HOPE

2017-2018
CANCER CARE
ANNUAL REPORT

Focus on the **HOPE** Clinic
(Clínica de **H**ematología/**O**ncología: **P**uente de **E**speranza)

Children's Mercy
KANSAS CITY

Alan S. Gamis, MD, MPH
Chief, Section of Oncology
Associate Division Director,
Division of Hematology/
Oncology/Bone Marrow
Transplantation
Children's Mercy Kansas City

This year's Children's Mercy Cancer Center Annual Report takes us back to our roots and focuses on our core tenant–do what is best for our children. Among the myriad of new therapies, the many new tests and ways to monitor cancer response, and the new ways to evaluate the human genome, and thus the ways mistakes in that genome may result in cancer, the oldest most important aspect of medicine remains clear communication between care providers and the families for whom they are responsible. This year's annual report begins with this basic, and yet most critical component of medicine. Then, it builds on this foundation by incorporating all the new advances in medicine that a child with cancer has available to them at Children's Mercy, ensuring we provide the best possible care for all children in Kansas City, and the surrounding region.

The HOPE Clinic and Hispanic Research Program, this year's highlighted program, has been developed to provide the highest quality of cancer care to all our children by ensuring we overcome language differences. It builds on ensuring this most basic of clinical needs of our current children, while simultaneously establishing a comprehensive research program examining how cultural and ethnic differences impact the types of cancers we see in children, as well as how cultural and genetic differences between children impact the curability of their cancers.

Through the collaborative efforts with Children's Mercy's Cancer Genomics and Clinical Pharmacology and Experimental Therapeutics programs, the HOPE program is guiding the development of joint international research efforts that will help the children of our region, as well as of the world. Complemented by our tumor-specific programs (e.g., leukemia/lymphoma and brain tumor programs), our other therapeutic and diagnostic programs (e.g., bone marrow transplant, cellular therapy) and our other population-focused programs (e.g., adolescent and young adult cancer, Survive & Thrive), the HOPE program further expands these efforts to all children. This is truly a unique program in the U.S., and adds to the growing resources available to the children of Kansas City and beyond.

We are told that the measure of humanity rests upon how we care for our most vulnerable members of society and that the future of humanity will depend upon how we care for our children. As found in this year's annual report, this team from the innovative Children's Mercy HOPE program not only believes in these principles, it lives them every day. How fitting that such a program is found in America's heartland and in a community where these principles have supported and aided the development of Children's Mercy as one of the leaders in the care of children. We are so proud of the HOPE program! I invite you to learn more about the important work this team is doing in the following pages.

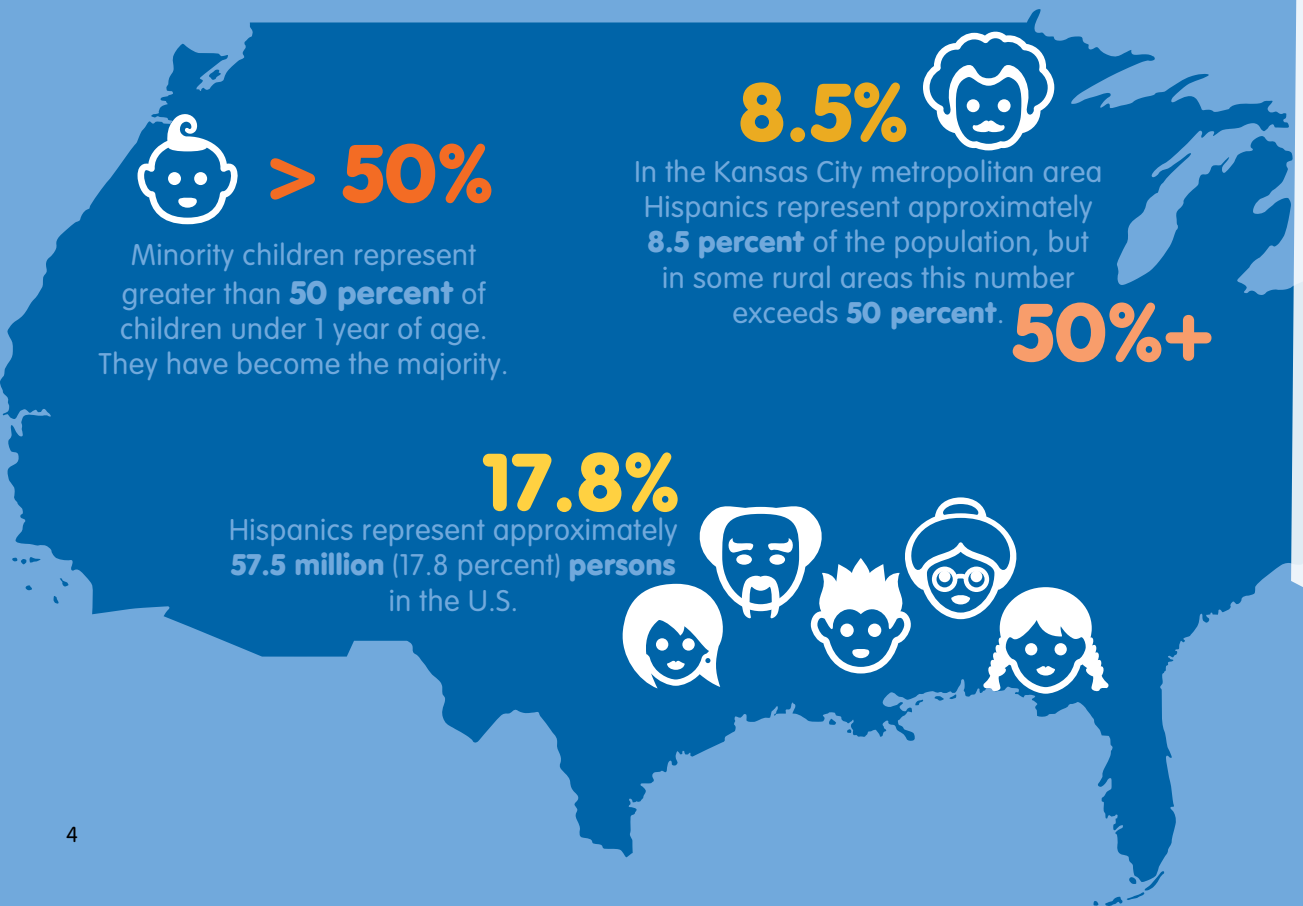
To a bright, healthy, and inclusive future!

INSIDE

The HOPE Clinic team:
Maria del Pilar Coromina, CCHI™, MA; Terrie Flatt, DO, MA; Sara Donnelly, MSW, LSCSW; Theresa Torres, APRN; and Julie Fournier, RN.

Why Does Minority Health Care Matter?

The face of the United States continues to change and the field of medicine is charged with the responsibility to meet the evolving needs of the country. Minority children represent greater than 50 percent of children under 1 year of age. They have become the majority. Hispanics represent approximately 57.5 million (17.8 percent) persons in the U.S. and of this group, 63 percent are of Mexican origin. In the Kansas City metropolitan area, Hispanics represent approximately 8.5 percent of the population, but in some rural areas this number exceeds 50 percent. Children's Mercy Kansas City has accepted the challenge to provide optimal clinical care to Hispanic patients and families with limited English proficiency.



With the support of the Division of Hematology/Oncology/BMT at Children's Mercy, the HOPE Clinic (Clínica de Hematología/Oncología: Puente de Esperanza) and Hispanic Research Program were developed by Terrie G. Flatt, DO, MA in 2012. The clinic has continued to grow and now represents one of the busiest clinical services in the division. This clinic provides bilingual clinical services, as well as all written materials in Spanish including medication calendars, medication lists, triage sheets, disease-specific materials and drug information sheets. There is a strong emphasis on parent/patient education and social support.

The primary mission of the clinic is to address health care disparities, which present themselves in many forms: language barriers, socio-economic constraints, cultural differences, health literacy and disease-specific findings.

The literature has demonstrated that patients/families that receive discordant language services often receive less education at clinic visits; they feel there is limited interpersonal interactions; and they are less satisfied with the care they receive. Our goal in this clinic is to engage patients and families with concordant language services, education and a holistic personal approach. It is often difficult to form a personal relationship via an interpreter, especially one that conveys elements of humor, emotion and empathy. And when all is said and done, this is what bonds us as humans. Our hope is that every patient and family leaves our clinic with a genuine human experience … a laugh, a conversation about a favorite sport, the antics of the new puppy … a hug.

Medical personnel will often criticize families about medication compliance and missed appointments, but we often neglect to factor in the burdens that families and patients experience, especially when they have limited English proficiency, low health literacy, economic hardships and other cultural constructs from which they perceive the world.

A large percentage of pharmacies in the U.S. are unable to provide language-specific medication labels. If a patient or caregiver is unable to read a medication label, it is very likely they will make a mistake when giving/taking the medication, and for a disease such as acute lymphoblastic leukemia (ALL), administering the oral chemotherapy correctly is imperative to outcome.

To mitigate medication administration errors, we supply the family with a medication calendar and medication box in Spanish. However, it goes one step further. For example, if the child is in maintenance chemotherapy for ALL, the caregiver must return the calendar to us and demonstrate with a check mark if the chemotherapy was given; or with an "X" if not given, and if not, the reason why. The calendar system is not meant to be punitive, but rather a system to find solutions so that the child receives all chemotherapy doses in the future. We also utilize a peer-to-peer model in small group settings for parent education so that Spanish-speaking parents who have been successful in achieving 99 to 100 percent compliance can share their strategies for success. Sometimes a parent will show a video of their child in the midst of a tantrum when attempting to give the oral chemotherapy, along with how they gave the medication in spite of this obstacle.

And finally, if the child is old and mature enough, they talk about their experiences, as well as how they resumed their lives in school, sports, music, etc., even while taking oral chemotherapy. This has been a successful strategy not only for improving medication compliance that is key to curing ALL, but it provides community support for parents; it reduces those pervasive feelings of isolation; and it enhances patient/caregiver engagement in the health care process. Education empowers patients and parents and there is no better teacher than a parent who has walked this journey with their child. This creates active partnerships in health care and, in the long run, it empowers parents and patients alike. As Maya Angelou states: "When you know better you do better," and this applies to health care. Our charge is to make the system better so each of us can do better.

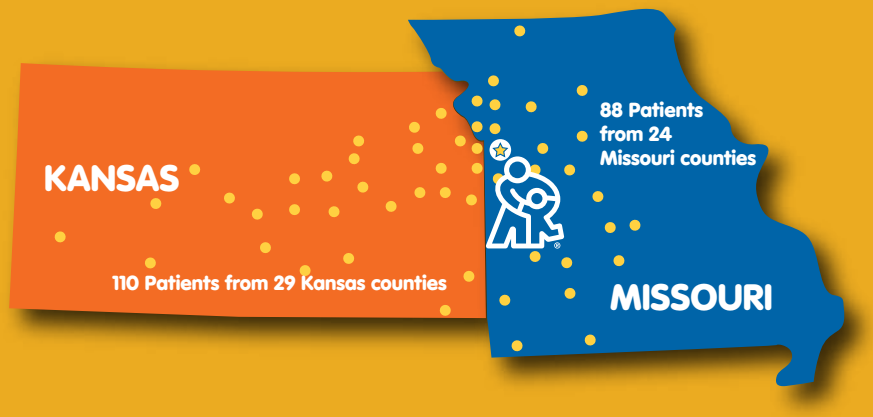
Some populations are more at risk for diseases than others and outcomes can be affected by race and ethnicity. Acute lymphoblastic leukemia (ALL) is the most common childhood cancer in the U.S., in Mexico, and in Latin America, and it represents a disease with significant racial and ethnic disparities. In the U.S., the overall survival rate for Caucasian children exceeds 92 percent and recent data suggests we are nearing 95 percent for standard risk pre-B ALL.

Hispanic children have not fared as well. They have a 15 percent higher incidence of ALL when compared to Caucasians and they continue to have the poorest outcomes when compared to other racial groups. As a group they have worse prognostic features at diagnosis: older age; increased prevalence of unfavorable prognostic markers such as CRLF-2 as an example; and they are more likely to experience relapse than any other racial group. Moreover, when an allogenic bone marrow transplant is indicated, Hispanic children are less likely to find a compatible donor, and, if a donor is identified, he/she is less likely to participate in the bone marrow donation when compared to Caucasians. Hence, treatment options can be limited in this setting.

