counseling and burial assistance.  media@kyssiandrewsfoundation.org
Project Joy and Hope	joyandhope.org	No	Support group for parents who have lost a child. 713-944-6569

## Hospice

HOSPICE EDUCATIONAL RESOURCES		
Bo's Place	bosplace.org	Bereavement center. Offers publications and resources surrounding grief. 713-942-8339
Children's Hospice International	chionline.org	Educational resource on hospice care and kids. Some to print and some to order for fee.  703-684-0330
Compassionate Friends	www.compassionatef riends.org	Local self-help groups of bereaved parents and siblings offer mutual support. Free. Some publications  1-877-969-0010
National Hospice and Palliative Care Organization	caringinfo.org	Information on hospice, grief and loss 703-837-1500

HOSPICE SUPPORT ORGANIZATIONS		
Abby's Gift	abbysgift.com	Created to help other families with a critically or terminally ill child. Assists with financial and practical expenses surrounding a child on hospice.  281-731-0713
Caring Connections	caringinfo.org	A program of the National Hospice and Palliative Care Organization that provides free resources to help people make decisions about end-of-life care and services.  1-800-658-8898
Cherish The Moments with Love	facebook.com/ cherishthemoments withlove	Photograph and video record beautiful moments of someone suffering a terminal illness.

Children's Hospice International	chionline.org	Referral source, publications 703-684-0330
Compassion Hospice	compassion hospice.org	Hospice Care for Orange, Chambers, Hardin, Galveston, Newton, Jasper, Tyler, Polk, Liberty and San Jacinto 409-835-8357
Compassionate Care Hospice	www.hospicecompas sionatecare.com	Hospice enables patients to continue an alert, pain-free life and to manage symptoms so that their last days may be spent with dignity and quality, surrounded by loved ones.  1-866-535-3247
Crown Hospice	crownhospice.com	Group has nurses with pediatric background. Counties served: Montgomery, San Jacinto, Polk, Liberty, Trinity, Walker, Waller, part of Harris.  361-575-5900
HeartsWay Hospice of Northeast Texas	heartswayhospice.org	Counties served: Harrison, Cass, Marion, Morris, Rusk, Panola, Shelby, Nacogdoches, Gregg, Upshur, Smith, Hopkins. 903-295-1680
Home Care and Hospice Agency Locator	nahc.org/services	The most comprehensive database of more than 33,000 home care and hospice agencies. Use this resource to find all the agencies in any particular area of the country.
Hospice Education Institute	heretoserve.org/reso urces/hospice- education-institute	Information about hospice services throughout the US  1-800-331-1620
HospiceLink	hospicelink.com	Information on hospice services throughout the US I-877-325-4032
Hospice Brazos Valley	hospicebrazos valley.org	Locations in Bryan, Brenham and La Grange. 979-821-2266 (Bryan location)

Hospice of East Texas	hospiceofeast texas.org	Coping with terminal illness presents many challenges – physical, emotional, social and spiritual. The caring, experienced team of professionals at The Hospice of East Texas is prepared to meet those challenges, and believes that no one, regardless of age, illness or financial circumstances, should have to face death alone or in pain.  903-266-3400
Hospice of the Pines	hospiceinthepines.org	Inpatient facility or home care services 936-632-1514
Houston Hospice	houstonhospice.org	Provides compassionate physical, social and spiritual support to individuals with a life-limiting diagnosis, and their loved ones, irrespective of their ethnicity or beliefs.  713-468-2441
Operation Snowdrop	operation snowstorm.org	Provides a winter wonderland to those children with cancer on hospice.

FERTILITY		
American Cancer Society	cancer.gov	Offers information regarding the effects of cancer treatment on fertility and methods to preserve fertility.  I-800-4-CANCER
American Society of Clinical Oncology - Patient Guide on Fertility Preservation	cancer.net	Search "fertility" and it will bring up a guide
American Association of Tissue Banks	aatb.org	Information on sperm banking 703-827-9582
American Cancer Society	cancer.org	Information on sexuality issues and cancer I-800-227-2345
American Society of Reproductive Medicine	reproductivefacts.org	Information on reproductive issues 202-863-4985
Cancer net	cancer.net/navigating- cancer- care/children/preserving- fertility-children-cancer	Preserving fertility in children with cancer
Children's Oncology Group	survivorshipguidelines.org	Guidelines for reproductive health issues facing adolescents & young adults. Please review with health care provider.
Fertility Issues in Girls and Women with Cancer	cancer.gov/about- cancer/treatment/side- effects/fertility-women	Article by the National Cancer Institute that describes fertility issues in girls and women with cancer. Discusses fertility preservation options and support resources  1-800-4-CANCER
Fertility Preservation	reprotech.com/fertility- preservation-101.html	Fertility preservation booklet (published by Reprotech) for both boys and girls who have undergone cancer treatment.

Fertility Preservation	fertilitypreservation.com	Explanation of various fertility preservation options. This website offers explanations for various procedures and additional resources
Genetics and In Vitro Fertilization Institute	givf.com	Information on ovary freezing and reproductive issues
<b>ISaveFertility</b>	iPhone app	Free iPhone app that has fact sheets on fertility and hormonal health after cancer treatment, as well as provider pocket guides for fertility preservation options
Livestrong	livestrong.org/what-we-do/program/fertility	Fertility assistance and information
National Infertility Network Exchange	nine-infertility.org	Offers support groups, resource materials, and provides professional referrals to find doctors, IVF/GIFT centers, attorneys, and counselors.  516-794-5772
Oncofertility Consortium	oncofertility.msu.edu	Provides information about fertility preservation options, connect with a patient navigator and search a database of providers.  866-708-FERT
Path 2 Parenthood	path2parenthood.org	Information on fertility and egg freezing, etc.
Plan Now, Parent Later	aphon.org/education/patient -family-resources	Fertility guide for males and females published by the Association for Pediatric Oncology Nurses
Save My Fertility	savemyfertility.org	Resource for adult cancer patients and the parents of children with cancer who want to learn more about preserving their fertility before and during cancer treatment and protecting their hormonal health after treatment.  312-503-2504

