

Beyond Diagnosis

Information for families dealing with Childhood Cancer and Blood Disorders

Compiled by Texas Children's Cancer and Hematology Centers

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Pediatric Cancer Foundation

Texas Children's Cancer and Hematology Centers 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, Arts in Medicine, 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 texaschildrens.org/cancer.



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Disease and Treatment

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DISEASE AND TREATMENT		
Cloves Syndrome Community	clovessyndrome.org	Group provides support, education and publications.
Cure Hereditary Hemorrhagic Telangiectasia Foundation	curehht.org	Provides education, research updates, links and a newsletter.
Klippel-Trenaunay Support Group	k-t.org	Provides factual information, resources and links
Lymphangiomatosis and Gorham Disease Alliance	lgdalliance.org	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.	lymphnet.org	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.
Angioma Alliance	angioma.org	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.
Birthmarks	birthmarks.com	Information, recommendations, active interchange, and lots of resources about port wine stains and hemangiomas. Provides a free private newsgroup and e-newsletter.
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	aad.org/public/kids/ camp-discovery/ about#dermadillo	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

Hereditary Hemorrhagic Telangiectasia (HHT) Foundation	hht.org	HHT provides advocacy and support. Includes factual information, research updates, helpful links, and a newsletter.
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.
Liam's Land	liamsland.org	Works to advance research and identify possible causes of lymphatic malformations by supporting a patient registry and funding further genetic testing and clinical trials.
National Organization for Rare Disorders	rarediseases.org	Resource which provides education, resources, awards grants and networking
National Organization for Vascular Anomalies	novanews.org	Provides a blog, education, transportation services and more.
Operation Smile	operationsmile.org	Provides free surgeries to kids who need them, teaches medical personnel.
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
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	<u>vhl.org</u>	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		
Little Tree: A Story for Children with Special Medical Problems It's OK To Be Different! Hi, My Name is Jack (A Book for the healthy siblings of chronically ill children)	amazon.com	This is a list of books that are written specifically for children with vascular anomalies and their families.
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.

The Periwinkle Arts In Medicine Program creates opportunities for self-expression, empowerment and development of coping skills. Making music, singing songs, performing dance, producing plays, writing and telling stories and decorating spaces with visual art enhances the healing environment and treatment experience. Below is a list of the community partners that perform activities with our patients and families.

COMMUNITY ART PARTNERS	
Aurora Picture Show	aurorapictureshow.org
CityArt Works	cityartworks.org
DaCamera	dacamera.com
Houston Center for Photography	hcponline.org
Houston Symphony	houstonsymphony.org
Katy Visual and Performing Arts Center	kvpac.org
Love Street Light Circus	ruf.rice.edu/~tannahil/love%20street.html
Museum of Fine Arts Houston	mfah.org
Purple Songs Can Fly	purplesongscanfly.org
The River (TUTS)	tuts.com/river
Watercolor Art Society Houston	watercolorhouston.org
Woodlands Children's Museum	woodlandschildrensmuseum.org
Writers In The Schools	witshouston.org
Young Audiences of Houston	yahouston.org
Volunteer opportunities	waystogive.texaschildrens.org periwinklefoundation.org/get-involved/volunteer
Making A Mark: An Exhibition of Art by Children with Cancer and Blood Disorders	periwinklefoundation.org/what-we-do/arts/making-a-mark
The Splendid Review	periwinklefoundation.org/what-we-do/arts/the-splendid-review

CLINICAL TRIALS		
American Childhood Cancer Organization	acco.org	Support organization with many publications, including: A Parent's Guide to Clinical Trials.
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 childrensoncologygroup.org/index.php/what-is-a-clinical-trial
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
Center Watch Clinical Trials Listing Service	centerwatch.com	Leading source of news, directories, for clinical research. Publications for patients and professionals
Coalition of Cancer Cooperative Groups	cancertrialshelp.org	Awareness of clinical trials, search database
National Institute of Health	clinicaltrials.gov	Information about clinical trials