The reasons for these disparities are poorly understood and are not clear cut. Population-focused research plays a critical role in narrowing survival outcome gaps for minorities. Whole genome sequencing, ancestral informative marker studies, drug metabolism testing that is genome based, along with research that encompasses critical areas such as patient engagement, may provide methods to understand and overcome language and socio-cultural barriers. Our goal is to include patients on both national and institutional trials to better understand cancer among Hispanic children. We are also conducting research in Mexico to further advance knowledge for Hispanics in the U.S. and Mexico. Our goal is to create medical alliances without borders.

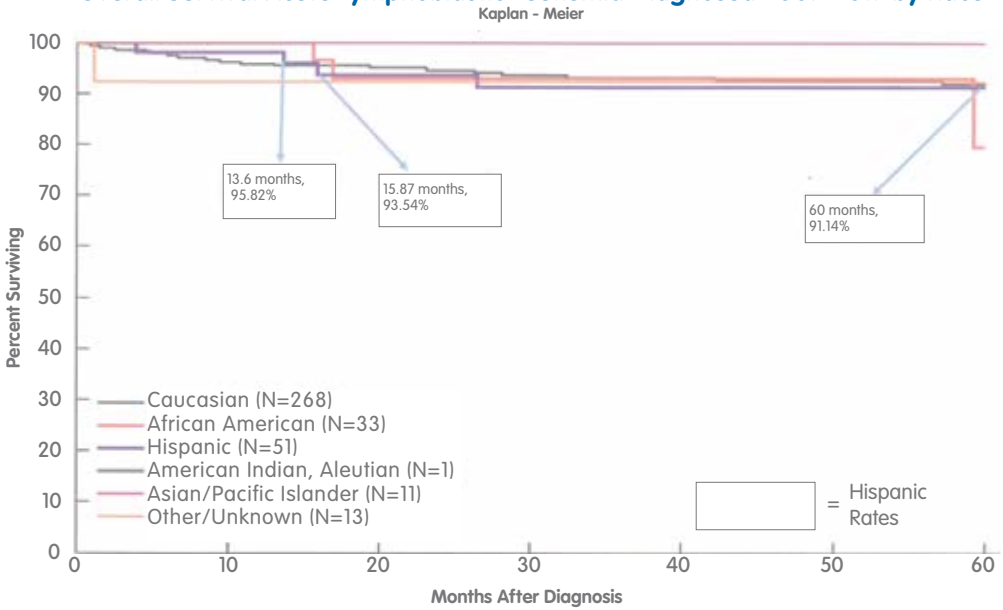
Solutions to minority health care disparities are multifaceted. The HOPE clinic and Hispanic research program strive to be part of the solution so that health care and outcomes are equal for all children.

All Missouri and Kansas Patients by County 2017

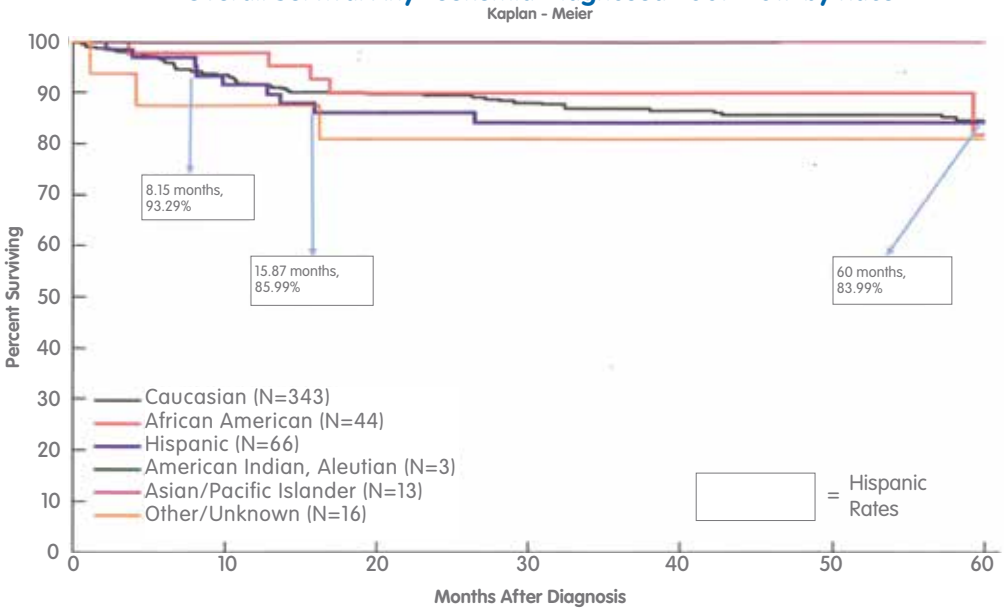


Missouri and Kansas Hispanic Patients by County 2017

Overall Survival Acute Lymphoblastic Leukemia Diagnosed 2007-2017 by Race



Overall Survival Any Leukemia Diagnosed 2007-2017 by Race



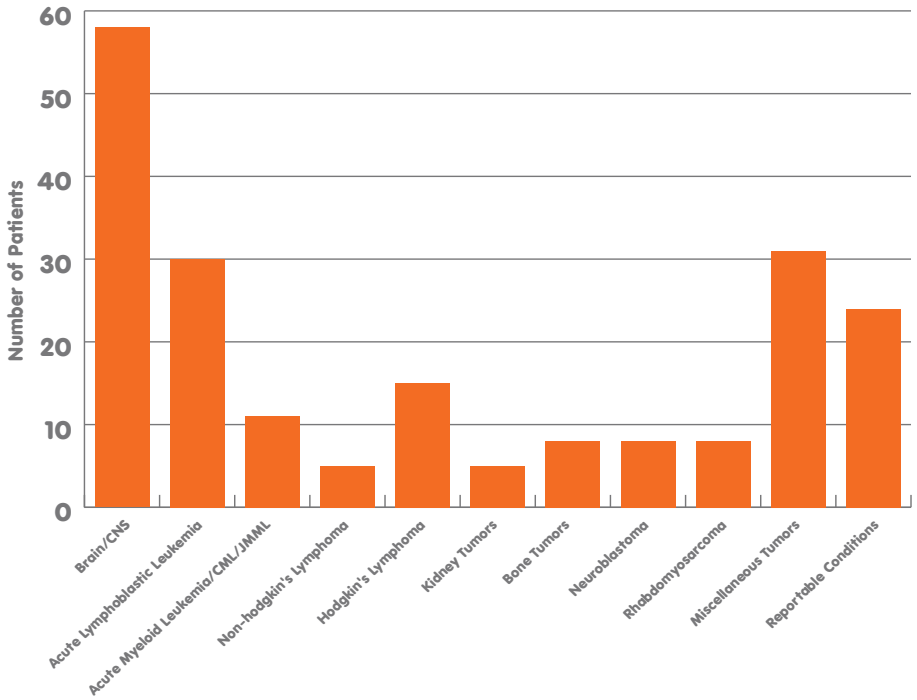
Cancer Registry Review 2017

The Cancer Registry at Children's Mercy Kansas City plays a vital part in the surveillance of cancer in the pediatric population. The Cancer Registry is a HIPAA-compliant confidential database comprised of malignant cancers, benign brain tumors and other specified benign tumors. The database is operated under the guidance of the Cancer Care Committee. Data collected, which includes diagnosis, treatment, recurrence and survival, is standardized for state and national comparisons.

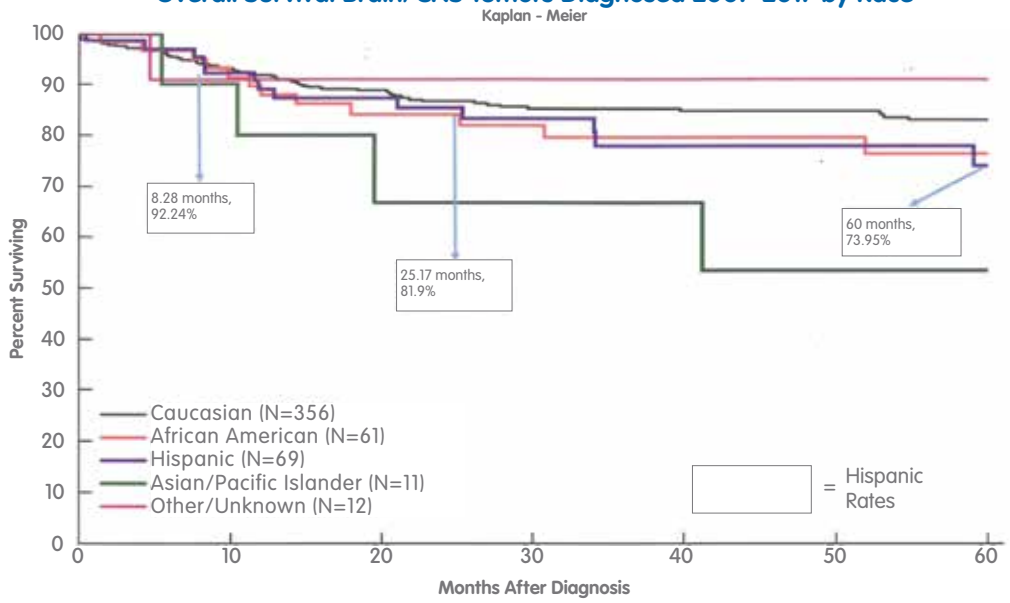
Following each patient's cancer status is a very important part of Cancer Registry data collection. Knowing outcomes of each cancer patient can assist care providers with determining best treatment methods and long-term effects of cancer treatment. Therefore, follow-up letters inquiring about a patient's cancer status are sent out yearly. Parents and older patients are encouraged to contact the registry by secure email at cancerregistry@cmh.edu to discuss follow-up.

During 2017, the Cancer Registry added 204 patients to the database. Of these patients, there were 180 patients who were diagnosed with malignancies and benign central nervous system tumors. There were 24 patients added to the registry who had benign reportable conditions. These conditions are collected at the request of the Cancer Care Committee for surveillance purposes and are not required to be reported outside our facility. Please see the frequency by diagnosis chart for a breakdown of cancers.

Frequency of Diagnosis by Disease Type - 2017



Overall Survival Brain/CNS Tumors Diagnosed 2007-2017 by Race



As Perla Gutierrez Varela cradles her daughter, Brisia, in her arms, it's hard to believe the chubby-cheeked 3-month-old is facing the life-threatening cancer diagnosis of acute lymphoblastic leukemia, or ALL, but she is.

Born at full term in a community hospital six hours west of Kansas City, Brisia appeared to be a healthy baby at first. But after just two nights at home, Perla took her back to the hospital.

"The doctors at the local hospital thought Brisia might have contracted an infection during childbirth," Perla explained. After being hospitalized for nearly a week, Brisia's white blood counts continued to climb. Doctors there diagnosed her with ALL and referred the baby to the Children's Mercy Cancer Center for treatment.

"Brisia's white blood count was over 300,000 by the time she came to us," explained Terrie Flatt, DO, MA, Director of the HOPE Clinic, the Children's Mercy Spanish-speaking cancer clinic.

"As a point of reference, a normal white blood cell count in a newborn would range from 9,000 to 25,000. This is an extremely aggressive form of leukemia," Dr. Flatt said.

ALL affects the blood and bone marrow, the spongy tissue inside bones where blood cells are made, and progresses rapidly, creating immature blood cells, rather than mature ones.

Distance, a significant language barrier and access to health insurance made Brisia's case

Brisia Gutierrez Varela


Terrie Flatt, DO, MA

even more challenging. But due to the life-threatening nature of her diagnosis, Dr. Flatt went to work immediately to enroll the baby on a Children's Oncology Group Pilot study clinical trial for ALL, a treatment only available at a handful of pediatric hospitals across the U.S. working in collaboration with COG.

"This treatment may possibly improve the outcome for Brisia, but we have a long way to go," Dr. Flatt said. The treatment course could last up to three years. That means for the time being, Brisia and her mother will be staying in Kansas City.

"Brisia was diagnosed at just 9 days old and has spent almost her entire life at Children's Mercy," Dr. Flatt said. "Her condition is improving, but her immune system is still fragile. She has received two cycles of intense chemotherapy so far."

If all continues to go well, Brisia can receive her next chemotherapy treatments in the HOPE Outpatient Clinic, a unique program that addresses the special needs of the hospital's Spanish-speaking patients. There, Dr. Flatt can closely monitor her progress, and she can stay close by at the Ronald McDonald House with her mother, just in case there is an emergency.

The extended nature of her treatment is a hardship for the family that could last months or even years. While Perla stays in Kansas City with Brisia, the rest of the family remains in Montezuma, Kan., so that Brisia's father, Miguel, can work, and the older children can attend school.

"What stands out to me about this family is the burden of health care at a personal, spiritual, financial and psychological level," Dr. Flatt said.

But it's a burden they are gladly willing to bear in exchange for the hope that Brisia may one day be healthy.

"Children's Mercy is a wonderful hospital and Dr. Flatt has explained everything to me in great detail in my own language so that I can understand this illness and the treatment," Perla said. "I am very thankful to him and to the hospital. They are taking excellent care of Brisia.

"Our hope is that when she finishes treatment, we can return home where she can live a normal life."


Brisia with her parents at a recent visit.

Ancillary Services Associated with the HOPE Clinic

FLOW CYTOMETRY LAB—PATHOLOGY AND LABORATORY MEDICINE

The Flow Cytometry Lab is a specialty testing area of the Department of Pathology and Laboratory Medicine. It is a supportive and diagnostic methodology that provides basic and specialty analyses to the physician in making patient diagnoses and prognoses.

Flow cytometry testing allows for comprehensive investigation of cells within a specimen. The lab performs basic lymphocyte immune monitoring plus evaluation of naïve and memory subsets. The test menu also includes cell lineage panels for assessing childhood leukemias and lymphomas. The panels contain antibodies specific for T-cells, B-cells, monocytic, myeloid, blasts and other cell types.

Additionally, the lab has developed leukemia-specific minimal residual disease (MRD) panels for monitoring after therapy. These panels can identify very small numbers of leukemia cells that may be present. DNA cell cycle and ploidy measurements are useful to exhibit abnormal genetic material content. The lab's screening panel for Autoimmune Lymphoproliferative Syndrome (ALPS) provides a rapid method to look for the T-cell subset present in ALPS.

The lab participates in sharing information on technical methodology and result interpretation with visiting physicians from hospitals in Mexico. The lab interprets the flow cytometry results the Hispanic patients had before they came to Children's Mercy. As a COG-certified lab for B-ALL MRD testing, the Children's Mercy team has lots of experience in MRD flow cytometry detection, which is very important for leukemia risk stratification and treatment adjustment.

SOCIAL WORK

In the Spanish-speaking clinic, the social worker works alongside an interpreter to provide services to the patients and families. Additional time is spent locating resources and partnering with community resources specific to the Hispanic population. The social worker assists families in navigating the health care system, locating financial assistance, seeking and connecting to necessary resources and utilizing legal services. The social worker also assesses and helps to educate medical staff on cultural beliefs and traditions within the family system, and how cultural issues may impact health care.

GENOME CENTER

Cancer cells contain genetic mutations and certain mutations can lead to more aggressive types of cancer with poorer outcomes. These types of genetic mutations in cancer can vary by the patient's ethnicity. The scientific community is just beginning to recognize that the Hispanic population is at higher risk for certain types of aggressive childhood leukemia and other cancers, and the reasons for the differences remain unclear.

At Children's Mercy, the commitment is to utilize the resources of the Center for Pediatric Genomic Medicine to study the role of ethnicity in pediatric cancer. The center is profiling the genomes of patients with cancer and analyzing their biological features and clinical outcomes with respect to ethnicity. This field has been under-studied to date, and Children's Mercy intends to make a substantial, lasting impact on the care and outcomes of Hispanic patients with cancer.

Sara Donnelly, MSW, LSCSW

CYTOGENETICS

Acute lymphoblastic leukemia (ALL) is the most common type of cancer in children. Racial/ethnic differences exist in both the incidence and treatment outcome of childhood ALL. The incidence of ALL during childhood and adolescence is significantly higher in Hispanics than in other groups. Hispanic children fare worse than white and Asian children with the same disease. The higher risk of ALL relapse in Hispanic children is partly attributable to genomic variations characteristic of Native American (NA) genetic ancestry.

Genome-wide association studies (GWAS) have identified single nucleotide polymorphisms (SNPs) in the *ARID5B* gene that are strongly associated with ALL susceptibility.[1] The incidence of ALL is higher among children aged 1 to 4 years than among infants or older children/teens, and higher among boys than girls.[2] In a recent study, the median age was lower and the WBC count was higher at diagnosis in Hispanic children compared with non-Hispanics. The risk of leukemia relapse (ALL and AML) was found to be significantly higher in Hispanic children younger than 10 years, with no association of ethnicity and risk of relapse for children 10 years old or older.[3]

The risk of relapse has been associated with the somatic genetic abnormalities that characterize the leukemia, e.g., there is a noted lower prevalence of the low-risk hyperdiploid and *ETV6/RUNX1* genetic subtypes of ALL[4] and a higher prevalence of high-risk subtypes, such as *CRLF2*-rearranged and *IKZF1* deleted ALL.[5] As there are a finite number of studies that have been done examining the genetic risk factors for leukemia in Hispanics, the etiologies of age differences and risk of relapse, additional multi-institutional studies are needed.

References
1. J Clin Oncol 2012;30:751-757.
2. JAMA. 2017;318(16):1533.
3. Clinical Pediatrics 2018;57(6) 656-659.
4. Cancer Epidemiol Biomarkers Prev. 2006;15(3):578-81.
5. Blood. 2010;115(26):5312-5321.

PROMISING NEW THERAPIES

Despite high survival rates for newly diagnosed children with acute lymphoblastic leukemia, or ALL, the treatment of relapsed or refractory ALL in children is a challenge. The standard treatment for patients with ALL that relapse is intense chemotherapy, often followed by a bone marrow or stem cell transplant. These treatments are risky and can lead to long-term side effects that can impact the quality of life of those patients that survive their leukemia.

Newly developed targeted therapies approved for the treatment of children and young adults with relapsed or refractory ALL are having an immediate and dramatic impact. Tisagenlecleucel (CAR T-cell therapy) and blinatumomab are immunotherapeutics that target the protein CD19, which is present on the leukemia cells in children with B-cell ALL. Tisagenlecleucel (or Kymriah™) is a cellular therapy where the T-cells from a patient with leukemia are collected, genetically modified to attack ALL cancer cells and given back to the patient as treatment for ALL. Nearly all patients treated with tisagenlecleucel will achieve remission within a month of therapy, and over half of these patients will remain disease-free more than a year after treatment.

Blinatumomab is an antibody therapy that stimulates the immune system of B-cell ALL patients to attack leukemia cells. These extremely promising therapies are currently used only for children with ALL who relapse or who do not respond to chemotherapy, but new clinical trials are being developed that will include them in the treatment of newly diagnosed patients with ALL.

ADVANCED PRACTICE PROVIDERS

The advanced practice provider is an integral member of the team that manages and cares for patients in the Spanish-speaking clinic. The advanced practice provider is the go-to person for the patient and their family throughout their treatment and follow-up. The advanced practice provider provides education about the specific diagnosis, treatment plan and how that treatment will affect the patient and their family.

Theresa Torres, APRN

All materials are provided in the primary language of the family. The advanced practice provider also performs physical exams, performs procedures such as lumbar punctures, prescribes medications and chemotherapy, orders labs and radiology tests. The advanced practice provider plays a valuable role in the emotional support of families. As a team, the primary oncologist, advanced practice provider and social worker, guide families through critical decision-making at diagnosis, during a relapse, or when they are facing end-of-life care.

Bilingual Patient Navigator

When a child is diagnosed with cancer, the information, choices, tests and treatments parents face can seem overwhelming. For a child whose family's first language is Spanish, the potential language barrier adds a layer of complexity to the child's diagnosis.

That's why Terrie Flatt, DO, MA, Director of the HOPE Clinic, the Children's Mercy Spanish-speaking cancer clinic, felt it was so critical to add the position of a bilingual patient navigator to the clinic's team.

"Even though the HOPE Clinic serves a minority population, it is one of the busiest clinics in the Hematology/Oncology/BMT Division at Children's Mercy," Dr. Flatt explained. "It's very important that we help these families understand not only the diagnosis, but all other aspects of their child's care by communicating with them in their first language."

Maria del Pilar Coromina,CCHI™, MA, an experienced interpreter with the hospital's Language Services department, is the clinic's bilingual patient navigator and a member of the interdisciplinary team dedicated to serving these culturally diverse families. Pilar's position originally was funded by a Hyundai Hope on Wheels Impact Award in 2015. She has been an asset to patient satisfaction and clinic flow, and her position has continued to be funded internally.

A native of Spain, Pilar has worked as an interpreter at Children's Mercy for nine years. She earned her undergraduate degree from the Complutense University of Madrid, her master's from the University of Missouri-Kansas City, and was the hospital's first CHI™ certified health care interpreter.

As the clinic's bilingual patient navigator, Pilar facilitates the health care process and performs support and liaison functions with physicians, nurses and other providers of the health care team.

Maria del Pilar Coromina, CCHI™, MA

She also helps patients and their families "navigate" the system of clinics and patient support services recommended.

In fact, Pilar often walks patients and their families through the hospital, helping them get acquainted with everything from where to find the cafeteria, to the location of the Ronald McDonald Family Room, to escorting them to other departments, such as Radiology. Her knowledge of the hospital system and her skills reduce language and cultural barriers, promoting patient health and comfort.

"I assist with communication for patients, families and the team," Pilar said. "I think it helps lessen the tremendous amount of stress they are under to know that they can talk with Dr. Flatt who understands their language and their culture, as well as to have a dedicated bilingual patient navigator to interpret for other providers and staff and help them navigate the hospital system."

Pilar also interprets and oversees Spanish language communication between providers and patients/families; helps with translations related to clinical and research materials; and translates and proofreads written materials.

"Having Pilar's assistance has made for a more positive and efficient experience for everyone involved," Dr. Flatt said. "She is a great asset to our patients, families and staff."

Miqueas Valdez Cisneros

The moment Terrie Flatt, DO, MA, Director of the HOPE Clinic, the Children's Mercy Spanish-speaking cancer clinic, walked into the exam room where Miqueas Valdez Cisneros was waiting for him, he knew the 14-year-old was facing a cancer diagnosis.

"Miqueas had a tumor that measured 16 centimeters by 10 centimeters on the side of his neck," Dr. Flatt explained. "It was about the size of half a small cantaloupe."


Terrie Flatt, DO, MA

Blood tests and a biopsy confirmed that Miqueas had stage IIB Hodgkin lymphoma, a cancer that begins in the lymphoid tissue which is part of the body's immune system, with bulk disease.

Although Hodgkin lymphoma can start in any lymph node, it often begins in the lymph nodes in the upper body. The most common sites are in the chest, neck or under the arms. For Miqueas, it started in that lymph node on the side of his neck.

"At first, it was a small, hard bump, like a bean," Miqueas said. "I told my mother about it and she took me to the doctor, but the doctor said it was my lymphatic system."

As the days and weeks went by, the bump got larger, and Miqueas began itching excessively.

"I itched all over, especially my feet," he said. "My mom tried to help me by changing my diet. I began exercising, and took baths in Epson salts to relieve the itching, but the bump was still there."

Maria, Miqueas' mother, speaks Spanish and limited English, but she knew something was wrong with her son, and took him to multiple providers in search of an answer. She also applied several times for medical insurance before being approved.

"The burden of the family's insurance and a possible language barrier may have contributed to a delay in Miqueas' diagnosis," Dr. Flatt said.


Mary Ireland, RN, and Audra Antes, RN

"We often see this with solid tumors in the Hispanic community. Fortunately, Hodgkin lymphoma is one of the most treatable forms of cancer. Miqueas' survival rate is 90 percent, even though his cancer was diagnosed late."

"I didn't want to hear the diagnosis," Miqueas admitted, "but I was relieved to know what I had and that it could be treated."

Dr. Flatt prescribed five rounds of chemotherapy delivered every 28 days in the Hope Outpatient Clinic. Radiation therapy to the original tumor site will follow to be sure all the cancer is gone.

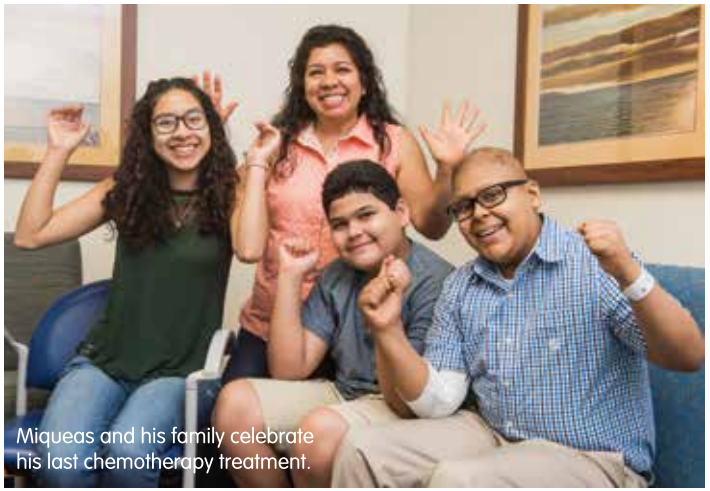
Though Miqueas said he was exhausted after his first chemotherapy treatment, the bump had disappeared.

"I couldn't believe it," Maria said. "We were so happy it was gone! Dr. Flatt has been a blessing from God—someone who could talk with Miqueas and who we could understand."

Over the next five months, Miqueas lost much of his hair, but he gained an appreciation for the people who made his diagnosis and treatment possible.

"Miqueas is a bright, articulate, young man with a positive attitude," Dr. Flatt said. "He is an advocate for himself, and very considerate of his parents and family."

As he wrapped up his last chemotherapy treatment on July 13, 2018, he was accompanied by his mom, older sister Micaya, and younger brother Asaf. His father, Leo, had to work, but Miqueas said he has been very supportive, too.



Miqueas and his family celebrate his last chemotherapy treatment.

"My family and I are a team," Miqueas said. "I could not have gotten through any of this without them."

He also gives Dr. Flatt and the nurses in the Hope Clinic credit for the outstanding care he has received.

"Dr. Flatt and everyone at Children's Mercy have been very kind and professional to me," Miqueas said. "They have made me feel at home and have brought me so much joy. I think it's good to have people like them in the world!"

Global Health

Children's Mercy is collaborating to improve outcomes in Hispanic populations

Approximately 200,000 children are diagnosed with cancer annually in the world. About 80 percent of those children live in low or middle income countries, and the survival rate is around 10 to 20 percent, compared to 80 percent in the United States. The HOPE Clinic and Research Program is committed to changing these global disparities through research and education. We envision the creation of hope without borders for all children battling cancer.

The research team for the HOPE program is led by Terrie Flatt, DO, MA; Trevor Cole, BHS, MBA-HCM, CCRC (project manager); and Lilia Garcia Rodriguez, MD (co-investigator and coordinator in Mexico). Of course, this research would not be possible without the efforts and commitment of all of our investigators in Mexico and here at Children's Mercy. Together, Drs. Garcia and Flatt have established research sites at five centers throughout Mexico. They are seeking clues about ethnicity and how it impacts leukemia.

"We are investigating how ethnicity impacts the tendency to develop leukemia, the way leukemia behaves, and the way it responds to therapy," Dr. Flatt said.

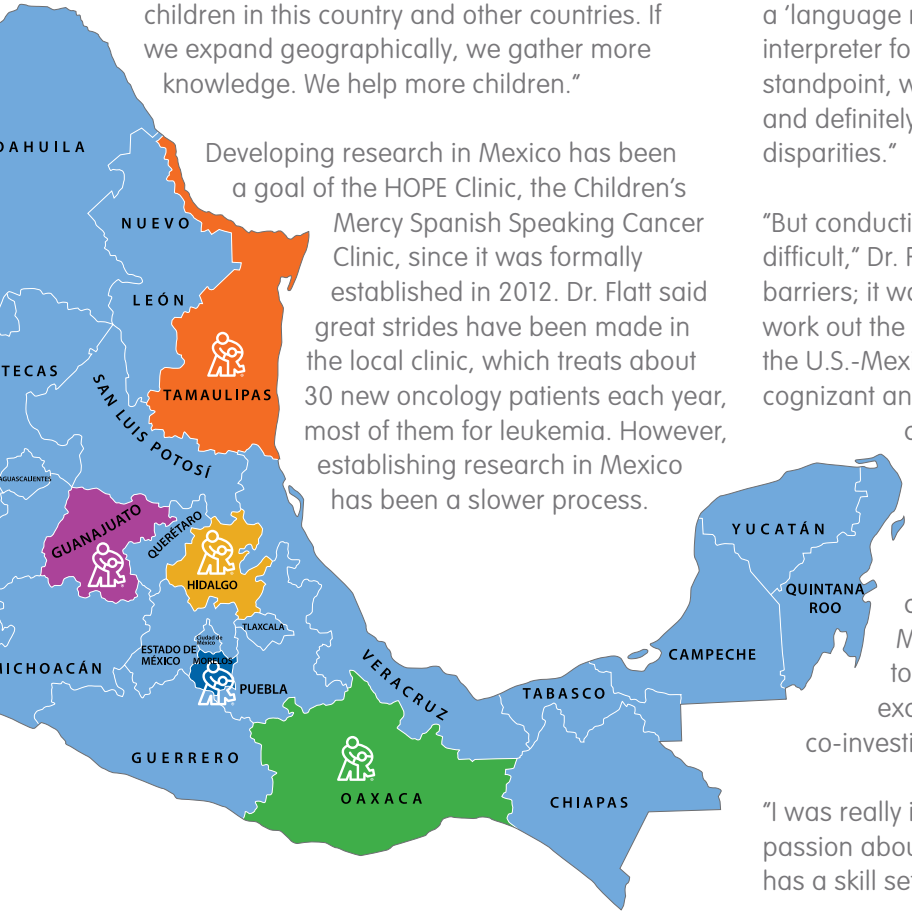
The incidence of acute lymphoblastic leukemia is approximately 15 percent higher in Hispanics than Caucasians, and the overall survival rate is lower in this population. Studies are being conducted to better understand how genetic markers play a role in these statistics, and in the effectiveness of drugs used to treat the disease.

Why is research in Mexico important to patients in Kansas City and the U.S. in general?

Hispanics are the largest ethnic minority group in the United States and the second largest in the Kansas City area; and it is a population that continues to grow. Hispanics represent about 17 percent of the population nationally, and 8.5 percent of the Kansas City area population. The vast majority are of Mexican ancestry. Over the last four years, approximately 20 percent of our patients diagnosed with acute lymphoblastic leukemia were Hispanic.

Lilia Garcia Rodriguez, MD, and Terrie Flatt, DO, MA

"It would take a very long time to obtain enough patient samples in this country alone for clinical trials to statistically analyze and make changes in treatment protocols for Hispanic children," Dr. Flatt said. "When you collaborate internationally, it opens up the pool of samples, which helps children in this country and other countries. If we expand geographically, we gather more knowledge. We help more children."



Developing research in Mexico has been a goal of the HOPE Clinic, the Children's Mercy Spanish Speaking Cancer Clinic, since it was formally established in 2012. Dr. Flatt said great strides have been made in the local clinic, which treats about 30 new oncology patients each year, most of them for leukemia. However, establishing research in Mexico has been a slower process.

"In terms of clinical services, we've established a really well-run program in the Spanish-speaking clinic," Dr. Flatt said. "We've reached many of our goals; all of our materials are in Spanish and English; I think we've done a good job in education. Another landmark has been having a 'language navigator,' who is a dedicated interpreter for the clinic. I feel like from a clinical standpoint, we've made pretty big strides and definitely have narrowed the gap in care disparities."

"But conducting international research is very difficult," Dr. Flatt said, "There are regulatory barriers; it was a monumental effort just to work out the logistics of getting samples across the U.S.-Mexican border. And, we have to be cognizant and respectful of the different cultural context and the different work flows that we encounter in international settings."

Helping Dr. Flatt face those challenges is Lilia Garcia Rodriquez, MD, a native of Mexico, who rotated to Children's Mercy as a fellow in an exchange program, and later became a co-investigator and coordinator for the studies.

"I was really impressed with her work and her passion about oncology," Dr. Flatt said. "She has a skill set that I don't have and that's made a significant difference in the success of the program. It goes without saying, when you have someone who is familiar with the health care system in Mexico, familiar with the challenges and who speaks the native language, your impact is going to be much greater than what I could ever do as a physician here in the U.S.," Dr. Flatt said. Much of our expansion is due to Dr. Garcia's efforts."

The working collaboration that has developed between Dr. Flatt and Dr. Garcia demonstrates the benefit of international trainee and professional educational exchanges. Dr. Flatt accepts at least two oncology fellows from Mexico annually, where they have exposure to both clinical and/or research rotations from one to six months. This option is available for attending physicians who would like to observe for a shorter period of time, and obtain more experience with U.S. pediatric cancer protocols.

But as Drs. Flatt and Garcia build the infrastructure for long-term research, they feel a strong responsibility to address the present conditions in Mexico. Pediatric cancer is the #1 cause of childhood mortality in that country, and approximately 90 percent of pediatric patients with cancer present with advanced-stage disease, which affects treatment and overall survival.

Marta Zapata, MD, recently visited Children's Mercy to collaborate on research with Dr. Flatt.

Lilia Garcia Rodriguez, MD (fourth from left) and Terrie Flatt, DO, MA, (fifth from left), posing with the Leon Group during a recent visit to Mexico.

"Late diagnosis is the biggest factor," Dr. Garcia said. Also contributing to the situation are the failure to recognize symptoms early, lack of diagnostic equipment such as MRI and CT scanners, and lack of resources to pay for needed medications, including chemotherapy and antibiotics.

"The research we're doing is important because three years down the line it may have an impact on therapy," Dr. Flatt said. "But there's also the here and now and the need to impact lives today." Global health demands a commitment to improve outcomes and access to basic care.

In conjunction with World Child Cancer, USA, a non-profit organization that is dedicated to improving outcomes for children with cancer around the world, Drs. Flatt and Garcia have been "full steam ahead" with the production of videos in seven different indigenous languages in Mexico. The videos explain the most common presenting signs and symptoms of cancer in an attempt to facilitate prompt referral to a pediatric oncologist.

"Mexico has over 96 different languages representing approximately 16 million people, and in some regions, indigenous people represent 30 to 40 percent of the population. Their first language may not be Spanish," Dr. Flatt explained. Drs. Flatt and Garcia are also committed to education efforts in Mexico for primary care physicians, nursing staff and even oncologists. Since 2016, more than 400 nurses and 200 primary care physicians have attended education conferences aimed at improving outcomes for Mexican children. Lectures have focused on early signs and symptoms of childhood cancer, recognition of fever and infection in the pediatric cancer patient, central line workshops and error prevention. Since 2016, Dr. Flatt has been an invited speaker in Mexico and Latin America, and has given more than 30 lectures in Spanish.

"We have made some strides," Dr. Flatt said, "but we have a lot yet to accomplish so that children everywhere continue to have better outcomes and bright futures."

Nursing workshop to improve central line care in Veracruz, Mexico.

Marta Zapata, MD, (far left), Terrie Flatt, DO, MA, (third from right) and Lilia Garcia Rodriguez, MD, (far right), posing with the INP Group in Mexico.

Terrie Flatt, DO, MA, (second from left) and Lilia Garcia Rodriguez, MD, (third from right) posing with the Oaxaca Group in Mexico.

Lilia Garcia Rodriguez, MD, with cancer patients in Mexico.

Terrie Flatt, DO, MA, leading a lecture in Mexico.

Theresa Torres, APRN, posing with a patient in Mexico.

A presentation to medical staff in Mexico.

Lilia Garcia Rodriguez, MD, filming informational video in Mexico.

The Black & Veatch Building, on the Children's Mercy Adele Hall Campus in Kansas City, Mo., houses the Division Of Hematology/Oncology/Bone Marrow Transplantation.

Cancer Center Program Areas

LEUKEMIA AND LYMPHOMA PROGRAM

The Leukemia and Lymphoma Program at Children's Mercy Kansas City includes experts in the diagnosis and management of hematologic malignancies in children and young adults. The program is a collaborative effort dedicated to delivering state-of-the-art clinical care and to generate innovative and collaborative research efforts. Members are multidisciplinary and include faculty from the sections of oncology, bone marrow transplant, hematopathology, cytogenetics and the cancer genomics program. Comprehensive patient care meetings occur every two weeks where cases are reviewed by program members and research efforts are discussed. Members are actively involved in the development of clinical trials for leukemia and lymphoma on a national and international level through the Children's Oncology Group and other clinical research consortiums.

NEURO-ONCOLOGY PROGRAM

The Children's Mercy Cancer Center Neuro-Oncology Program is a multidisciplinary program led by Kevin Ginn, MD, with a primary focus on providing access to advanced cancer therapy to improve outcomes for children in the Kansas City region with brain and spinal cord tumors. Central nervous system tumors remain one of the leading causes of cancer-related death and morbidity, and these patients benefit from the individualized care plans developed by multiple subspecialists available at Children's Mercy. The frequent multidisciplinary tumor board allows for in-depth discussion regarding each individual patient, ensuring proper planning to improve patient care. Involvement in national consortiums such as Beat Childhood Cancer and the Children's Oncology Group, or COG, allows Children's Mercy to provide enrollment in clinical trials for both new and relapsed patients. Exciting research collaborations through the Midwest Cancer Alliance Partners and the University of Kansas Cancer Center have resulted in funded research investigating new therapies for glioblastoma and atypical teratoid rhabdoid tumor, which are two of the most devastating tumors in pediatrics. The goal of the Neuro-Oncology Program continues to be to provide comprehensive care and cutting-edge therapy close to home for every patient with a central nervous system tumor who enters the doors of Children's Mercy.

HISTIOCYTOSIS PROGRAM

The Histiocytosis Program at Children's Mercy provides a comprehensive setting for children with a group of rare diseases. The program, led by J. Allyson Hays, MD, pediatric hematologist/oncologist, provides current and inclusive clinical care, while collaborating with Jenn Hudson, APRN, and Sara Donnelly, LCSW. Regular, multidisciplinary tumor boards offer opportunities to discuss management of these challenging diseases with pediatric orthopaedic surgeons, pediatric endocrinologists, pediatric dermatologists and pediatric pathologists familiar with Langerhans cell histiocytosis, hemophagocytic lymphohistiocytosis, sinus histiocytosis with massive lymphadenopathy/Rosai Dorfman, juvenile xanthogranulomatous disease and Erdheim-Chester disease. Children's Mercy is a member of NACHO, the North American Consortium for Histiocytosis, and participates in international and national clinical trials to improve the care of children with histiocytic diseases.

BONE AND SOFT TISSUE SARCOMA PROGRAM

Sarcoma accounts for approximately 15 percent of all childhood cancers. Each year, Children's Mercy treats approximately 30 children with bone or soft tissue tumors. The Bone and Soft Tissue Sarcoma Program at Children's Mercy is led by Joy Fulbright, MD, who is board certified in both pediatrics and internal medicine and trained at MD Anderson. The program consists of specialists in: oncologic orthopaedic surgery (Howard Rosenthal, MD, and Kyle Sweeney, MD), radiation oncology (Vickie Massey, MD), rehabilitative medicine (Kimberly Hartman, MD), pediatric oncology, pathology, interventional radiology and radiology. The goal is to provide seamless care coordination from radiation oncology to pathology and orthopaedic surgery, with a multidisciplinary tumor board and enhanced collaborative research across disciplines.

The multidisciplinary Bone and Soft Tissue Clinic allows patients to receive all services on one campus. Commonly treated diagnoses include osteosarcoma, Ewing sarcoma, rhabdomyosarcoma and non-rhabdomyosarcoma soft tissue sarcoma.

PATIENT AND FAMILY RESEARCH

The Patient and Family Research Program focuses on individual and family development, as well issues that occur across the treatment trajectory and which could compromise individual and family well-being. This includes supportive care, symptom management and psychosocial needs for all members of the family.

Mandy Riffel and Jennifer Kemble, BFA, of the Children's Research Institute Biorepository

CHILDREN'S MERCY ONCOLOGY BIOREPOSITORY

The Children's Mercy Oncology Biorepository, known as the Tumor Bank, is a collection of blood, bone marrow and tumor biopsy samples donated by Children's Mercy oncology patients, as well as by bone marrow transplant patients and donors. Each of the samples is collected during routine clinical procedures and is annotated with information about the patient's age at diagnosis, type of cancer, treatment and response to therapy. Samples are obtained at multiple time points, including the time of initial diagnosis, at remission and at relapse, if it occurs.

The rights and privacy of participants in the Tumor Bank are protected by a research protocol approved by the Children's Mercy Hospital Institutional Review Board (IRB). The result is a robust collection of biological samples and accompanying clinical data that is available for use by researchers at Children's Mercy and their scientific collaborators. New this year, generous philanthropic support is making it possible to perform genomic profiling studies on all Tumor Bank samples. The results will help Children's Mercy researchers to identify causes of pediatric cancers, predictors of response, and targets for new therapies. If you would like more information about the Tumor Bank, or if you are interested in becoming a participant, contact the Tumor Bank at (816) 302-6808.

CANCER GENOMICS

The Cancer Genomics Program at Children's Mercy is led by a team of doctors who are using genomic profiling to study cancer in infants, children and adolescents. This team is sequencing the whole genome (complete DNA), whole exome (coding regions of genes), and RNA (protein coding molecules) from both cancer cells and healthy, non-cancer cells. This team is working closely with the Genomic Medicine Center at Children's Mercy to use cutting-edge research technologies, such as methylation sequencing and single-cell sequencing, to discover the driving molecular features of pediatric cancers and to search for new treatment targets. The program offers a clinical test for more than 100 genes that can identify mutations in genes which place a patient at risk for cancer. In children, approximately 15 percent of cancers are caused by inherited genetic mutations and patients with increased risk of cancer are offered genetic counseling and routine health check-ups and cancer screening in the oncology clinic. The molecular tumor board, consisting of oncologists, molecular pathologists, radiologists, surgeons, radiation oncologists and other pediatric subspecialists, reviews each child's molecular test results and makes recommendations regarding treatment options. For further information on the Cancer Genomics Program or the molecular testing available, contact the Cancer Genomics Program at (816) 302-6808.

IMMUNOTHERAPEUTICS PROGRAM

The Cancer Immunotherapeutics Program at Children's Mercy Kansas City promotes innovative basic and translational investigations designed to support and launch clinical trials targeting pediatric and adult malignancies. The program supports local investigator-initiated cancer-directed cellular therapeutics trials at Children's Mercy and the University of Kansas Medical Center, and participates in pharmaceutical company sponsored trials of cellular therapeutics and complex biologics.

Erin Guest, MD
and Midhat Farooqi, MD, PhD

SURVIVE & THRIVE

The Survive & Thrive Program offers comprehensive medical and emotional care to childhood cancer survivors who are at least two years off treatment and five years from the date of diagnosis. The program offers four clinics per month with more than 300 survivors receiving care. Childhood cancer survivors are at risk for health problems or late effects from their cancer and treatment. Late effects can be physical or emotional, and typically appear in the second decade of life. The development of late effects may be influenced by the type of cancer, the treatment, age at diagnosis and genetic predisposition. An estimated 95 percent of childhood cancer survivors will develop at least one late effect at some point during their life. Late effects may be preventable or modifiable, which is why lifelong follow-up is important for all survivors.

Examples of late effects that may occur in survivors include hearing loss, heart dysfunction, infertility, organ dysfunction (i.e., restrictive or obstructive lung disease), endocrine dysfunction and development of a second cancer. In the Survive & Thrive Clinic, survivors are monitored for development of late effects according to the Children's Oncology Group Long-term Follow-up Guidelines. The team ensures diagnostic tests and labs are completed according to the guidelines and referrals are made to other specialists when necessary. The Survive & Thrive team works closely with health care providers in other specialties to ensure each survivor's unique health needs are met. Specialists the team works closely with include endocrinology, cardiology and developmental and behavioral sciences.

In 2016, Children's Mercy launched the Cardio-Oncology Program to better meet the needs of cancer patients at risk for developing cardiotoxicity (damage to the heart and vascular system). Anthracyclines are a class of chemotherapy drugs used in many pediatric cancer treatment regimens. Anthracyclines, even in low doses, increase the risk of heart problems in cancer survivors. Radiation therapy that involves the heart or major vessels (vena cava and aorta) also increases the risk of developing heart problems. The Cardio-Oncology Program offers specialized treatment that incorporates screenings by pediatric cardiologists during cancer treatment and after for survivors. Monitoring for and addressing cardiac concerns early can reduce the risk of severe or life-threatening heart problems. Examples of heart problems that may arise during and after cancer treatment include: heart failure, valvular heart disease, left ventricular function, elevated cholesterol, elevated blood pressure and arrhythmia. The collaboration with the pediatric cardiologists ensures survivors at risk for cardiac problems receive comprehensive screening, education and intervention as needed.

A visit to the Survive & Thrive Clinic includes a thorough physical exam, recommendations for long-term follow-up care, education on late effects of cancer treatment and how to maintain a healthy lifestyle. Assessments by a dietitian and social worker are included in the survivorship clinic visit to ensure all needs of the survivor are met. In conjunction with the hospital-wide Transition to Adulthood Program, preparation for transition to adult providers is incorporated into each visit once survivors reach 15 years of age. The Survive & Thrive team works with each survivor to teach skills to advocate for their health care needs and develop an individualized transition plan. At the time of transition, the team works with the survivor, family and adult health care providers to ensure the transfer of care is smooth for everyone involved in the process.

FAMILY CARE TEAM (FACT)

Multidisciplinary care is integral to the overall outcomes and well-being of patients. Outside of medically directed care, patients and families have many other needs that are addressed by the Family Care Team (FaCT). Regular FaCT rounds and collaboration ensures that all physical, developmental, emotional, educational and spiritual needs are met for patients and families. The Family Care Team is available to assist from point of diagnosis through the completion of treatment and beyond for patients with cancer.

The Patient and Family Support Team consists of child life specialists, a school teacher, music therapy, and a patient activity assistant, who is also the handler of the facility dog on staff working on the inpatient unit. Together, the team works collaboratively to support the psychosocial and developmental needs of children and families.

Child life specialists are trained professionals who help children cope with the stress and uncertainty of illness and hospitalization. They are child development experts who work to ensure life remains as normal as possible for children in a health care setting through preparation, coping and normalization.

Preparation is provided by child life specialists to explain and teach patients about medical procedures, coping skills and other health care experiences. Coping facilitation promotes effective coping strategies to help reduce anxiety and enhance cooperation with the health care event or diagnosis. As advocates of family-centered care, child life specialists work in partnership with the medical team to meet the unique emotional, developmental and cultural needs of each child.

Facility dog Hunter, along with his handler, Aimee Hoflander, visit a patient.

Hospital-based school teachers establish a positive learning climate of success for students with chronic and serious medical conditions, and coordinate educational plans with home schools. Music therapists provide opportunities for self-expression and development of positive coping skills to promote increased comfort, and to support developmental growth.

Patient activity coordinators provide patient and family activities and volunteer supervision.

Clinical social workers are master's-level licensed professionals working as part of the primary team to provide comprehensive and compassionate family-centered care. Social workers understand that any change in the child's health can alter a family's life in many ways, and are trained to provide a thorough assessment and address the ongoing needs of the patients and families.

Social workers can help with therapeutic support including adjustment to illness, crisis intervention, development of coping skills, family concerns, end-of-life and bereavement; care planning including education on advance directives, school concerns, legal issues, transition to adult care, and end-of-life concerns; and community/resource referrals to assist with financial concerns, transportation and lodging needs, support and mental health referrals. Every patient has an assigned clinical social worker who follows the patient and family through diagnosis, treatment, relapse, survivorship or bereavement.

In the Spanish-speaking Clinic, the social worker works alongside an interpreter to provide services to the patients and families. Additional time is spent locating resources and partnering with community resources specific to the Hispanic population. The social worker assists families in navigating the health care system, locating financial assistance, seeking and connecting to necessary resources and utilizing legal services. The social worker also assesses and helps to

educate medical staff on cultural beliefs and traditions within the family system and how cultural issues may impact health care.

The **Parent to Parent Program**, or PTP, continues to offer support and comfort to all of the families within the division through the use of specially trained parent volunteers and a clinical social worker dedicated specifically to PTP program management.

There are many services offered through the PTP program, including parent volunteers available to share, listen and support current parents; two stocked parent rooms that offer weekly dinners, breakfasts, therapeutic and educational activities and a safe place to unwind while a child is hospitalized; "care bags" for families upon unexpected admissions to help ease some burden of a hospital stay; and new parent journals. The Parent to Parent Program also offers an extensive bereavement follow-up program that supports families for approximately 13 months after a child's death.

The PTP has successfully introduced social media into the bereavement follow-up program and has been able to offer additional support in that way. PTP has worked closely with a number of local organizations, as well as the Children's Mercy Cancer Center, and has established ongoing philanthropic support of the parent rooms to serve the increasing needs of inpatient families. The Children's Mercy Hematology/Oncology Parent to Parent Program has been innovative in establishing this program model and was recently highlighted at the Association of Pediatric Oncology Social Workers conference in 2017.

The Lisa Barth Chapel

The **Chaplain** is a member of the Hematology/Oncology/BMT team and regularly provides spiritual and emotional support to patients and families during the course of a child's illness. This includes end-of-life discussions as necessary, and support at the time of death and beyond.

Providing tailor-made rituals for patients and families at the time of significant events like bone marrow transplant is another way a chaplain provides support. At the request of the family, the chaplain can contact a family's own clergy person/spiritual leader. For families who live outside the Kansas City area, again at the request of the family, the chaplain can contact a local leader from the family's faith tradition to provide additional support.

The chaplain provides education about the spiritual resources that are available within the hospital, such as the activities in the Lisa Barth Chapel like Sunday worship, concerts and celebrations from various faith traditions. The chaplain participates in team meetings. Providing support to the staff is another important role of the chaplain.

Music Therapy services are offered to patients and families at the bedside to address the specific needs of each individual patient. Music interventions are designed after an assessment of need and generally involve the use of both live vocal and instrumental music, as well as technology. Goals may include but are not limited to the reduction of pain or anxiety; increased self-expression and positive changes in mood; increased physical strength and endurance; greater relaxation; learning positive coping strategies; and the support of developmental skills. Patients are encouraged to take an active role in making music and learning how to use music as a helpful and fun tool.

An on-site **School Teacher** works with patients primarily on the inpatient floor with some availability in clinic as needed to assist with the challenge of keeping up with school work while a patient is undergoing treatment. The school teacher is able to communicate directly with the child's school to get current assignments and also to advocate for the patient's needs once they return to the school setting.

ADOLESCENT AND YOUNG ADULT PROGRAM

The Adolescent and Young Adult Cancer Program at Children's Mercy, better known as the AYA Program, was developed to improve outcomes for teens and young adults who have been diagnosed with cancer. The program focuses on increasing awareness of the unique needs of AYA patients, improving compliance with treatment regimens and follow-up care. Addressing the psychosocial, educational and occupational needs of patients on and off treatment to improve overall quality of life is also a major focus of the program. At Children's Mercy, we offer patients in this age group access to clinical trials through the Children's Oncology Group and the Children's Mercy Experimental Therapeutics Program. Members of the program are also available to discuss cases with adult oncologists treating patients with pediatric cancer who are unable to receive treatment at Children's Mercy. The program can assist in guiding their therapy and providing psychosocial support to the families. Three key areas of focus within the AYA Program include:

Fertility Preservation Team:

This team serves patients hospital-wide to discuss fertility preservation options prior to receiving surgery or medical therapy that could affect the patient's future fertility. The team consists of physicians, social workers and advanced practice nurses who have received specialized training to discuss the risks of therapy on the patient's fertility, options to preserve their fertility, and how to refer patients to appropriate specialists. This team works closely with the University of Kansas Medical Center to be able to offer sperm, egg, ovarian tissue and testicular tissue cryopreservation.

PEEPS (Patients Encouraging and Engaging Peer Support):

Teens share a unique perspective regarding life-changing medical experiences. The PEEPS Program is designed to match teen patients, ages 13 and older, with a positive young adult role model who has had a similar experience. PEEPS is a network of volunteer mentors who are young adults (ages 18-26) interested, trained and available for occasional phone or e-mail contact with a patient 13 and older facing a new medical diagnosis or life-changing event.

Hem/Onc Teen (HOT) Board:

The Hem/Onc Teen (HOT) Board was started in 2013 with the goal of providing Children's Mercy with a hematology/oncology-focused patient advisory board representing various ages, backgrounds and communities. The HOT Board meets monthly and communicates direct concerns, ideas and suggestions to the AYA Program staff and hospital administration. The board has supported/is in process of supporting several projects that affect hospital policies, procedures and literature, including designing the 4 Henson Teen Unit and Teen Room, providing ideas for both outpatient and inpatient social event activities, assisted in the creation of the hospital transition video, assisted in the creation of fertility preservation educational handouts, and participated in the hospital Get Well Network design teams, and several other accomplishments.

NURSING ROLE

The Hematology/Oncology Division provides a multidisciplinary approach in caring for pediatric patients and their families. The division includes experienced, highly skilled registered nurses, many who are certified pediatric hematology/oncology nurses. Nursing staff provides a vast range of nursing services and play a vital role in coordination of patient care, assessment, obtaining laboratory specimens, chemotherapy, biotherapy, medication administration, sedations and transfusions in a safe and nurturing environment. Nursing staff provide sedation to assist with calming and relaxing a patient requiring lumbar punctures or bone marrows.

Patients and their families are treated in the Hematology/Oncology Clinic and inpatient floor with compassion in a family-centered environment that recognizes their physical, emotional, spiritual and social needs. The nurse advocates and provides support to patients and their families during their treatment by answering questions, listening to patient/family concerns, and educating patients/families about central line care, medications and their side effects. Nursing staff work with interpreter services in order to communicate with patients and families with language barriers to deliver the highest level of safe, quality care.

The nurses in Hematology/Oncology are involved with patients from the time of the initial diagnosis through treatment, and even after treatment is completed. Many patients develop strong, supportive relationships with their nurse, who is an important part of the care team.

RESEARCH

Research at Children's Mercy is aimed at trying to find a better or more effective way to treat a child with a medical condition. Research can be in the form of chart reviews, surveys, device studies and drug studies that take aim to improve the care of a given population.

Research plays a vital role in the care of children with cancer and other blood disorders. Current standard of care medications have proven to be the best treatment in a given state of a disease through research studies prior to now. The testing of medications that are approved for the treatment of adults could potentially have therapeutic/curative effects in children. Research protocols allow for the administration of medications, which would be otherwise unavailable to children, in a safe and controlled environment. Therapeutic efficacy is analyzed periodically throughout the studies and after completion of a study to determine if standard of care should be revised. In addition, the testing of new medications could lead to future therapy, changing to a treatment that could have fewer side effects, yet be just as or more effective than what is currently being used.

Research teams are comprised, but not limited to physicians, nurses and coordinators who work together to remain compliant with approved protocols, and to monitor the safety of children who receive new medications in the pediatric population.

Kara Hoolehan, RN, and Theresa Torres, APRN

DIVISION OF HEMATOLOGY/ ONCOLOGY/BMT MANUSCRIPTS AND PRESENTATIONS (2017-2018)

MANUSCRIPTS

Genomics of Primary Chemoresistance and Remission Induction Failure in Pediatric and Adult Acute Myeloid Leukemia. Brown FC, Cifani P, Drill E, He J, Still E, Zhong S, Balasubramanian S, Pavlick D, Yilmazel B, Knapp KM, Alonzo TA, Meshinchi S, Stone RM, Kornblau, SM, Marcucci G, Gamis AS, Byrd JC, Gonen M, Levine RL, Kentsis A. British Journal of Haematology. (2017) 176(1):86-91.

Disease Characteristics and Prognostic Implications of Cell Surface FLT3 Receptor (CD135) Expression in Pediatric Acute Myeloid Leukemia: A Report from the Children's Oncology Group. Tarlock K, Alonz T, Loken M, Gerbing R, Ries R, Aplenc R, Sung L, Raimondi S, Hirsch B, Kahwash S, McKenney A, Kolb E, Gamis A, Meshinchi S. Clinical Cancer Research. (2017) 23(14):3649-3656.

Health-related Quality of Life and Chronic Health Conditions in Survivors of Childhood AML with Down Syndrome. Schultz KAP, Chen L, Kunin-Batson A, Chen Z, Woods WG, Gamis AS, Kawashima T, Oeffinger KC, Nicholson HS, Neglia JP. Journal of Pediatric Hematology Oncology. (2017) 39(1):20-25.

Improvement in Treatment Outcome and Identification of a New Prognostic Parameter in Myeloid Leukemia of Down Syndrome (ML-DS): Results of the Children's Oncology Group (COG) Phase III AAML0431 Trial. Taub J, Berman JN, Hitzler JH, Sorrell AD, Lacayo NJ, Mast K, Head D, Raimondi SC, Hirsch B, Ge Y, Gerbing RB, Wang YC, Alonzo TA, Campana D, Coustan-Smith E, Mathew P, Gamis AS. Blood. (2017) 129(25):3304-3313.

Genomic Architecture and Treatment Response in de novo Pediatric Acute Myeloid Leukemia: A Report from the Children's Oncology Group. Vujkovic M, Attiyeh EF, Ries RE, Goodman EK, Ding Y, Kavcic M, Alonzo TA, Wang YC, Gerbing RB, Sung L, Hirsch B, Raimondi S, Gamis AS, Meshinchi S, Aplenc R. Blood, (2017) 129(23):3051-3058.

Central Nervous System Disease in Pediatric Acute Myeloid Leukemia: A Report from the Children's Oncology Group. Johnston DL, Alonso TA, Gerbing RB, Aplenc R, Woods WG, Meshinchi S, Gamis AS. Pediatric Blood & Cancer, 64(12): e26612. Prepublished 2017 Apr 28.

Gemtuzumab Ozogamicin in Infants with Acute Myeloid Leukemia: Combined Results from the Children's Oncology Group Trials, AAML03P1 and AAML0531. Guest EM, Aplenc R, Sung L, Raimondi SC, Hirsch BA, Alonzo TA, Gerbing RB, Wang YC, Kahwash SB, Heerema-McKenney, A, Meshinchi S, Gamis AS. Blood. (2017) 130(7):943-945.

CD33 Splicing Polymorphism Determines Gemtuzumab Ozogamicin Response in de novo AML: Report from Randomized Phase III Children's Oncology Group Trial AAML0531. Lamba JK, Chauhan L, Shin M, Loken MR, Pollard JA, Wang YC, Ries RE, Hirsch BA, Raimondi SC, Walter RB, Bernstein ID, Gamis AS, Alonzo TA, Meshinchi S. Journal of Clinical Oncology. (2017) 35(23):2674-2682.

Arsenic Trioxide Consolidation Allows Anthracycline Dose Reduction for Pediatric Patients with Acute Promyelocytic Leukemia (APL): A Report from the Children's Oncology Group Phase III Historically Controlled Trial AAML0631. Kutny MA, Alonzo TA, Gerbing RB, Wang YC, Raimondi SC, Hirsch BA, Fu CH, Meshinchi S, Gamis AS, Feusner JH, Gregory J. Journal of Clinical Oncology. 2017 Aug 2:JCO2016716183. doi: 10.1200/JCO.2016.71.6183. [Epub ahead of print].

The Molecular Landscape of Pediatric Acute Myeloid Leukemia Reveals Recurrent Structural Alterations and Age-specific Mutational Interactions. Bolouri H, Farrar JE, Ries RE, Triche Jr T, Lim EL, Alonzo TA, Ma Y, Moore R, Mungall A, Marra MA, Guidry A JM, Davidsen TM, Gesuwan P, Salhia B, Capone S, Ramsingh G, Hermida LC, Kolb EA, Gamis AS, Smith MA, Gerhard DS, Meshinchi S. Nature Medicine. 2017 Dec 11. doi: 10.1038/nm.4439. [Epub ahead of print].

Pharmacokinetics of Two 6-Mercaptopurine Liquid Formulations in Children with Acute Lymphoblastic Leukemia. Tolbert J, et al. Pediatric Blood and Cancer 64 (8). 2017 Mar 10.

Neuroblastoma in Children: Update on Clinicopathologic and Genetic Prognostic Factors. Ahmed AA, Zhang L, Reddivalla N, Hetherington M. Pediatr Hematol Oncol. 2017 Apr;34(3):165-185. doi: 10.1080/08880018.2017.1330375. Epub 2017 Jun 29. Review.

Increasing Rates of Thrombosis in Children with Congenital Heart Disease Undergoing Cardiac Surgery. Silvey M, Hall M, Bilynsky E, Carpenter SL. Thrombosis Research. 2018 Feb; 162: 15-21.

Prophylaxis, and Treatment of Venous Thromboembolism in Congenital Heart Disease Patients. Silvey M, Brandao L. Risk Factors, Front. Pediatr. 2017 Jun; 5 (146): e1-e8.

Building Blocks for Institutional Preparation of CTL019 Delivery. McGuirk J, Waller E, Qayed M, Abhyankar S, Ericson S, Holman P, Keir C, Myers GD. Cytotherapy 2017.

Parental Perceptions of Obesity and Obesity Risk Associated with Childhood Acute Lymphoblastic Leukemia. Jones G, McClellan W, Raman S, Sherman A, Guest E, August KJ. Pediatric Hematology Oncology 2017 Jul;39(5):370-375.

Updates in the Biology and Therapy for Infant Acute Lymphoblastic Leukemia. Guest E, Stam R. Curr Opin Pediatr. 2017 Feb;29(1)20-26.

Radionuclide Synovectomy/Synoviorthesis (RS) in Persons with Bleeding Disorders: A Review of Impact of National Guidance on Frequency of RS Using the ATHNdataset. Sharma R, Dunn A, Aschman D, Cheng D, Wheeler A, Soni A, McGuinn C, Knoll C, Stein D, Young G, French J, Sanders J, Davis J, Tarantino MD, Lim MY, Gruppo RA, Sidonio R, Ahuja S, Carpenter S, Pipe SW, Shapiro A. Haemophilia 2017; DOI: 10.1111/hae.13273.

Factor VII Deficiency Diagnosed after Minor Genital Trauma. Reeves J, Dowlut-McElroy T, Mou S, Strickland JA, Carpenter SL. Haemophilia 2017; 23: e133-e135.

Radionuclide Synovectomy/Synoviorthesis (RS) in Patients with Bleeding Disorders: A Review of Patient and Procedure Demographics and Functional Outcomes in the ATHNdataset. McGuinn C, Cheng D, Aschman D, Carpenter SL, Sidonio R, Soni A, Tarantino MD, Wheeler AP, Dunn AL, and the ATHN 3 Working Group. Haemophilia. 2017; 23: 926-933.

Novel HLA-DP Region Susceptibility Loci Associated with Severe Acute GvHD. Goyal RK, Lee SJ, Wang T, Trucco M, Haagenson M, Spellman SR, Verneris M, Ferrell RE. Bone Marrow Transplant. 2017 Jan; 52(1):95-100. doi: 10.1038/bmt.2016.210. Epub 2016 Sep 5. PMID: 27595289.

Abnormal B-Cell Maturation in the Bone Marrow of Patients with Germline Mutations in PIK3CD. Dulau Florea AE, Braylan RC, Schafernak KT, Williams KW, Daub J, Goyal RK, Puck JM, Rao VK, Pittaluga S, Holland SM, Uzel G, Calvo KR. J Allergy Clin Immunol. 2017 Mar; 139(3):1032-1035.e6. doi: 10.1016/j.jaci.2016.08.028. Epub 2016 Sep 30. PMID: 27697496.

Forced Deflation PFT: A Novel Method to Evaluate Lung Function in Infants and Young Children. Goyal R, Ibrahimova A, Escolar M, Szabolcs P, Vander Lugt M, Windreich R, Weiner DJ. Pediatr Blood Cancer. 2017 Apr; 64(4). doi: 10.1002/pbc.26356. Epub 2016 Nov 22. PMID: 27873442.

Natural Killer Cells from Patients with Recombinase-Activating Gene and Non-Homologous End Joining Gene Defects Comprise a Higher Frequency of CD56bright NKG2A+++ Cells, and Yet Display Increased Degranulation and Higher Perforin Content. Dobbs K, Tabellini G, Calzoni E, Patrizi O, Martinez O, Giliani SC, Moratto D, Al-Herz W, Cancrini C, Cowan M, Bleesing J, Booth C, Buchbinder D, Burns SO, Talal A. Chatila, Chou J, Daza-Cajigal V, Otto LM,de Bruin O, la Morena M, Di Matteo G, Finocchi A, Geha R, Goyal RK, Hayward A, Holland S, Huang C, Kanariou MG, King A, Kaplan B, Kleva A, Kuijpers TW, Lee BW, Lougaris V, Massaad M, Meyts I, Morsheimer M, Neven B, Pai S, Plebani A, Prockop S, Reisli I, Soh JY, Somech R, Torgerson TR, Kim Y, Walter JE, Gennery AR, Keles S, Manis JP, Marcenaro E, Moretta A, Parolini S, Notarangelo L. Front Immunol. 2017 Jul 17;8: 798. PMID: 28769923.

Tandem Thiotepa with Autologous Hematopoietic Cell Rescue in Patients with Recurrent, Refractory, or Poor Prognosis Solid Tumor Malignancies. Osorio D, Dunkel IJ, Cervone KA, Goyal RK, Lo KMS, Finlay J, Gardner S. Pediatr Blood Cancer. 2018 Jan. PMID: 28905508.

Abnormalities of T Cell Receptor Repertoire in CD4+ Regulatory and Conventional T cells in Patients with RAG Mutations: Implications for Autoimmunity. Rowe JH, Stadinski BD, Henderson LA, de Bruin LO, Delmonte O, Lee YN, de la Morena T, Goyal RK, Hayward A, China-Hui H, Kanariou M, King A, Kuijpers TW, Soh JY, Neven B, Walter JE, Huseby ES, Notarangelo LD. J Allergy Clin Immunol. 2017 Aug 31. Epub ahead of print. PMID: 28864286.

Medium-term Assessment of Cardiac Function in Pediatric Cancer Survivors. Comparison of Different Echocardiographic Methods, Cardiac MRI and Cardiac Biomarker Testing in Adolescent Cancer Survivors. Shah SS, McClellan W, Knowlton JQ, Mehta J, Goudar S, Ferguson A, Sherman A, Shirali G, Fulbright J. Echocardiography. 2017 Feb;34(2):250-256. doi: 10.1111/echo.13418.

Non-GVHD Ocular Complications After Hematopoietic Cell Transplantation: Expert Review from the Late Effects and Quality of Life Working Committee of the CIBMTR and Transplant Complications Working Party of the EBMT. Inamoto Y, Petriček I, Burns L, Chhabra S, DeFilipp Z, Hematti P, Rovó A, Schears R, Shah A, Agrawal V, Ahmed A, Ahmed I, Ali A, Aljurf M, Alkhateeb H, Beitinjaneh A, Bhatt N, Buchbinder D, Byrne M, Callander N, Fahnehjelm K, Farhadfar N, Gale RP, Ganguly S, Hildebrandt GC, Horn E, Jakubowski A, Kamble RT, Law J, Lee C, Nathan S, Penack O, Pingali R, Prasad P, Pulanic D, Rotz S,Shreenivas A, Steinberg A, Tabbara K, Tichelli A, Wirk B, Yared J, Basak GW, Battiwalla M, Duarte R, Savani BN, Flowers MED, Shaw BE, Valdés-Sanz N. Bone Marrow Transplant. (2018) Dec 7.

Ocular Graft-Versus-Host Disease After Hematopoietic Cell Transplantation: Expert Review from the Late Effects and Quality of Life Working Committee of the CIBMTR and Transplant Complications Working Party of the EBMT. Inamoto Y, Valdés-Sanz N, Ogawa Y, Alves M, Berchicci L, Galvin J, Greinix H, Hale GA, Horn B, Kelly D, Liu H, Rowley S, Schoemans H, Shah A, Lupo Stanghellini MT, Agrawal V, Ahmed I, Ali A, Bhatt N, Byrne M, Chhabra S, DeFilipp Z, Fahnehjelm K, Farhadfar N, Horn E, Lee C, Nathan S, Penack O, Prasad P, Rotz S, Rovó A, Yared J, Pavletic S, Basak GW, Battiwalla M, Duarte R, Savani BN, Flowers MED, Shaw BE, Petriček I. Bone Marrow Transplant. (2018) Dec 7.

Characteristics of Late Fatal Infections after Allogeneic Hematopoietic Cell Transplant Short title: Late Fatal Infections after Transplant. Norkin M, Shaw BE, Brazauskas R, Tecca HR, Leather HL, Gea-Banacloche J, Kamble R, DeFilipp Z, Jacobsohn DA, Ringden O, Inamoto Y, Kasow K, Buchbinder D, Shaw P, Hematti P, Schears R, Badawy SM, Lazarus HM, Bhatt N, Horn B, Chhabra S, Page K, Hamilton B, Hildebrandt GC, Yared JA, Agrawal V, Beitinjaneh A, Majhail N, Kindwall-Keller T, Olsson RF, Schoemans H, Gale RP, Ganguly S, Ahmed I, Schouten HC, Liesveld J, Khera N, Steinberg A, Shah AJ, Solh M, Marks DI, Rybka W, Aljurf M, Dietz AC, Gergis U, George B, Seo S, Flowers M, Battiwalla M, Savani BN, Riches ML, Wingard JR. Biol Blood Marrow Transplant. Volume 25, Issue 2, February 2019, Pages 362-368.

Increased Risk of Early Pain/Symptoms and Higher Risk of Pain/Non-Recovery at 1 Year in 13-17-Year-Old Females After Pediatric BM Donation: Primary Analysis of the Pediatric Related Donor Safety Study Cohort, in preparation. Pulsipher MA, Logan BR, Kiefer DM, Chitphakdithai P, Riches ML, Rizzo JD, Anderlini P, Leitman SF, Varni JW, Kobusingye H, Besser RM, Miller JP, Drexler RJ, Abdel-Mageed A, Ahmed IA, Ball ED, Bolwell BJ, Bunin NJ, Cheerva A, Delgado D, Dvorak CC, Gillio AP, Hahn TE, Hale GA, Haight AE, Hayes-Lattin B, Kasow KA, Linenberger M, Mori S, Prasad VK, Quigg TC, Sahdev I, Schriber J, Shenoy S, Magalhaes-Silverman M, Tse W, Yanik GA, King RJ, Navarro W, Horowitz MH, Confer DL, Shaw BE, Switzer GE.

Risk of Acute Myeloid Leukemia and Myelodysplastic Syndrome after Hematopoietic Cell Autotransplants in Adults for Lymphoma and Plasma Cell Myeloma. Radivoyevitch T, Dean RM, Shaw BE, Brazauskas R, Tecca HR, Molenaar RJ, Battiwalla M, Savani BN, Flowers MED, Cooke KR, Hamilton BK, Kalaycio M, Maciejewski JP, Ahmed I, Akpek G, Bajel A, Buchbinder D, Cahn J-Y, D'Souza A, Daly A, DeFilipp Z, Ganguly S, Hamadani M, Hayashi RJ, Hematti P, Inamoto Y, Khera N, Kindwall-Keller T, Landau H, Lazarus H, Majhail NS, Marks DI, Olsson RF, Seo S, Steinberg A, William BM, Wirk B, Yared JA, Aljurf M, Abidi MH, Allewelt H, Beitinjaneh A, Cook R, Cornell RF, Fay JW, Hale G, Chakrabarty JH, Jodele S, Kasow KA, Mahindra A, Malone AK, Popat U, Rizzo JD, Schouten HC, Warwick AB, Wood WA, Sekeres MA, Litzow MR, Gale RP, Hashmi SK. Leuk Res. 2018 Jul 19. pii: S0145-2126(18)30160-7. doi: 10.1016/j.leukres.2018.07.016. [Epub ahead of print].
Combined Heparin/Acid Citrate Dextrose Solution A Anticoagulation in the Optia Continuous Mononuclear Cell Protocol for Pediatric Lymphocyte Apheresis. DeSimone RA, Myers GD, Guest EM, Shi PA. J Clin Apher. (2018) Nov 29.

Factors Affecting Adolescents' Willingness to Communicate Symptoms During Cancer Treatment: A Systematic Review from the Children's Oncology Group. McLaughlin CA, Gordon K, Hoag J, Ranney L, Terwilliger NB, Ureda T, Rodgers C. J Adolesc Young Adult Oncol. (2018) Nov 29. [Epub ahead of print].

The Why Behind the Questions: Question-Asking in Parents of Children Newly Diagnosed with Cancer—A Report From the Children's Oncology Group. Kelly KP, Withycombe J, Stegenga K, Rodgers C. J Pediatr Nurs. (2018) Nov - Dec;43:23-28.

Effect of Aging and Predonation Comorbidities on the Related Peripheral Blood Stem Cell Donor Experience: Report from the Related Donor Safety Study. Pulsipher MA, Logan BR, Chitphakdithai P, Kiefer DM, Riches ML, Rizzo JD, Anderlini P, Leitman SF, Varni JW, Kobusingye H, Besser RM, Miller JP, Drexler RJ, Abdel-Mageed A, Ahmed IA, Akard LP, Artz AS, Ball ED, Bayer RL, Bigelow C, Bolwell BJ, Broun ER, Bunin NJ, Delgado DC, Duckworth K, Dvorak CC, Hahn TE, Haight AE, Hari PN, Hayes-Lattin BM, Jacobsohn DA, Jakubowski AA, Kasow KA, Lazarus HM, Liesveld JL, Linenberger M, Litzow MR, Longo W, Magalhaes-Silverman M, McCarty JM, McGuirk JP, Mori S, Prasad VK, Rowley SD, Rybka WB, Sahdev I, Schriber JR, Selby GB, Shaughnessy PJ, Shenoy S, Spitzer T, Tse WT, Uberti JP, Vusirikala M, Waller EK, Weisdorf DJ, Yanik GA, Navarro WH, Horowitz MM, Switzer GE, Shaw BE, Confer DL. Biol Blood Marrow Transplant. (2018) Nov 10.

Related Peripheral Blood Stem Cell Donors Experience More Severe Symptoms and Less Complete Recovery at 1Year Compared to Unrelated Donors. Pulsipher MA, Logan BR, Kiefer DM, Chitphakdithai P, Riches ML, Rizzo JD, Anderlini P, Leitman SF, Kobusingye H, Besser RM, Miller JP, Drexler RJ, Abdel-Mageed A, Ahmed IA, Akard LP, Artz AS, Ball ED, Bayer RL, Bigelow C, Bolwell BJ, Broun ER, Delgado DC, Duckworth K, Dvorak CC, Hahn TE, Haight AE, Hari PN, Hayes-Lattin BM, Jacobsohn DA, Jakubowski AA, Kasow KA, Lazarus HM, Liesveld JL, Linenberger M, Litzow MR, Longo W, Magalhaes-Silverman M, McCarty JM, McGuirk JP, Mori S, Parameswaran V, Prasad VK, Rowley SD, Rybka WB, Sahdev I, Schriber JR, Selby GB, Shaughnessy PJ, Shenoy S, Spitzer T, Tse WT, Uberti JP, Vusirikala M, Waller EK, Weisdorf DJ, Yanik GA, Navarro WH, Horowitz MM, Switzer GE, Confer DL, Shaw BE. Haematologica. (2018) Oct 31.

Using a Heuristic App to Improve Symptom Self-Management in Adolescents and Young Adults with Cancer. Erickson JM, Ameringer S, Linder L, Macpherson CF, Elswick RK Jr, Luebke JM, Stegenga K. J Adolesc Young Adult Oncol. (2018) Oct 24. doi: 10.1089/jayao.2018.0103. [Epub ahead of print].

Outcome of Children with Rhinovirus Detection Prior to Allogeneic Hematopoietic Cell Transplant. Mowrer C, Lee BR, Goyal R, Selvarangan R, Schuster JE. Pediatr Transplant. (2018) Dec;22(8):e13301. doi: 10.1111/petr.13301. Epub 2018 Oct 19.

Brentuximab Vedotin for Paediatric Relapsed or Refractory Hodgkin's Lymphoma and Anaplastic Large-Cell Lymphoma: A Multicentre, Open-label, Phase 1/2 Study. Locatelli F, Mauz-Koerholz C, Neville K, Llort A, Beishuizen A, Daw S, Pillon M, Aladjidi N, Klingebiel T, Landman-Parker J, Medina-Sanson A, August K, Sachs J, Hoffman K, Kinley J, Song S, Song G, Zhang S, Suri A, Gore L. Lancet Haematol. (2018) Oct;5(10):e450-e461.

Prevalence and Management of Iron Overload in Pyruvate Kinase Deficiency: Report from the Pyruvate Kinase Deficiency Natural History Study. van Beers EJ, van Straaten S, Morton DH, Barcellini W, Eber SW, Glader B, Yaish HM, Chonat S, Kwiatkowski JL, Rothman JA, Sharma M, Neufeld EJ, Sheth S, Despotovic JM, Kollmar N, Pospisilova D, Knoll CM, Kuo K, Pastore YD, Thompson AA, Newburger PE, Ravindranath Y, Wang WC, Wlodarski MW, Wang H, Holzhauer S, Breakey VR, Verhovsek M, Kunz J, McNaull MA, Rose MJ, Bradeen HA, Addonizio K, Li A, Al-Sayegh H, London WB, Grace RF. Haematologica. 2018 Sep 13. pii: haematol.(2018).196295. doi: 10.3324/haematol.2018.196295. [Epub ahead of print].

Association of Infections and Venous Thromboembolism in Hospitalized Children with Nephrotic Syndrome. Carpenter SL, Goldman J, Sherman AK, Selewski DT, Kallash M, Tran CL, Seamon M, Katsoufis C, Ashoor I, Hernandez J, Supe-Markovina K, D'alessandri-Silva C, DeJesus-Gonzalez N, Vasylyeva TL, Formeck C, Woll C, Gbadegesin R, Geier P, Devarajan P, Smoyer WE, Kerlin BA, Rheault MN. Pediatr Nephrol. (2018) Sep 7. doi: 10.1007/s00467-018-4072-6. [Epub ahead of print].

Clinical Pharmacology of Tisagenlecleucel in B-cell Acute Lymphoblastic Leukemia. Mueller KT, Waldron E, Grupp SA, Levine JE, Laetsch TW, Pulsipher MA, Boyer MW, August KJ, Hamilton J, Awasthi R, Stein AM, Sickert D, Chakraborty A, Levine BL, June CH, Tomassian L, Shah SS, Leung M, Taran T, Wood PA, Maude SL. Clin Cancer Res.(2018).

Identification of Risk Markers for Significant Bleeding and Thrombosis in Pediatric Acute Promyelocytic Leukemia; Report From the Children's Oncology Group Study AAML0631. Rajpurkar M, Alonzo TA, Wang YC, Gerbing RB, Gamis AS, Feusner JH, Gregory J, Kutny MA. J Pediatr Hematol Oncol. (2018) Aug 8. doi: 10.1097/ MPH.0000000000001280. [Epub ahead of print].

Molecular Assessment of Circulating Exosomes Toward Liquid Biopsy Diagnosis of Ewing Sarcoma Family of Tumors. Zhang P, Samuel G, Crow J, Godwin AK, Zeng Y. Transl Res. (2018) Nov;201:136-153. doi: 10.1016/j.trsl.2018.05.007. Epub 2018 Jun 23.

Increasing Rate of Pulmonary Embolism Diagnosed in Hospitalized Children in the United States from 2001 to 2014. Carpenter SL, Richardson T, Hall M. Blood Adv. (2018) Jun 26;2(12):1403-1408. doi: 10.1182/bloodadvances.2017013292.

Prophylactic Bypassing Agent Use Before and During Immune Tolerance Induction in Patients with Haemophilia A and Inhibitors to FVIII. Carpenter SL, Khair K, Gringeri A, Valentino LA. Haemophilia. (2018) Jul;24(4):570-577. doi: 10.1111/hae.13534. Epub 2018 Jun 14. Review.

Treatment of Pediatric Plasma Cell Myeloma Type Post-Transplant Lymphoproliferative Disorder with Modern Risk-Directed Therapy. Epperly R, Ozolek J, Soltys K, Cohen D, Goyal R, Friehling E. Pediatr Blood Cancer. (2018) Oct;65(10):e27283. doi: 10.1002/pbc.27283. Epub 2018 Jun 12.

The Role of Inflammation in Venous Thromboembolism. Branchford BR, Carpenter SL. Front Pediatr. (2018) May 23;6:142. doi: 10.3389/fped.2018.00142. eCollection 2018. Review.

Relevance of Abusive Head Trauma to Intracranial Hemorrhages and Bleeding Disorders. Anderst JD, Carpenter SL, Presley R, Berkoff MC, Wheeler AP, Sidonio RF Jr, Soucie JM. Pediatrics. (2018) May;141(5). pii: e20173485. doi:10.1542/peds.2017-3485.

A 16-Year-Old Girl With Eye Pain. Richardson KM, Chen KS, Goubeaux DL, Atkinson CS, Poulose A, Woods G, Goldman JL. J Pediatric Infect Dis Soc. (2018) Apr 21.

Child and Parent Access to Transplant Information and Involvement in Treatment Decision Making. Stegenga K, Pentz RD, Alderfer MA, Pelletier W, Fairclough D, Hinds PS. West J Nurs Res. (2018) Apr 1:193945918770440. doi:10.1177/0193945918770440. [Epub ahead of print].

Utility of Pediatric Female Fertility Preservation Discussions Following Pelvic Radiation. Rentea RM, Poola AS, Fulbright JM, St. Peter SD, Shah SR. Pediatr Surg Int. (2018) Jun;34(6):647-651. doi: 10.1007/s00383-018-4257-x. Epub 2018 Apr 4.

Potential Value of YAP Staining in Rhabdomyosarcoma. Ahmed AA, Habeebu SS, Sherman AK, Ye SQ, Wood N, Chastain KM, Tsokos MG. J Histochem Cytochem. (2018) Aug;66(8):577-584. doi: 10.1369/ 0022155418766515. Epub 2018 Mar 29.

Comparative Oncology Approach to Drug Repurposing in Osteosarcoma. Parrales A, McDonald P, Ottomeyer M, Roy A, Shoenen FJ, Broward M, Bruns T, Thamm DH, Weir SJ, Neville KA, Iwakuma T, Fulbright JM. PLoS One. (2018) Mar 26;13(3):e0194224. doi: 10.1371/journal.pone.0194224. eCollection 2018.

Country-Level Macroeconomic Indicators Predict Early Post-Allogeneic Hematopoietic Cell Transplantation Survival in Acute Lymphoblastic Leukemia: A CIBMTR Analysis. Wood WA, Brazauskas R, Hu ZH, Abdel-Azim H, Ahmed IA, Aljurf M, Badawy S, Beitinjaneh A, George B, Buchbinder D, Cerny J, Dedeken L, Diaz MA, Freytes CO, Ganguly S, Gergis U, Almaguer DG, Gupta A, Hale G, Hashmi SK, Inamoto Y, Kamble RT, Adekola K, Kindwall-Keller T, Knight J, Kumar L, Kuwatsuka Y, Law J, Lazarus HM, LeMaistre C, Olsson RF, Pulsipher MA, Savani BN, Schultz KR, Saad AA, Seftel M, Seo S, Shea TC, Steinberg A, Sullivan K, Szwajcer D, Wirk B, Yared J, Yong A, Dalal J, Hahn T, