



Beyond Diagnosis

Information for families
dealing with childhood cancer
and blood disorders

Compiled by Texas Children's
Cancer and Hematology Centers

Generously funded by Bear Necessities
Pediatric Cancer Foundation

Commented [T11]: Can have picture of group of kids
(multi-ethnicity)
Think of Title

Table of Contents
Disease and Treatment

Table of Contents	2
HEMATOLOGY	4
Disease and Treatment	5
Bone Marrow Failure	5
General Hematology	6
Hemophilia	8
Sickle Cell Disease	9
Additional Resources	12
Adult Providers	12
ONCOLOGY	15
Disease and Treatment	15
Bone Marrow / Stem Cell Transplant	16
Brain Tumor	19
Genetic Predisposition	23
Histiocytosis	24
Leukemia and Lymphoma	25
Solid Tumors	26
Additional Resources	30
Books for Oncology	30
Camps for Oncology	35
Cancer Survivorship	38
Counseling for Oncology	39
Financial Assistance for Oncology	40
Getting through School while on Treatment	42
Kindness Kits	44
Major Organizations for Oncology	46
Scholarships for Cancer Patients	50
Siblings and Cancer	52
Social Support for Cancer Patients and Families	53
Teens with Cancer	56
Wish Organizations	59
VASCULAR ANOMALIES	60
Disease and Treatment	61
TEXAS CHILDREN'S CANCER AND HEMATOLOGY CENTERS	2

Commented [T12]: Table of Contents with headings – each subheading below can be in TOC

Sickle Cell Disease

EDUCATION		
	http://web.texaschildrens.org/multimedia/fliobook/sickle-cell-handbook	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. This site has recommended care plans, education, news, and resources.
Centers For Disease Control and Prevention	cdc.gov/nchddd/sickle-cell	Education, publications, medical statistics and resources about sickle cell disease and sickle cell trait.
SUPPORT ORGANIZATIONS		
Foundation for Women and Girls with Blood Disorders	fwbgd.org	Provides support, education and resources to women and girls with blood disorders such as Von Willebrand disease, sickle cell disease, etc.
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	periwinklefoundation.org	The Periwinkle Foundation develops and provides several camping opportunities for patients of Texas Children's Hospital including Camp YOLO (teen camp), Camp Periwinkle Days at Texas Children's Cancer and Hematology Centers and Periwinkle Day Camp. ☎ 713-807-0191

HEMATOLOGY
Disease and Treatment

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.
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.
Sickle Cell Association of Houston	sicklecellhouston.org	Resource for those living with sickle cell disease. Main focus is education, programming and research.
Sickle Cell Association of Texas	sicklecelltexas.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. ☎ 844-994-HOPE
Sickle Cell Kids	sicklecellkids.org	Online kids' education about sickle cell, game format
Your Genes Your Health	yourgenesyourhealth.org/sickle/whatisit.htm	Facts, treatment, testing and screening.

SUPPORT GROUPS FOR SICKLE CELL

Above The Crisis	facebook.com/AboveTheCrisis	Facebook page for connecting to adult sickle cell support group.
Supporting our Sickers	sosparentgroup.wix.com/gr@trhstn facebook.com/groups/SOSSupportGroup	Parent and guardian support group

SCHOLARSHIPS FOR SICKLE CELL		
The Kermit B. Nash Academic Scholarship	sicklecelldisease.org/kermit-b-nash-academic-scholarship	This scholarship is named after former UNC Chapel Hill professor, Dr. Kermit B. Nash, this scholarship will give its 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 GPA of 3.0 or higher and intend to pursue a 4-year college/university education. Scholarship amount is for 4 years
Candice's Sickle Cell Fund	candicesicklecellfund.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 Reshod K. Robinson Scholarship	facebook.com/rkrscholar	In honor of Reshod, who passed away in 2012 from sickle cell disease, this scholarship presents rising college sophomores and above, who have a GPA of at least 2.5 and who are members of a nationally recognized sickle cell association, with \$1,500.
The International Association of Sickle Cell Nurse and Physicians Assistants Scholarship	iascnapa.org/scholarship.shtml	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.)

Adult Providers

Physician	Address	Phone	Restrictions
Harinder Juneja Modupe Idowu Shilpan Shah	UT Physicians Comprehensive Sickle Cell Center 1200 Binz, Ste. 850 Houston, TX 77004	713-486-5660	ages 14 and up
Elham Abbasi-Hafshejani, MD	3115 College Park Dr. Woodlands, 77384	936-439-5213	Over 18, No Medicaid
	3233 Woodward Dr. Huntsville, TX 77340	936-439-5213	
Joel William Abramowitz, MD	925 Gessner, Ste. 310 Houston, TX 77024	713-467-1630	Traditional Medicaid, Commercial
Sohail Akbani, MD	3555 Stag Dr. Beaumont, TX 77701	409-212-5922	Over 18, No Medicaid
Amir Rasheed, MD, PA	13111 E. Frwy., Ste. 108 Houston, Texas 77015	281-837-2288	Over 16, Traditional Medicaid
	1610 W Baker Rd., Ste. A Baytown, TX 77521	281-837-2288	Over 16, Traditional Medicaid
Jack Alperin, MD (also Dr. Shedid and Dr. Jana)	2240 Gulf Freeway South, Ste. 2.110 League City, TX 77573	281-534-8380 Update: 832-505-1910	Over 18, No Medicaid
	301 University Blvd. Galveston, TX 77555	409-772-2222	
Mohsen Arani, MD (plus Yen, Grisou, etc.)	17232 Red Oak Dr. Houston 77090	281-440-5006	Over 18, Traditional Medicaid
Mary Crow, MD	Red Oak 17232 Red Oak Dr. Houston, TX 77090	281-440-5006	None
	Kingwood 22710 Professional Dr. Kingwood, TX 77339	281-312-8566	

HEMATOLOGY
Additional Resources

	Tomball 506 Graham Dr., Ste. 120 Tomball, TX 77375	281-516-0236	
	7500 Beechnut, Ste. 239 Houston, TX 77074	713-772-0793	
Kelty Baker, MD	6560 Fannin St., Ste. 1260 Houston, TX 77030	713-797-0466	None
John Ibrahim, MD Lawrence Rice, MD	6550 Fannin St., Ste. 1100 Houston, TX 77030	713-441-1111	
Ethan Natelson, MD	6550 Fannin St., Ste. 1101 Houston, TX 77030	713-441-0000	
Michelina Cairo, MD Susan Escudier, MD Lawrence Foote, MD	7515 W. Main St., Ste. 740 Houston, TX 77030	713-795-0202	
Mark Udden, MD Courtney Miller-Chism, MD Romina Sosa, MD	6620 Main Ste., Ste. 1375 Houston, TX 77030 (transfusions off site at Kelsey Seybold Clinic)	713-798-3750	
Oncology Consultants	Medical Center (Cancer Ctr.) 2130 W. Holcombe Blvd., 10 th fl. Houston, TX 77030	713-600-0900	
	Memorial City 925 Gessner, Ste. 600 Houston, TX 77024	713-827-9525	
	Sugar Land 16675 SW Frwy., Ste. 250 Sugar Land, TX 77479	281-491-5511	
	Katy 18400 Katy Frwy, Ste. 670 Houston, TX 77094	281-578-0201	
	Willowbrook 18220 Tomball Pkwy., Ste. 240 Houston, TX 77070	281-477-8600	

HEMATOLOGY
Additional Resources

	Southwest 7737 SW Frwy., Ste. 575 Houston, TX 77074	713-778-0300	
	Northwest 1631 North Loop W., Ste. 155 Houston, TX 77008	713-802-9000	
	Tomball 888 Graham Dr. Tomball, TX 77375	281-477-8600	
Selvarnai Nallusamy, MD	Spring Medical and Diagnostic Ctr. 156 Cypress Woods Medical Dr., Ste. 100 Houston, TX	713-442-1700	
	Main Campus 2727 W. Holcombe Blvd. Houston, TX 77024	713-442-0000	
Veena Chandrakar, MD Jorge Darcourt, MD Kirk Heyne, MD Janet Macheledt, MD Miguel Miro-Quesada, MD Shagufta Naqvi, MD Alex Nguyen, MD Sunil Patel, MD Rakkhit Ronjay, MD Amir Rasheed, MD	Houston Methodist, West Campus 18400 Katy Frwy., Ste. 320 Houston, TX 77094	281-647-7766	