Worth The Wait	https://worththewaitcharity.com/	Mission is to ease the burden for young adult cancer patient/survivors pursuing parenthood by providing financial support for fertility treatments, adoption and surrogacy. Eligibility requirements: ages 13 – 39, family income requirement, two types of grants: emergency preservation and family building.
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SUPPORT ORGANIZATIONS / FINANCIAL ASSISTANCE		
Fertility Within Reach	fertilitywithinreach.org	National non-profit organization providing fertility preservation education and financial assistance. They will pay for fertility storage with select preservation centers. Ages up to 21.  857-636-8674
Livestrong Financial Assistance	livestrong.org/fertile hope	Fertility Discount Programs to provide financial assistance to cancer patients seeking fertility preservation services. Will discount fee for overnight male kit. Ages 18+
Reprotech Overnight Male Kit	overnitemalekit.com	Sperm collection option from the privacy of your home. The kit includes everything needed to store sperm: required testing, shipping and storage for one year. Through Reprotech company.  1-888-586-3389
The Sam Fund	thesamfund.org/get- help/grants/	The SAM Fund provides scholarships to young adult cancer survivors for a wide range of cancer-associated costs. They offer two categories of family building grants: Storage of eggs, embryos, or sperm (up to \$1000.00) and Expenses for fertility procedures such as testing, IUI, IVF, gestational carrier, adoption, etc. (up to \$4000).
Team Maggie	teammaggieforacure .org	The Team Maggie for a Cure Grant is available to uninsured/underinsured USA residents who are receiving treatment for cancer. Participants must complete an application form and provide documentation of financial need and medical treatment. Up to \$2500 for fertility preservation. Ages 15 - 38
Verna's Purse	reprotech.com/images/docs/vp_fa_application_semen.pdf	Reprotech has a financial assistance program called Verna's Purse. Short application required and must submit a 1040 form. Qualifying applicants would pay a fertility storage fee of \$75 a year. Ages 21+

### **Financial Assistance**

Many of these organizations require a social work referral. Speak with your social worker for more information about availability and specific requirements for each organization.

Andre Sobel River Foundation	compassioncantwait.org	Financial assistance program for single parent families who have a child in medical crisis. Application required.
Assistance League of Houston	assistanceleague.org/ houston	Serves the educational and emotional needs of disadvantaged children and young adults, as well as families in crisis in the greater Houston area.  713-526-7983
Catholic Charities	catholiccharities.org	Provides food, clothing and shelter for people in need and a network of services supporting infants to seniors.  713-874-6590
Community Living Assistance and Support Services	hhs.texas.gov/doing- business-hhs/provider- portals/long-term-care- providers/community- living-assistance-support- services-class	Provides home and community-based services to people with related conditions as a cost-effective alternative to an intermediate care facility for individuals with an intellectual disability or related conditions (ICF/IID). A related condition is a disability, other than an intellectual disability, that originated before age 22 that affects the ability to function in daily life.
Gia Nicole Angel Foundation	joniandfriends.org	Awards assistance through purchase of specific items for children with physical disability  1-800-736-4177
HelpHopeLive	helphopelive.org	Provides small grants, information and support for fundraising and patient awareness.  1-800-642-8399
Immune Deficiency Foundation	primaryimmune.org	Dedicated to improving the diagnosis, treatment and quality of life of persons with primary immunodeficiency diseases through advocacy, education and research. This group has a patient advocate to help with insurance companies and getting them to pay, etc.
Lifeline Chaplaincy	lifelinechaplaincy.org	A ministry of the Churches of Christ that places a high emphasis on supportive care of members and community.

Medically Dependent Children Program	hhs.texas.gov/doing- business-hhs/provider- portals/long-term-care- providers/medically- dependent-children- program-mdcp	Provides services to support families caring for children and young adults who are medically dependent and to encourage de-institutionalization of children in nursing facilities. Texas Department of Aging and Disability Services employees provide case management services
Social Security Disability	ssa.gov/disabilityssi/ apply-child.html	At this time, only the Child Disability Report can be completed online. Contact them by phone or in person to schedule an appointment to complete the SSI application.
Temporary Assistance for Needy Families	acf.hhs.gov	Designed to help needy families achieve self-sufficiency. States receive block grants to design and operate programs that accomplish one of the purposes of the TANF program.
Special Supplemental Nutrition Program for Women, Infants, and Children	fns.usda.gov/wic/women- infants-and-children-wic	Provides federal grants to states for supplemental foods, health care referrals, and nutrition education for low-income pregnant, breastfeeding, and non-breastfeeding postpartum women, and to infants and children up to age five who are found to be at nutritional risk.

GRANTS		
Financial Counselors at Texas Children's Cancer and Hematology Center		Oncology 832-822-3483  BMT 832-826-5527  Hematology 832-822-1430
Aubrey Rose Foundation	aubreyrose.org	Assists families with medical expenses.
Modest Needs	modestneeds.org	Assists families who don't qualify for conventional types of social or charitable assistance, and who are facing a financial crisis because they've encountered a single, unexpected expense they just can't afford on their own.
Maggie Welby Foundation	maggiewelby.org	Provides grants to families in need 314-330-6947

United Healthcare Children's Foundation	uhccf.org	Provides medical grants to help children access health-related services not covered, or not fully covered, by their parents' commercial health insurance plan. Families can receive up to \$5,000 annually per child (\$10,000 lifetime maximum per child). See your social worker for assistance applying
		I-855-MY-UHCCF

## Insurance

		Incurance information publications on incurance and conserve
American Cancer Society	cancer.org	Insurance information, publications on insurance and cancer 713-266-2877
American Childhood Cancer Organization	acco.org	Helps parents and childhood cancer survivors exercise their rights under the law.  1-855-858-2226
American Council of Life Insurance	acli.com	Information about insurance questions 202-624-2000
American Family Life Assurance Council (AFLAC)	aflac.com	Offers ways to buy supplemental health insurance.  1-800-992-3522
American Health Insurance Plans	ahip.org	Insurance industry trade association that will provide information on insurance and health care issues  202-778-3200
Centers for Medicare and Medicaid Services	cms.gov	Information on Medicaid programs and benefits  1-877-267-2323
Department of Health and Human Services Hotline for the Office of the Inspector General	oig.hhs.gov/fraud/ report-fraud	Hotline for complaints about Medicaid. Provides assistance with issues of entitlements, benefits, insurance, and community resources.  1-800-447-8477
Family Law Hotline		Attorney advises persons on legal rights and possibly other legal resources available  I-800-777-FAIR
Medical Care Management Corporation	mcmcllc.com	Helps families work with insurance companies on paying for necessary treatment including hematology, phase I, BMT, etc.  1-800-227-1464

National Association of Insurance Commissioners	naic.org	Offers help with situations in which you feel you or your family are not being treated fairly by your insurance carrier.  816-842-3600
National Coalition for Cancer Survivorship	canceradvocacy.org/ resources/health- insurance	Information on health care for cancer survivors 301-650-8868
National Patient Advocate Foundation	npaf.org	Provides legal consulting and referral service for patients confronting denial of insurance coverage or need for negotiating support for public assistance through both state and federal agencies.  202-347-8009
Patient Access Network (PAN) Foundation	panfoundation.org	PAN has provided nearly one million underinsured patients with over \$2.6 billion in assistance in over 60 disease-specific programs, hemophilia being the newest.  Patients who qualify for their Hemophilia Premium Assistance Program are eligible to receive \$4,500 per year. Eligible patients must reside and receive treatment in the U.S. and have health insurance. Several informative publications are available to download, including: Nose Bleeds, The Child with A Bleeding Disorder: Guidelines for Finding Childcare, Family Emergency Kit Checklist, and more.
Social Security Administration	ssa.gov	Provides benefits to persons who can't work. Eligibility for social security benefits often means you may qualify for other programs or benefits.  1-800-772-1213
Texas Dept. of Insurance - Risk Pool	tdi.texas.gov	Call for details about insurance for anyone
Houston Volunteer Lawyers	https://www.makejust icehappen.org/	Assistance with legal rights, insurance issues 713-228-0732

WealthMark Advisors	wealthmark advisors.com	Helps you figure out a plan for insurance. They underwrite individual policies and temporary insurance, if needed.  I-800-274-2844
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# **Medical Equipment Assistance**

Challenged Athletes Foundation	challenged athletes.org	Provides opportunities and support to people with physical challenges, so they can pursue active lifestyles through physical fitness and competitive athletics. CAF believes that involvement in sports at any level increases self-esteem, encourages independence and enhances quality of life  858-866-0959
Chariots of Hope	https://cpfamilynetwo rk.org/	Collects used wheelchairs and repairs and distributes them with no cost to recipient. Driver's license required. 860-242-4673
Cody's Wheels of Hope	cwoh.org	Any child, age 15 or under, suffering from a life-threatening illness is eligible for a bike, scooter, trike etc. Application on website.
Friends of Man	friendsofman.org	Assists with medical and mobility equipment and prosthesis
McLindon Family Foundation	mclindonfamilyfounda tion.org	Provides special needs children with adaptive bikes
MY GYM Challenged America	mygymfoundation.org	Provides equipment and services to improve quality of life of children coping with chronic illness and/or are physically or developmentally challenged  818-907-6966
Project Mend	projectmend.org	Refurbishes mobility devices and assists families with medical equipment needs.  210-223-MEND
Ramps.org	ramps.org	Connects those in need of a wheelchair ramp with the necessary suppliers and installers  847-680-7700
Ride to Give	ridetogive.com	Raise funds for medical equipment, travel expenses, and other out of pocket costs related to having a medically fragile child

Stepping Stones for Stella	community- links.net/resources/c ommunity- directory/17663/step ping-stones-for-stella	Provides buggies to children with disabilities to ensure they and their families experience the freedom of being outdoors
United Health Care Children's Foundation	uhccf.org	Financial assistance grants for families with children that have medical needs not covered or not fully covered by their health insurance. They aim to fill the gap between what medical services/items a child needs and what their commercial health benefit plan will pay for. 16 years old and younger.
Variety — The Children's Charity	usvariety.org	Provides equipment and services for mobility, independence and social inclusion. 323-954-0820
Wheelchairs For Kids	wheelchairs4kids.org	Provides custom wheelchairs, widens doors, builds ramps and provides wheelchair lifts and carriers for vehicles. Other services include standers and gait trainers.  727-946-0963

## **Medication Assistance**

Amgen	www.amgen.com/abo ut/how-we- operate/policies- practices-and- disclosures/transpare ncy- disclosures/donation- and-grant-recipients	A variety of patient assistance programs. Amgen makes the drugs Aranesp, Neulasta, Neupogen, Nplate and Epogen.
Bridges To Access	bridgestoaccess.com	A patient assistance program that provides GlaxoSmithKline prescription medicines to qualified patients who need help paying for treatment.
Community Assistance Program	caprxprogram.org	The Community Assistance Program (CAP) prescription discount card saves cardholders an average 15% on brand name medications and 55% on generic medications. The cards are accepted at over 80% of pharmacies in the US and its territories, including Puerto Rico. Anyone may use the card, regardless of age or income.  1-888-311-6224
Good Rx	goodrx.com	Prescription drug savings. Compare prices, print free coupons and save money.
Health Well Foundation	healthwell foundation.org	Assists patients living with chronic and life-altering illnesses in paying prescription drug copayments, deductibles, and health insurance premiums.
National Children's Cancer Society	thenccs.org	Services include: an online support network for parents of children with cancer, educational materials, and financial assistance for treatment-related expenses. Printable publications. They partner with Agility, a national provider of discount prescription drug cards.
NeedyMeds, Inc.	needymeds.org	Information about patient assistance programs which provide no cost prescriptions to eligible participants
Patient Advocate Co- Pay Relief	copays.org	Financial assistance to qualified patients, with prescription drug co-payments their insurance requires relative to their diagnosis. Call counselors work directly with the patient and physician to obtain medical, insurance and income information to expedite the process.

Patient Services, Inc.	patientservicesinc.org	Helps chronically ill patients locate health insurance, subsidize the cost of health insurance premiums, obtain pharmacy and treatment co-payment assistance, assisting with Medicare Part D Co-insurance, and advocacy for Social Security Disability.
Partnership for Prescription Assistance	pparx.org	Single point of access to more than 275 patient assistance programs, including over 150 offered by pharmaceutical companies.
Pfizer RSVP	www.rxresource.org/ prescription- assistance/pfizer- rsvp-program.html	Reimbursement solutions, verification, and payment HELPline. Program to help both insured and uninsured patients access Pfizer medicines (including Rapamune/Sirolimus).  1-888-773-0121
Pharmaceutical Research and Manufacturers of America	pparx.org	Offers a single point of contact to access over 475 public and private prescription assistance programs.  1-888-477-2669
RxAssist Volunteers in Health Care	rxassist.org	Search engine for patient assistance programs that offer free medication to patients in financial need; downloadable information packet describing options for assistance.
RxHope	www.rxhope.com	Helping hand to people in need of obtaining critical medications that they are unable to afford.
RxOutreach	rxoutreach.com	A non-profit pharmacy whose mission is to provide affordable medications.
ScriptSave	scriptsave.com	Prescription drug saving program; a discount card for numerous participating pharmacies providing savings through membership to individuals without consideration of income.
Safety Net	safetynet foundation.com	Program to held with drug reimbursement for Amgen medicines (Neulasta and others)

HEARING		
AG Bell College Scholarship Program	agbell.org	AG Bell Scholarships are for high-achieving students who have bilateral hearing loss that was diagnosed before age 4.
American Society for Deaf Children	deafchildren.org	Provides education and online support for parents and families of deaf children.  I-800-942-ASDC
Apraxia Kids	apraxia-kids.org	Awards iPads and protective cases to kids for aid in communication.
Better Hearing Institute	betterhearing.org	Provides publications, financial assistance information related to hearing loss.  202-975-0905
The Center for Hearing and Speech	centerhearingand speech.org	Birth to 18 years who have speech and language delays relating to hearing impairment.  713-523-3633
Ear Community	starkeyhearingfoundation. org	Supportive community for individuals with varying degrees of hearing loss. Resources available for school, financial assistance, and more. Hear now is the assistance program for hearing aides.  1-800-328-8602
Hearing Aid Express	hearingaidexpress.com	Retail provider of hearing aids, hearing aid repairs and batteries. Multiple locations.  1-888-259-2126
Hike Fund	thehikefund.org	Provides hearing devices for children in need.
Miracle Ear Foundation	miracle-ear.com	Provides hearing aides to those in need.  1-877-632-6320

National Association of the Deaf	nad.org	Works to protect the civil rights of deaf individuals. Provides an information center and the answers to many questions regarding rights of the deaf in the work force.
National Scholarship for Deaf Students	collegescholarships.org/sc holarships/deaf.htm	Scholarship programs exist for students with every level of hearing loss, and are supported by a variety of national organizations and advocacy groups, as well as by colleges and universities across the country. Requirements and award amounts will vary greatly according to program.
Self Help for Hard of Hearing People, Inc.	hearingloss.org	Provides links, education and advocacy for the hard of hearing.
SERTOMA - Service to Mankind	sertoma.org	Offers scholarships to individuals with hearing impairments and communicative disorders. Scholarships are available in \$1,000 amounts
Audiology Center at Texas Children's Hospital	www.texaschildrens.org/d epartments/ear-nose-and- throat-otolaryngology	Identifies, evaluates and provides habilitation of hearing impairment in children.
Texas Department of Assistive and Rehabilitative Services- Deaf and Hard of Hearing	www.sunset.texas.gov/reviews-and-reports/agencies/department-assistive-and-rehabilitative-services	Links to programs and resource information for the deaf and hard of hearing in Texas.
Texas School for the Deaf	www.tsd.state.tx.us	Provides education for children with hearing loss. Also provides residential facilities for school aged children.
Travelers Protective Association Trust for Deaf	tpahq.org/scholarshiptrust. html	Provides assistance for mechanical devices, medical care, and/or specialized education or treatment, to those who demonstrate financial need. U.S. citizens only. Grants may be used to purchase hearing aids, assistive listening equipment, or may help with the cost of a cochlear implant.

HOTELS			Ask for the medical rate!
Aishel House	aishelhouse.org	Apartment style hotel with shut	tle service
Americas Best Value Inn Medical Center Downtown	www.redlion.com/am ericas-best-value- inn/tx/houston/ameri cas-best-value-inn- medical-center- downtown	A few rooms have kitchen, no s 2419 Riverside Dr. Houston, TX 77004	huttle <b>L</b> 281-974-4432
Astro Best Motor Inn	astrobestinn.com	Hotel, no shuttle, no kitchen 9430 S. Main St. Houston, TX 77025	<b>L</b> 713-668-0691
Braeswood Park Condiminiums	braeswoodpark.org	Apartments, shuttle to medical of 2255 Braeswood Blvd. Houston, TX 77030	center; kitchen. <b>1</b> 713-797-0662
Econo Lodge Medical Center	choicehotels.com/ texas/houston/ econo-lodge-hotels	Hotel with microwave and refrig 7905 S. Main St. Houston, TX 77025	gerator <b>5</b> 713-667-8200
Doubletree by Hilton Hotel & Suites Houston By the Galleria	doubletreesuites houston.com	Hotel with kitchen, shuttle servi 5353 Westheimer Rd. Houston, TX 77056	Ce \$\int 713-961-9000\$
Hampton Inn & Suites Houston Medical Center/Reliant	www.hilton.com/en/hotels/houmdhx-hampton-suites-houston-medical-center-nrg-park	Hotel with kitchen and shuttle s 1715 Old Spanish Tr. Houston, TX 77054	ervice \$\frac{1}{6} 713-797-0040

Holiday Inn NRG Arena	ihg.com/holidayinn/ hotels/us/en/houston/ houad/hoteldetail?cm _mmc=GoogleMaps- HIUSA HOUAD	Hotel with no kitchen. Provides shuttle service to medical center.  8111 Kirby Dr. Houston, TX 77054
Extended Stay America - Houston Medical Center - NRG Park - Fannin	www.extendedstaya merica.com/hotels/tx /houston/med-ctr- reliant-pk- braeswood- blvd?propertyCode= EA%3BHFHS&checkI n=2024-04- 21&checkOut=2024- 04- 22&rooms=1&adults =2&children=0&rate Type=ESH&code=&r ate=Best Available Rate&accessible=off& mid=nmeta- Google&iata=HSD11 500&dclid=ClrFxuek q4QDFdPPTwldYs0L rw&com.dotmarketin g.htmlpage.language= 1	Hotel with kitchen and shuttle service  7979 Fannin St. Houston, TX 77054
Hilton Houston Plaza/Medical Center	hilton.com	Hotel with no kitchen. Provides shuttle service to medical center.  6633 Travis St. Houston, TX 77030
Crown Plaza Houston Near Reliant - Medical	www.ihg.com/crown eplaza/hotels/us/en/h ouston/hougp/hoteld etail	Hotel with no kitchen. Provides shuttle service to medical center.  8686 Kirby Dr. Houston, TX 77054
Mainstay Suites Texas Medical Center/Reliant Park	www.choicehotels.co m/texas/houston/mai nstay-hotels/tx933	Hotel with kitchen and shuttle service  3134 Old Spanish Tr. Houston, TX 77054

Country and Hauston	www.marriott.com/e n-us/hotels/houbs-	Hotel with kitchen and shuttle service
Courtyard Houston - West University	courtyard-houston- rice- university/overview	2929 Westpark Dr.
Houston Marriott Medical Center	marriott.com/hotels/ travel/houmc- houston-marriott- medical- center/?scid=bb1a189 a-fec3-4d19-a255- 54ba596febe2	Hotel with kitchen and shuttle service  6580 Fannin St. Houston, TX 77030
Lexington Hotel – Houston Medical Center	lexingtonhotels.com/ property.cfm?idp=22 021&rcode=sim2016	Hotel with kitchen and shuttle service  1025 Swanson St. Houston, TX 77030
Spring Hill Suites Houston Medical Center/NRG Park	marriott.com/hotels/t ravel/hourp- springhill-suites- houston-medical- center-nrg-park/	Hotel with kitchen and shuttle service  1400 Old Spanish Tr. Houston, TX 77054
Quality Inn & Suites NRG Park	choicehotels.com/ texas/houston/quality -inn- hotels/txc23?source= gyxt	Shuttle service; contract with Medicaid  2364 South Loop W. Houston, TX 77054
Residence Inn Houston Medical Center/NRG Park	marriott.com/hotels/t ravel/houas- residence-inn- houston-medical- center-nrg-park/	Hotel with kitchen and shuttle service  7710 S. Main St. Houston, TX 77030  Contract with Texas Children's
Residence Inn Houston West University	marriott.com/hotels/t ravel/houbf- residence-inn- houston-west- university/	Hotel with kitchen and shuttle service  2939 Westpark Dr. Houston, TX 77005

Spring Hill Suites	marriott.com/hotels/t	Hotel with kitchen and shuttle service	
Houston Medical Center/NRG Park	springhill-suites- houston-medical- center-nrg-park/	1400 Old Spanish Tr. Houston, TX 77054	713-796-1000
Wyndham Houston Medical Center	www.wyndhamhotels .com/wyndham/houst on-texas/wyndham- houston-near-nrg- park-medical- center/overview	Hotel with shuttle service, no kito 6800 Main St. Houston, TX 77030	chen \$\bigs\\ 713-528-7744
Rodeway Inn & Suites	www.choicehotels.co m/texas/houston/rod eway-inn- hotels/tx448	Hotel with kitchen and shuttle se 6712 Morningside Houston, TX 77030	rvice \$\bigs\ 713-663-6200

HOUSING GENERAL HOUSING		
American Cancer Society	www.cancer.org/supp ort-programs-and- services/patient- lodging.html	Free hotel lodging for 4 nights/15 nights per year. Needs 2-3 weeks notice. Some restrictions may apply. Also has a partnership with Extended Stay America for some lodging assistance. It is limited and something that the family or adult patient has to apply to directly.  1-800-227-2345
Angel House at St Dominic Village	www.stdominicvillage .org/angel-house	This is an extension of the St. Dominic Village Senior Care Community and offers room rentals for \$75 per night. Sleeps up to three individuals with Chapel on site. No kitchen.
A Shelter for Cancer Families	www.cancerfamilies.o	One and two bedroom apartments offered to out of town patients and families receiving cancer treatment at the Texas Medical Center. Must be US citizen or legal resident, must be from out of town, background check required, maximum 8 weeks. There is a security deposit and cleaning fee. No daily fees.
Ballard House	www.theballardhouse .org	Provides a private room and bathroom at a shared house to patient and families who are receiving treatment for a life threatening or critical illness. Background check required, accommodate up to 4 individuals including patient/caregiver, patient or caregivers must be 18 years plus. No cost. Referral must come from social worker.
Dan's House of Hope	danshouseofhope.org	Private room and bathroom, shared communal spaces. For oncology patients ages 15 – 39 only and limited to patient and one caregiver. No cost, minimum of 5 nights with maximum of two months.
Faith House	faithhouse houston.org	\$35 daily. Refundable \$100 deposit. 8 days-4 months 713-664-3048
Halo House Foundation	halohouse foundation.org	Families with child undergoing leukemia or lymphoma treatment may apply to stay at an apartment through this foundation. Speak with social work about getting on the waiting list. They are currently fundraising however, they have apartments that are available for leukemia/lymphoma and myeloma families. Their wait list can be long, per social work so typically they have been encouraging them to get on the wait list early. Must live 50 plus miles away, background check required, and other restrictions.

Hope Lodge	www.acsresources.or g/uncategorized/hope -lodge	Provides rooms with shared communal spaces while individuals are receiving outpatient cancer treatment. This is a free service but limited to patient and one caregiver.  800-227-2345
Hospitality Apts.	hospitality apartments.org	Free housing for 3 months. Some restrictions may apply.  Apartments have a max of 4 people. Children under 18 cannot stay unless they are the patient as they do not have facilities for children. They have about a three-month wait-list and a three-month maximum stay. Check out joeshouse.org for a list of possibilities (choose "TX" and then "Houston metro.")  713-790-9120
Healthcare Hospitality Network	www.hhnetwork.org	Provides free or significantly reduced cost lodging to patient and families while receiving medical care away from home. Some restrictions may apply.  1-800-542-9730
Houston Haven	www.houstonhaven.c om	Provides homes of varying sizes to patients undergoing active treatment. Background check required. Daily fee of \$20 - \$35 depending on the size of the home. Cleaning fee of \$120.
Joe's House	joeshouse.org	Online directory of places to stay that are near hospitals and cancer treatment centers, which offer discounts to family members and caregivers. The site is designed for patients/families to search the list of lodging options and find the best lodging solution for their situation.
Medical Accommodations	medicalaccommodati ons.com/	These apartments offer the comforts of home: fully-equipped kitchens, in-unit laundry, free parking and WiFi, along with cozy linens and cookware. Enjoy ease of access with stair-free entries and relax in power-lift-recliners. With discounted medical rates, clean spaces are locally owned and expertly managed. Fees subject to apartment chosen.  888-900-2559
InSpirit Patient Housing	app.inspirithousing.or g/user/apply	Fully furnished 1 or 2 bedroom apartments that are leased and maintained by volunteers. Able to accommodate 4 – 5 individuals including patient and caregiver. May require a background check. Daily rate is \$45 - \$70. If unable to complete online form, may request to complete by phone by completing a contact request at: <a href="https://www.inspirithousing.org/contact">https://www.inspirithousing.org/contact</a>

Project Joy and Hope: Tulip Project	joyandhope.org	3 bedroom duplex homes for children/adolescence with life limiting illness and their families. Can accommodate entire family. Requires SSN and current photo ID for all adults 18 plus. Monthly service fee of \$450. Social worker must refer family.
Ronald McDonald House Charities Greater Houston	rmhc.org	Housing for families and patients. Some restrictions may apply. 713-795-3500

PALLIATIVE CARE		
Caregiver Action Network	caregiveraction.org	Education, support, respite care and advocacy for caregivers.  Toll-free information line provides referrals to caregiver support groups and a caregiver resource guide.  1-855-227-3640
Caregiver Survival Resources	caregiver.com	Provides education, support and guidance for family and professional caregivers. They produce <i>Today's Caregiver</i> magazine, the first national magazine dedicated to caregivers, the "Fearless Caregiver Conferences", and a website, which includes topic-specific newsletters, online discussion lists, back issue articles of the magazine, chat rooms and an online store.
Compassionate Friends	compassionatefriends .org	Provides hope, comfort, and support to families experiencing the death of a child, sibling, or grandchild and helps others assist the grieving family. Offers brochures, sibling chats, cyber friends, and pen pals to people suffering the loss of a child.  1-877-969-0010
Growth House	caringcommunity.org/ self- help/compendiumsgui des/growth-house	Online community for end-of-life care. Offering resources to improve the quality of compassionate care for people who are dying. Links to home care, pain management, quality of life issues and grief.
Cure Search	curesearch.org	Website provides information and resources to help with end- of-life grief. Resources about end of life, recent death, and months or years after death.
National Hospice and Palliative Care Organization	nhpco.org/pediatric	NHPCO is committed to improving access to hospice and palliative care for children and their families—both nationally and internationally. Brochures for family and more.  703-837-1500
National Institute of Nursing Research	ninr.nih.gov/newsandi nformation/conversat ionsmatter/conversat ionsmatter-patients	A fact sheet, a resource card to help families find support, and a series of family stories. The materials are available in English and Spanish. NINR is part of the National Institutes of Health.

PALLIATIVE CARE		
Caregiver Action Network	caregiveraction.org	Education, support, respite care and advocacy for caregivers.  Toll-free information line provides referrals to caregiver support groups and a caregiver resource guide.  1-855-227-3640
Caregiver Survival Resources	caregiver.com	Provides education, support and guidance for family and professional caregivers. They produce <i>Today's Caregiver</i> magazine, the first national magazine dedicated to caregivers, the "Fearless Caregiver Conferences", and a website, which includes topic-specific newsletters, online discussion lists, back issue articles of the magazine, chat rooms and an online store.
Compassionate Friends	compassionatefriends .org	Provides hope, comfort, and support to families experiencing the death of a child, sibling, or grandchild and helps others assist the grieving family. Offers brochures, sibling chats, cyber friends, and pen pals to people suffering the loss of a child.  1-877-969-0010
Growth House	caringcommunity.org/ self- help/compendiumsgui des/growth-house	Online community for end-of-life care. Offering resources to improve the quality of compassionate care for people who are dying. Links to home care, pain management, quality of life issues and grief.
Cure Search	curesearch.org	Website provides information and resources to help with end-of-life grief. Resources about end of life, recent death, and months or years after death.  1-800-458-6223
National Hospice and Palliative Care Organization	nhpco.org/pediatric	NHPCO is committed to improving access to hospice and palliative care for children and their families—both nationally and internationally. Brochures for family and more.  703-837-1500
National Institute of Nursing Research	ninr.nih.gov/newsandi nformation/conversat ionsmatter/conversat ionsmatter-patients	A fact sheet, a resource card to help families find support, and a series of family stories. The materials are available in English and Spanish. NINR is part of the National Institutes of Health.

## **Parking**

Parking at Texas Children's Hospital	www.texaschildrens. org/patients- families/visitor- information/parking- and- directions?gad_sourc e=I&gclid=EAlalQob ChMliPyyxKarhAMVt TGtBh0NpgaYEAAY ASAAEgKYRvD_BwE	Pricing and location of all medical center parking areas.
Big Love Cancer Care	&gclsrc=aw.ds biglovecancer care.org	Provides parking vouchers to oncology families. This service is based on need and provided as funds allow.  1-888-522-7339
Candlelighters	candle.org	Provides parking vouchers to oncology families. This service is based on need and provided as funds allow.  713-270-4700
Emma's Hugs	emmashugs.com	Provides assistance paying for parking in the medical center.  Referral must be made by social worker, nurse or family friend.  281-943-9398
Leukemia Society	lls.org/texas-gulf- coast	For families with a child who has leukemia. They will reimburse for outpatient parking (need to fill out an application)  1-888-557-7177
Allright Parking	Not applicable	6800 Main, next to Tides II \$5.00 per day. 713-651-7810
Texas Department of Motor Vehicles	txdmv.gov/motorists/ disabled-parking- placards-plates	Provides handicap stickers for parking. Must fill out application and have physician sign.  I-888-DMV-GOTX

We'll Get This	Support child with cancer and their families with transportation costs and other challenges
	713-817-3035

## **Transportation to the Medical Center**

Texas Children's Kangaroo Crew	texaschildrens.org/ departments/ kangaroo-crew	Kangaroo Crew brings critically ill babies and children to Texas Children's Hospital from all over the nation and Central America for expert care.
Alex's Lemonade Stand Foundation	alexslemonade.org	Provides travel for patients who are traveling to clinical trials and non-standard of care treatments (MIBG, Proton Beam Therapy, etc.).
American Red Cross	redcross.org/local/te xas/gulf-coast	Provides free transportation to and from the Medical Center. Se habla Española. Dependent on volunteer availability.  713-526-8300
American Red Cross  — Pasadena	redcross.org/local/te xas/gulf-coast	Provides transportation within Pasadena and to and from the Medical Center, se habla Español. Operates within Pasadena - 8:00 am - 2:00 pm Mon-Fri, to Medical Center 8:00 am - 1:00 pm Tues and Thur. (arrive between 9:00-9:30 am and ready to pick-up @ 1:00 pm)
Angel Wheels to Healing	mercymedical.org	Provides non-emergency, long-distance ground transportation to financially disadvantaged, ambulatory patients who are traveling for treatment. A typical trip supported by Angel Wheels does not exceed 300 miles (one-way), and they do not normally handle trips within a local area or community. Exceptions are made on a case-by-case basis, routinely for cancer patients traveling daily for treatment. They utilize the following resources for assisting patients:  • Gas cards (provided to off-set fuel costs for patients)  • Bus Tickets (Greyhound, Trailways, etc.)  • Train Tickets (Amtrak)
Compass to Care	compasstocare.org	Schedules and pays for travel arrangements to the hospital where the child is being treated for cancer. Child must be under 18, on active treatment, demonstrate financial need, live in and be traveling within the US.  312-515-9490

Grind for Life	grindforlife.org	Provides financial assistance to cancer patients and their families when traveling long distances to doctors and hospitals. Those who qualify may request assistance for travel and lodging expenses, meals, and personal needs.  561-252-3839
METRO	ridemetro.org	Houston Public Transportation 713-635-4000
METROLift	ridemetro.org/Pages/ MLEligibility.aspx	METROLift provides transportation for persons with disabilities who cannot board, ride or disembark from a METRO fixed-route bus, even if that bus is equipped with a wheelchair lift or ramp.
We'll Get This	wellgetthis.org	Provides transportation for families who need assistance to and from medical appointments.  713-817-0328

## **Air Transportation**

Aero Angel	aeroangel.org	Provides free air transportation for medical care using high performance aircraft and a crew of professional pilots.
Air Care Alliance Mercy Medical Angels	aircarealliance.org	Mission is to ensure that no financially stressed patient is denied access to care for lack of long-distance, medically-related transportation. Some restrictions may apply.  1-888-675-1405
Air Charity Network	aircharitynetwork.or	Provides access for people in need who seek free flights to specialized health care facilities due to crisis. Serves all 50 states. Volunteer pilots utilize their own aircraft, fuel and time to provide free flights to medical facilities for financially distressed citizens or otherwise unable to use public transportation. Also coordinates flights for organ transplant candidates, clinical trial participants, chemotherapy or other repetitive treatment. Some restrictions may apply.
Aero National	aeronationalinc.com	Provides air transportation for fee. Some insurance will pay.  No Medicaid accepted. Some restrictions may apply.  1-800-245-9987
American Airlines: Kids in Need	americanairlines.gcs- web.com/news- releases/news- release- details/american- airlines-supports- kids-need-program- through-aadvantage	Provides worldwide support to children, families, and organizations dedicated to improving the quality of life for children with medical, educational or social services needs. Application takes 2 weeks to review, several criteria - consult social worker. Email miles.kids@mercymedical.org to set up a flight. Some restrictions may apply.
Angel Airlines for Cancer Patients (a.k.a. Angel Airline Samaritans, Mercy Medical Angels)	angelairlines forcancerpatients.org	Facilitates no-cost or reduced rate commercial airline tickets for needy cancer patients and their families. AACP encourages patient transport referrals through the National Patient Travel Center.  They use commercial airlines to provide charitable cancer patient travel. AACP does not duplicate any of the efforts of any other charity.  1-800-296-1217

Angel Flight, Inc.	angelflightsc.org	Arranges travel through a network of volunteer pilots for people who require specialized medical treatment not available to them locally. Social worker must assist as there is an application with medical signature needed. Some restrictions may apply.  972-458-0700
Children's Flight of Hope	childrensflightofhope. org	Free air transportation to and from medical facilities for children who—due to medical, financial or logistical reasons—are not able to travel to treatment any other way. Some restrictions may apply.  919-466-8593
Corporate Angel Network	corpangel network.org	The only charitable organization in the United States whose mission is to help cancer patients access the best possible treatment by arranging free travel using empty seats on corporate jets. Some restrictions may apply.  914-328-1313
Critical Care Medflight	ccmedflight.com	Provides air transport to patients and families. Uses state-of-the-art medical equipment and works with insurance carriers. Some restrictions may apply.  1-800-426-6557
Lifeline Pilots	lifelinepilots.org	The volunteer pilots are FAA certified pilots. Passengers must have financial need, be able to sit upright, be ambulatory and be willing to fly in a small, unpressurized aircraft. No limit on the number of times a passenger can utilize the service. Some restrictions may apply.  1-800-822-7972
Miracle Flights	miracleflights.org	Provides free flights to distant specialized care and valuable second opinions. Some restrictions may apply.  1-800-359-1711
National Patient Air Transport Helpline - Air Care Alliance	<u>patienttravel.org</u>	Provides information about all forms of charitable, long-distance medically-related transportation and provides referrals to sources of help available in the national charitable medical transportation network. Health care professional or family can call. Some restrictions may apply.  1-800-296-1217

Operation Liftoff	operationliftoff.com	Operation Liftoff provides air transportation for children with a life-threatening illness for a treatment trip.
Volunteer Pilots Association	aopa.org/training- and-safety/online- learning/safety- advisors-and-safety- briefs/volunteer- pilots	Provides flights to people in need who must travel to receive necessary medical treatment. Check criteria for patients prior to requesting a flight. Some restrictions may apply.

## **Medicaid Transportation**

Texas Medicaid and Chip Transportation  www.hhs.te ervices/heal id-chip/med chip-members/m transportati program	a. Medicaid number b. Child name and date of birth c. Name, address, and phone for hospital or
Out Of Town Assistance	Medicaid helps with gas reimbursement and food assistance in some cases

SOCIAL SUPPORT		
Caring Bridge	caringbridge.org	Personal, protected websites for patients and caregivers to stay connected.
Chai Lifeline	chailifeline.org	Chai Lifeline is an international non-profit organization dedicated to meeting the non-medical needs of seriously ill children, their families and communities. Their mission is to enhance lives through programs and services that offer friendship, good times, great memories, and social and emotional support. Texas is considered to be in the Southeast area.  I-877-CHAI-LIFE
Courageous Parent Network	courageousparentsne twork.org	A safe space for parents caring for seriously ill children. It has a blog, news, guides and testimonials.
Family Voices	familyvoices.org	Resources, tips, brochures and a newsletter that advocates children's health care needs.
Famous Fone Friends	famousfone friends.org	Comprised of volunteers connect seriously ill and hospitalized children with celebrities through phone calls and customized videos. Hospitals refer patients, indicating specific requests or interests, and FFF then coordinates the phone call from the requested celebrity list to the child.
Give In Kind	giveinkind.com	Personal, protected websites for patients and caregivers to stay connected.
Gracie's Gowns	graciesgowns.org	This group specializes in making a free hospital gown for specific children. Each gown is made from fabric that interests the child and we even go one step further and embroider their first name or nickname onto the gown as well. Must be under age 18 and treated for a chronic or life-threatening illness.
Icing Smiles	icingsmiles.org	Provides custom celebration cakes to families impacted by the critical illness of a child. Can be for the ill child, or the sibling.  443-420-7096
Lifextra Ordinary	liveextra.org	Through an easy-to-use blog system, you can share your story through words, vivid pictures and videos. Has crowd funding and connection opportunities.

My Music R <sub>x</sub>	joyrx.org/programs/j oyrxmusic	MyMusicRx.org reaches thousands of kids and teens in pediatric hospitals across the country with topical music content that makes a difference. Medical research shows music can play a powerful role in their daily experience, with measurable benefits that are social, emotional, and physiological. You can play games, learn how to play instruments, listen to concerts and more.
Project Joy and Hope for Texas	Joyandhope.org	Project Joy and Hope strives to prevent and relieve suffering for children with life-limiting conditions and their families through community awareness, education, and special supportive care services and programs.  1-888-835-4674
Team Impact	goteamimpact.org	Works at improving quality of life for children facing life threatening and chronic illnesses through the power of team. They do this by drafting courageous kids with a local college athletic team.  617-801-0248
Texas Parent to Parent	txp2p.org	TxP2P empowers families to be strong advocates through parent-to-parent support, resource referral, and education
Wishers and Dreamers	wishersand dreamers.org	Will send children suffering from illness, disease, a disabling condition or fighting medical challenges a hospital gown for their doll, bear or little buddy.

VISION EDUCATION ORGANIZATIONS		
American Association for Pediatric Ophthalmology and Strabismus	aapos.org	Provides doctor search, information about childhood eye disorders and additional information. Available in Spanish and Chinese.
Eye Cancer Network	eyecancer.com	Information about the diagnosis and treatment of ocular tumors, eye cancer, and orbital diseases for patients, their families, and the health professionals who care for them.  212-832-8170

VISION SUPPORT ORGANIZATIONS AND SCHOLARSHIPS		* indicates scholarship HIPS available
Addi's Faith	addisfaith.org	Children that are in need of a prosthetic eye due to cancer may now apply for assistance with that purchase. We will consider funding up to \$3,750 per eye. Submit a diagnosis letter and estimate from a ocular prosthetic facility. Payments will be made to the facility directly.
American Council of the Blind*	acb.org	Membership organization, information and referral, advocacy, specific college scholarships, job listings on the web site, monthly magazine.  Annually awards approximately 20 scholarships ranging in amounts from \$1,000 to \$4,000 to vocational, entering freshmen, undergraduate and graduate college students who are legally blind, maintain a 3.3 GPA and are involved in their school/local community.  I-800-424-8666

American Foundation for the Blind*	afb.org	Information requests, publications, talking books and other materials, disability specific scholarships.  Scholarships for blind students pursuing a college degree.  212-502-7600
American Printing House for the Blind	aph.org	Creates educational, workplace and lifestyle products and services for blind catalogs at no cost in print and on cassette.  1-800-223-1839
Anne Lowe Scholarship	christianrecord.org/ member-services/ scholarship	Awarded to blind students based on academic achievement and citizenship
Association for Education and Rehab of the Blind and Visually Impaired	aerbvi.org	Disability specific scholarships, information and referral. 703-671-4500
Association on Higher Education and Disability	ahead.org	Newsletter, bibliography of resources, employment exchange, journal.  704-947-7779
Vision Council of America	thevisioncouncil.org	Information on general eye care and specific eye diseases and conditions.
Blind Children's Center	blindchildrens center.org	Infant-preschool level services in Los Angeles, CA, publications for teachers/parents.  323-664-2153
Braille Institute	brailleinstitute.org	Information and referral, youth and adult programs, student and library services, catalog for the visually impaired, national resource line, Braille Press.  I-800-BRAILLE
Council of Citizens with Low Vision International	cclvi.org	College scholarships, pamphlets, quarterly newsletter 865-766-0477
Hadley School for the Blind	hadley.edu	Distance education for the blind or visually impaired  1-800-323-4238

Institute for Families	institutefor families.org	Support for families of visually impaired children books, videos, and support services.
Library Reproduction Service	largeprintschool books.com	Large print reproductions of any and all educational materials.  Delivery 2-8 weeks, order catalog.  1-800-255-5002
Lighthouse of Houston*	lighthouseguild.org	Education programs, camps, tech training, job placement.  Each year, the Lighthouse Guild scholarship program helps outstanding and deserving legally blind high school students from across the country attend college with scholarships of up to \$10,000. Scholarships are based on strong academic accomplishments and merit to provide additional financial support to help students successfully transition from high school to a college or university of their choice. Candidates are not required to demonstrate financial need.
Mira Foundation	www.mirausa.org	Provides guide dogs for blind children ages 11-17. Provides ongoing seminars for families with reference to daily living skills, psychology of blindness, what to emphasize in orientation and mobility training  910-944-7757
National Alliance of Blind Students	acb.org	Newsletter, job bank I-800-424-8666
National Braille Press	nbp.org	Braille printing and publishing house, catalogs free of charge, weekly newspapers, publications on employment, computers and more  1-888-965-8965
National Federation of the Blind*	nfb.org	Education about blindness, referral information, literature and publications about blindness; scholarships for students who are blind and in post-secondary education, listservs, etc.  Annually offers blind college students in the United States and Puerto Rico the opportunity to win one of 30 merit-based, national-level scholarships worth from \$3,000 to \$12,000. All scholarships awarded are based on academic excellence, community service and leadership.

National Organization of Parents of Blind Children	nopbc.org	Magazine for parents, toy suggestions for the blind 717-658-9894
Recording for the Blind or Dyslexic- Renamed to: Learning Ally	<u>learningally.org</u>	Educational books free on loan, books on diskette, library services, other resources. Fee-based service for employers to place printed work materials in formats accessible to the blind.  1-800-221-4792

WIGS		
Andre of Houston Wig Salon	wigsbyandre .com	A family owned and operated wig salon located minutes from the Texas Medical Center in Houston, Texas.  713-622-6933
Apollo Hair Replacement	apolloimage.net	Offers cutting edge, non-surgical hair loss solutions for men. 713-766-5592
Billie Jean's	billiejeans.com	A full-service wig salon near the Texas Medical Center that cuts, cleans, conditions and restyles wigs.  713-523-7895
Childhood Leukemia Foundation (Hug u wear)	clf4kids.org	Custom made, 100% human hair wigs with kid-friendly hats to children around the country.  1-888-253-7109
Children with Hair Loss	childrenwith hairloss.us	Provides human hair replacements at no cost to children and young adults facing medically-related hair loss. Human hair replacements are provided at no cost to qualifying recipients every year until age 21.  734-379-4400
Crowns of Coverage	crownsof courage.com	Group that provides halo wigs (hat with hair attached) to children undergoing chemotherapy. Free of charge.  602-717-4422
Forever Sewn In	Foreversewnin.c	High quality cranial prosthesis medical wigs for children, youth and adults facing hair loss due to medical conditions. 713-535-0654
Glamour Tress Wigs	glamourtress.co m	Large wig selection
Hair Club for Kids	hairclub.com/hai rclub-for-kids	Offers free hair restoration services to children with disease-related hair loss  1-888-888-8986

Hair Replacements by Eddie Pritchard	hairreplacement byeddieprichard. com	Custom hair loss solutions for those who want to look and feel their best.
Locks of Love	locksoflove.org	Free wig to patient who has financial hardship  888-896-1588
Look Good Feel Better	lookgoodfeelbet ter .org/programs/te ens/	Sponsored by the American Cancer Society and dedicated to improving the self-esteem and quality of life of people undergoing treatment for cancer.
Magic Yarn Project	themagicyarn project.com	Magic yarn wigs are inspired by beloved Disney characters, and invite children back to the world of play and daydreaming. They are beacons of fun, laughter, and play, during scary times.
National Alopecia Areata Foundation	naaf.org	Organization that assists people with hair loss 833-438-6223
Pink Heart Funds	pinkheartfunds.o rg	Provides cranial prosthetics (wigs) for children and adults with hair loss disorders, including those receiving cancer treatment.  228-575-8299
Ruby's Wigs	rubyswigs.com	Offers a large selection of wigs and hairpieces from t designers. Over 100 wigs on. Ruby's has been serving Houston and surrounding area for over 40 years.
Wigs For Kids	wigsforkids.org	Free wigs to kids. Apply online and give child's measurements

HATS/SCARVES		
Ellie's Hats	ellieshats.org	Provides hats to kids with cancer. Complete request online.
Hats Off For Cancer	www.hatsoff4cancer.	Sponsors drives for hats and gives to kids with cancer

Hats, Scarves, and More	hatsscarves andmore.com	Good selection of cute, unusual, and useful head coverings 877-838-6151
Headbands Of Hope	headbandsof hope.com	Social worker or other professional request required 919-323-4140
Headcovers Unlimited	headcovers.com	Wigs and hats in kids sizes. I-800-264-4287
Heavenly Hats	heavenlyhats.org	Distributes hats to those who have lost their hair due to cancer or medical treatment 920-362-2668
Love Your Melon	loveyourmelon.com	Will provide a hat to any child fighting cancer