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.
Alcoholics Anonymous	aahouston.org	12-step self-help group for those abusing alcohol. Call 24-hour number for nearest group meeting.
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
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.
Center for Family Consultation	cffconline.weebly.com	Counseling for individuals, families, adolescents, and children
Community Family Centers	communityfamily centers.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.
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
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.
Houston Galveston Institute	talkhgi.org	Provides individual counseling and therapy for individuals and groups (on occasion). Spanish speaking available.
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
MHMRA	mhmraharris.org	Provides group and individual counseling. 713-970-7000
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.
United Way Referral Service	unitedwayhouston.org/ our-211-helpline	Provides referral service. Spanish, French, Vietnamese, Cantonese, and Mandarin speakers available. 713-957-4357

Scholarships

Federal Student Aid	fafsa.ed.gov	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
Gulf Coast APON Scholarship	Visit our social work office	This scholarship provides funding for college/vocational education to pediatric hematology/oncology patients, on or off therapy. Ask for Maureen Carroll.
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

School

American Disabilities Act — Disability and Business Technical Assistant Center	ada.gov	Counseling, self-esteem classes, social skills training classes
Association on Higher Education and Disability	ahead.org	Parents of children can join (membership fees vary). Bimonthly newsletter <i>Alert</i> . Jobs postings, publications such as <i>How To Choose A College</i> 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 \$\mathbb{7} 713-923-2316

Council for Exceptional Children	cec.sped.org	Information for parents of gifted or handicapped children, ERIC clearinghouse 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	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	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. \$\mathbb{C}\$713-439-7530
Equal Employment Opportunity Commission	Publications, fact sheets, posters and a resource direct people with disabilities. L-800-669-4000	
GED Hotline	gedtest.org	GED applications with a learning disability. Information on local GED classes, testing services and accommodations guide I-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
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	heath.gwu.edu	Clearinghouse on post-secondary education for individuals with disabilities. Great resource. Puts out a publications for guidance counselors for working with students with disabilities 1-800-544-3284
HISD	houstonisd.org	All questions related to HISD.
Homebound School Services	houstonisd.org/ Domain/15044	If a child is not able to attend school due to illness, they can utilizes 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.
Hope Cam	hopecam.org	Hopecam connects children undergoing treatment for cancer with their friends at school using tablet computers, high speed internet connections and web cameras. Apply online.
Learning Disabilities Association of America	<u>Idanatl.org</u>	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.
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	texaschildrens.org/ departments/ developmental- pediatrics	Diagnoses and evaluates developmental learning disorders referral by doctor, nurse practitioner, or social worker. 832-822-3400

National Center for Learning Disabilities	Information and referral service, educational programs, pub outreach. Also provides a list of scholarships for students we 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	Families with a child who has a disability often need information about the disability of their child, about exintervention (for babies and toddlers), school services school-aged children), therapy, local policies, transportant much more 281-969-5944	
Speech, Language and Learning Clinic at Texas Children's Hospital	Neuro-psychological evaluation, social skills groups, pa classes referral by doctor, PNP, or social worker. Neuro-psychological evaluation, social skills groups, pa classes referral by doctor, PNP, or social worker.	
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.

Vocational Training

VOCATIONAL TRAINING HOUSTON AREA		
Houston Community College Vocational Advancement and Social Skills Training	central.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	dars.state.tx.us	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.
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.

VOCATIONAL TRAINING NATIONAL		
American Civil Liberties Union	For almost 100 years, the ACLU has worked to defend an 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.

Texas Children's Cancer and Hematology Centers 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.com	No	Created to help other families with a critically or terminally ill child.
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.
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.
Clayton Dabney Foundation	claytondabney.org	Yes	Assistance in creating everlasting memories to families with children in the last stages of terminal cancer.
Compassionate Friends	compassionatefriends.org	Yes	Newsletter, information, support groups, resource catalog. Multiple locations. 713-730-2335

Family 2 Family	cbtf.org/connections/family-2-family	No	Connects bereaved parents and family members to be eaved mentors.
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. \$\int 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. \$\int 713-944-6569\$

Hospice

HOSPICE EDUCATIONAL RESOURCES		
Bo's Place	bosplace.org	Bereavement center. Offers publications and resources surrounding grief.
Children's Hospice International	chionline.org	Educational resource on hospice care and kids. Some to print and some to order for fee.
Compassionate Friends	compassionate friends.org	Local self-help groups of bereaved parents and siblings offer mutual support. Free. Some publications
National Hospice and Palliative Care Organization	caringinfo.org	Information on hospice, grief and loss

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.
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.
Central Texas Medical Center Hospice	ctmc.org/care- services/hospice	Hospice services, bereavement counseling, and more.
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	<u>cchnet.net</u>	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. 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.	
HeartsWay Hospice of Northeast Texas	Counties served: Harrison, Cass, Marion, Morris, Rusk, Shelby, Nacogdoches, Gregg, Upshur, Smith, Hopkins. 903-295-1680		
Home Care and Hospice Agency Locator	agencylocator. nahc.org	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	hospiceworld.org	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. \$\int_{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.
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.
Operation Snowdrop	operation snowstorm.org	Provides a winter wonderland to those children with cancer on hospice.

FERTILITY		
Texas Children's Hospital	texaschildrens.org/health/ fertility-after-cancer- treatment	Preserving Fertility for Pediatric Oncology Patients. Brochures in Spanish and English for boys and girls fertility issues.
American Society Of Clinical Oncology Patient Guide on Fertility Preservation	cancer.net	Search "fertility" and it will bring up a guide
Adoptive Families of America	adoptivefamilies.com	Information and referral services to adoptive families. Publishes a magazine too.
American Association of Tissue Banks	aatb.org	Information on sperm banking
American Cancer Society	cancer.org	Information on sexuality issues and cancer
American Society of Reproductive Medicine	reproductivefacts.org	Information on reproductive issues
Cancer net	cancer.net/navigating- cancer- care/children/preserving- fertility-children-cancer	Preserving fertility in children with cancer
Genetics and In Vitro Fertilization Institute	givf.com	Information on ovary freezing and reproductive issues
Kids Health	kidshealth.org	Publication on effects of cancer treatment on fertility
ISaveFertility	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/ we-can-help/fertility- services/fertility-women	Fertility assistance and information

Mayo Clinic	mayoclinic.org/healthy- lifestyle/getting- pregnant/in- depth/fertility- preservation/art- 20047512	Fertility preservation options detailed
My Onco Fertility	myoncofertility.org/ articles/how_can_cancer affect_my_childs fertility	Fertility preservation information
Path 2 Parenthood	path2parenthood.org	Information on fertility and egg freezing, etc.
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.

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	andreriveroflife.org	Financial assistance program for single parent families who have a child in medical crisis. Application required.
Assistance League of Houston	assistanceleaguehou.org	Serves the educational and emotional needs of disadvantaged children and young adults, as well as families in crisis in the greater Houston area.
Catholic Charities	catholiccharities.org	Provides food, clothing and shelter for people in need and a network of services supporting infants to seniors.
Community Living Assistance and Support Services	dads.state.tx.us/services/ faqs-fact/class.html	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.
First Hand Foundation	firsthandfoundation.org	Provides funding for children—both domestically and globally—who need assistance with clinical necessities (such as surgery, medication and therapy), medical equipment and travel related to care.
Gia Nicole Angel Foundation	joniandfriends.org/ help-and-resources/ organizations/gia- foundation	Awards assistance through purchase of specific items for children with physical disability
HelpHopeLive	helphopelive.org	Provides small grants, information and support for fundraising and patient awareness.
Home and Community Based Services	dads.state.tx.us/providers/ hcs	Individualized services and support to persons with intellectual disabilities who are living with their family, in their own home or in other community settings, such as small group homes.

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	dads.state.tx.us/providers/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/programs/ofa/ programs/tanf	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		Concology 832-822-3483
at Texas Children's Cancer and		L BMT 832-826-5527
Hematology Centers		L 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
United Healthcare Children's Foundation	<u>uhccf.org</u>	Provides medical grants to help children gain access to 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 with application

Insurance

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.
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 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.
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 financial assistance through 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 in financial assistance. Eligible patients need to be residing and receiving 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.
Texas Dept. of Insurance - Risk Pool	tdi.texas.gov	Call for details about insurance for anyone I-800-252-3439
Houston Volunteer Lawyers	hba.org/services/ houston-volunteer- lawyers	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. L-800-274-2844

Medical Equipment Assistance

The Arya Foundation	aryafoundation.org	Provides medical equipment such as ramps, special beds and walking aides.
Building Blocks for Kids	bb4k.org	Provides grants/funding for therapy, hearing and communication, medical equipment, and more
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
Chariots of Hope	chariotsofhope.org	Collects used wheelchairs and repairs and distributes them with no cost to recipient.
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.
Danielle's Foundation	danielles foundation.org	Helps families gain access to therapies, equipment and other benefits for children with cerebral palsy or brain Injuries.
Different Needz Foundation	differentneedz foundation.org	Grants for medical equipment awarded once a year.
First Hand Foundation	firsthand foundation.org	Provides financial assistance for medical care, vehicle modification and travel
Friends of Man	friendsofman.org	Assists with medical and mobility equipment and prosthesis
Gia Nicole Angel Foundation	giafoundation.com	Assists with the purchase of medical equipment
McLindon Family Foundation	mclindonfamily foundation.org	Provides special needs children with adaptive bikes
MY GYM Challenged America	challenged america.com	Provides equipment and services to improve quality of life of children coping with chronic illness and/or are physically or developmentally challenged

Project Mend	projectmend.org	Refurbishes mobility devices and assists families with medical equipment needs.
Ramps.org	ramps.org	Connects those in need of a wheelchair ramp with the necessary suppliers and installers
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	steppingstonesfor stella.org	Provides buggies to children with disabilities to ensure they and their families experience joy and freedom of being outdoors
United Health Care Children's Foundation	uhccf.org	Grants provide financial assistance for families with children that have medical needs not covered or not fully covered by their commercial health insurance plan. 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
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.
Wheel To Walk Foundation	wheeltowalk.com	Helps children with disabilities, 20 years and younger, obtain medical equipment or services not provided by insurance.

Medication Assistance

Amgen	amgen.com/responsib ility/access-to- medicine/reimbursem ent-support-services- and-financial- assistance-programs	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.
Good R _X	goodrx.com	Prescription drug savings. Compare prices, print free coupons and save money.
Jump Start Program	erwinaze.com	Specialist that can help to investigate benefits and verify patient coverage; provide information on reimbursement process and connect patients with financial assistance 888-837-4397
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 more than 150 offered by pharmaceutical companies.
Pfizer RSVP	pfizerhelpful answers.com	Reimbursement solutions, verification, and payment HELPline. Program to help both insured and uninsured patients access Pfizer medicines (including Rapamune/Sirolimus).
Pharmaceutical Research and Manufacturers of America	pparx.org	Offers a single point of contact to access more than 475 public and private prescription assistance programs. 888-477-2669
R _X Assist 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.
R _x Hope	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)

American Society for Deaf Children	deafchildren.org	Provides education and online support for parents and families of deaf children.
Apraxia Kids	apraxia-kids.org	Awards iPads and protective cases to kids for aid in communication.
The Center for Hearing and Speech	centerhearingand speech.org	Birth to 18 years who have speech and language delays relating to hearing impairment.
First Hand Foundation	firsthandfoundation.org	Provides financial assistance for some treatments, equipment, and vehicle modifications
Hearing Aid Express	hearingaidexpress.com	Retail provider of hearing aids, hearing aid repairs and batteries. Multiple locations.
Hike Fund	thehikefund.org	Provides hearing devices for children in need.
Miracle Ear Foundation	miracle-ear.com	Provides hearing aides to those in need.
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.
Self Help for Hard of Hearing People, Inc.	hearingloss.org	Provides links, education and advocacy for the hard of hearing.
Audiology Center at Texas Children's Hospital	texaschildrens.org/ departments/audiology	Identifies, evaluates and provides habilitation of hearing impairment in children.
Texas Department of Assistive and Rehabilitative Services- Deaf and Hard of Hearing	dars.state.tx.us	Links to programs and resource information for the deaf and hard of hearing in Texas.
Texas School for the Deaf	tsd.state.tx.us	Provides education for children with hearing loss. Also provides residential facilities for school aged children.

HOTELS			Ask for the medical rate!
Aishel House	aishelhouse.org	Apartment style hotel with shute 713-522-2004	tle service
Americas Best Value Inn Medical Center Downtown	americasbestvalueinn. com/hotel- photos.cfm?idp=1672	A few rooms have kitchen, no sl 2419 Riverside Dr. Houston, TX 77004	huttle \$\bigs\cdot\ 281-974-4432
Astro Best Motor Inn	astrobestinn.com	Hotel, no shuttle, no kitchen 9430 S. Main St. Houston, TX 77025	% 713-668-0691
Braeswood Park Condiminiums	braeswoodpark.org	Apartments, shuttle to medical of 2255 Braeswood Blvd. Houston, TX 77030	center; kitchen.
Econo Lodge Medical Center	choicehotels.com/ texas/houston/ econo-lodge-hotels	Hotel with microwave and refrig 7905 S. Main St. Houston, TX 77025	gerator 5 713-667-8200
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\colon 713-961-9000\$
Hampton Inn & Suites Houston Medical Center/Reliant	hamptoninn3.hilton .com/en/hotels/texas/ hampton-inn-and- suites-houston- medical-ctr-reliant- park-HOUMDHX/	Hotel with kitchen and shuttle so 1715 Old Spanish Tr. Houston, TX 77054	ervice \$\bigs\ 713-797-0040

Holiday Inn NRG Arena	ihg.com/holidayinn/ hotels/us/en/houston/ houad/hoteldetail?cm _mmc=GoogleMapsHIUSA 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	extendedstayamerica. com/hotels/tx/housto n/med-ctr-reliant-pk- fannin-st	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	ihg.com/crowneplaza/ hotels/us/en/houston/ houcp/hoteldetail?cm _mmc=GoogleMaps- CPUSA HOUCP	Hotel with no kitchen. Provides shuttle service to medical center. 8686 Kirby Dr. Houston, TX 77054
Mainstay Suites Texas Medical Center/Reliant Park	choicehotels.com/tex as/houston/mainstay- hotels/tx933?source= gyxt	Hotel with kitchen and shuttle service 3134 Old Spanish Tr. Houston, TX 77054
Courtyard Houston - West University	marriott.com/hotels/ travel/houbs- courtyard-houston- west-university/	Hotel with kitchen and shuttle service 2929 Westpark Dr. Houston, TX 77005
Houston Marriott Medical Center	marriott.com/hotels/ travel/houmc- houston-marriott- medical- center/?scid=bbla189 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 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
Wyndham Houston Medical Center	wyndhamhouston medcenter.com	Hotel with shuttle service, no kitchen 6800 Main St. Houston, TX 77030
Rodeway Inn & Suites	rodewaysuites houston.com	Hotel with kitchen and shuttle service 6712 Morningside Houston, TX 77030

HOUSING GENERAL HOUSING		
American Cancer Society	cancer.org/treatment /supportprogramsser vices/patientlodging	Free hotel lodging for 4 nights/15 nights per year. Needs 2-3 weeks notice. Some restrictions may apply.
		L-800-227-2345
Catholic Charities Of the Archdiocese of Galveston-Houston	catholiccharities.org	Affordable home ownership initiative, refugee resettlement, transitional housing for women and their children. Some restrictions may apply.
		L 713-227-9981
Baytown Housing		Low cost housing. Applications online, waiting list.
Authority	baytownhousing.org	L 281-427-6686
	cjd.org	Shelter place, food, clothing
Casa Juan Diego		L 713-869-7376
Faith House	faithhouse houston.org	Daily rate: \$35. Refundable \$100 deposit. 8 days- 4months 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 luekemia/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.
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 we do not have facilities for children. We have about a three month waiting list time. We have a three month maximum stay. Check out joeshouse.org for listing of possibilities, choose TX and then Houston metro.

Houston Housing Authority	housingfor houston.com	Public housing. Se habla español. 713-260-0600
Housing and Urban Development (HUD)	portal.hud.gov/hudpo rtal/HUD?src=/states /texas	Apartments and houses for low-income persons. Some restrictions may apply.
Healthcare Hospitality Network	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
Joe's House	joeshouse.org	Online directory of place to stay that are near hospitals and cancer treatment center and 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. 877-563-7468
Pasadena Housing	ci.pasadena.tx.us	Low cost housing, Section 8 housing. Some restrictions may apply. 5 713-475-5544
Reside (away from home)	residehouston.com	Housing for families and patients. Some restrictions may apply. \$\mathbb{\cappa}\$713-791-9454
Ronald McDonald House	rmhc.org	Housing for families and patients. Some restrictions may apply. \$\mathbb{L}\$ 713-795-3500

CHURCH APARTMENTS		
Church Apartment Ministry	churchapartment ministry.org	Medical diagnosis. Call to put name on waiting list for all church apartments. Families treated in the Texas Medical Center. 2 week minimum. \$39 a night and the non-profit pays for utilities, TV, internet etc. Most have I bedroom, 5 have 2 bedroom. Siblings are allowed. No pets. Waitlist is usually not bad. Some families need immediate assistance, some not until months out. Family should complete application or call. There is a secretary who speaks Spanish at the "2640" number.

First Methodist Church, Kingwood Church of Christ 713-524-2640
South Main Baptist 713-529-4167
Serenity House 713-874-6663

LESBIAN, GAY, BISEXUAL, TRANSGENDER AND QUESTIONING		
The Trevor Project	thetrevorproject.org	Provides crisis intervention for and suicide prevention for LGBTQ youth. They have many educational resources and an online curriculum for teachers.
GLBT National Help Center	glbthotline.org	Serves gay, lesbian, bisexual, transgender and questioning people by providing free and confidential peer-support and local resources.
HATCH Youth	hatchyouth.org	Houston area support and social group for LGBTQ teens ages 13-20. Meets at the Montrose Center several nights each week. Provides an affirming environment with role models and peer support activities, education on health issues, and community outreach on issues affecting LGBTQ youth.
Montrose Center	montrosecenter.org	Specializes in sexual identity issues. Spanish speaking available. They offer discounted rates based on financial need. Also offers numerous support groups.
PFLAG	pflag.org pflaghouston.org	A group for parents and families who are dealing with a child or loved one that is coming out. Dedicated to supporting families by keeping them in loving relationships. Confidential small group discussions are led by a trained facilitator. Group members are encouraged to share stories regarding their loved ones, thereby creating an atmosphere of understanding and support. A small group is dedicated exclusively to transgender issues. PFLAG Houston also maintains a confidential voice mail helpline staffed by caring PFLAG parents who take turns returning phone calls.
Trans Lifeline	translifeline.org	This line is primarily for transgender people experiencing a crisis. This includes those who may be struggling with their gender identity and are not sure that they are transgender 877-565-8860

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.
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 better assist the grieving family. Offers brochures, sibling chats, cyber friends, and pen pals to people suffering the loss of a child.
Growth House	growthhouse.org	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.
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	texaschildrens.org/ maps-and- directions/parking	Pricing and location of all medical center parking areas.
Big Love Cancer Care	biglovecancer care.org	Provides parking vouchers to oncology families. This service is based on need and provided as funds allow.
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.
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)
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.
We'll Get This	wellgetthis.org	Support child with cancer and their families with transportation costs and other challenges

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.
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	angelwheels.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.
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.

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
Your Ride is Here	yourrideishere.org	Provides transportation to and from treatment for those fighting cancer. No charge.

Air Transportation

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. 888-675-1405
Air Charity Network	aircharity network .org	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	hub.aapubs.com/en/ju /american-airlines- kids-in-need	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	childrensflightof hope.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.
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.
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.
Freedom Flight Charitable	freedomflightusa.com	They fly people in need of distant medical treatments who are geographically isolated from airline travel or financially depleted due to illness. Some restrictions may apply. \$\square\$ 940-242-3838\$
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.
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	patienttravel.org	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.

Operation Liftoff	operationliftoff.com	Operation Liftoff provides air transportation for children with a life threatening illness for a treatment trip.
Volunteer Pilots Association	volunteerpilots.org	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	hhsc.state.tx.us/ medicaid/mtp/	Sets up non-emergency rides for people who have no other way to get to their Medicaid health-care visits. This includes people with Medicaid, children who get services through the Children with Special Health Care Needs program, and people in the Transportation of Indigent Cancer Patients program. The program does not set up rides in an ambulance, even for non-emergency purposes, but the program can pay back (reimburse) someone who uses their personal car to drive a Medicaid member to and from their Medicaid-related health visit. 855-687-4786 (Houston/Beaumont) 855-687-3255 (Dallas) 877-MED-TRIP (all other areas) How to set up: 1. Call at least 2 work days or more before you need a ride 2. Call at least 5 days in advance for out of town travel 3. Have the following items when you call: - Medicaid ID number - Name, address of where you will be picked up - Name, address, phone number of where you need to go If your child has special needs (wheelchair), please explain this so they can send the correct vehicle.
Out Of Town Assistance		Medicaid helps with gas reimbursement and food assistance in some cases

SOCIAL SUPPORT		
Capes 4 Heroes	capes4heroes.com	Free superhero cape for any child with disability or life threatening illness
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.
Courageous Parent Network	courageousparent network.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.
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.
Hugginz By Angel	hugginzbyangel.com	A hand-sewn blanket is made for any child who is battling medical fragile. Parent must nominate child.
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.

My Music R _x	mymusicrx.org	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.
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.
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.

VISION SUPPORT ORGANIZATIONS AND SCHOLARSHI		* indicates scholarship HIPS available
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.
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.
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.
Association for Education and Rehab of the Blind and Visually Impaired	aerbvi.org	Disability specific scholarships, information and referral.
Association on Higher Education and Disability	ahead.org	Newsletter, bibliography of resources, employment exchange, journal.

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.
Blinded Veterans Association	bva.org	Disability-specific scholarships
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.
Council of Citizens with Low Vision International	<u>cclvi.org</u>	College scholarships, pamphlets, quarterly newsletter
Hadley School for the Blind	<u>hadley.edu</u>	Distance education for the blind or visually impaired
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.
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, and 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	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

National Alliance of Blind Students	acb.org	Newsletter, job bank
National Braille Press	nbp.org	Braille printing and publishing house, catalogs free of charge, weekly newspapers, publications on employment, computers and more
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
Recording for the Blind or Dyslexic- Renamed to: Learning Ally	learningally.org	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.

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.
Apollo Hair Replacement	apolloimage.net	Offers cutting edge, non-surgical hair loss solutions for men.
Billie Jean's	billiejeans.com	A full service wig salon near the Texas Medical Center that cuts, cleans, conditions and restyles wigs.
Childhood Leukemia Foundation (Hug u wear)	clf4kids.org/ hugsuwear.php	Custom made, 100% human hair wigs with kid-friendly hats to children around the country.
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.
Crowns of Coverage	crownsof courage.com	Group that provides halo wigs (hat with hair attached) to children undergoing chemotherapy. Free of charge.
Glamour Tress Wigs	glamourtress.com	Large wig selection
Hair Club for Kids	hairclub.com/hairclub -for-kids	Offers free hair restoration services to children with disease-related hair loss
Hair Replacements by Eddie Pritchard	hairreplacementbyed dieprichard.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
Look Good Feel Better	lookgoodfeelbetter .org/programs/teens/	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

Pink Heart Funds	pinkheartfunds.org	Provides cranial prosthetics (wigs) for children and adults with hair loss disorders, including those receiving cancer treatment.
Ruby's Wigs	rubyswigs.com	Offers a large selection of wigs and hairpieces from top designers. Over 100 wigs on. Ruby's has been serving the 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	hatsoffforcancer.org	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
Headbands Of Hope	headbandsof hope.com	Social worker or other professional request required
Headcovers Unlimited	headcovers.com	Wigs and hats in kids sizes.
Heavenly Hats	headcovers.com	Distributes hats to those who have lost their hair due to cancer or medical treatment
Hip Hats with Hair and Hairdana by Fashion with Compassion	hatswithhair.com	Hats with hair attached
Love Your Melon	loveyourmelon.com	Will provide a hat to any child fighting cancer
Mad Capz	madcapz.net	Festive and various prints of hats. Cost associated



Cancer and Hematology Centers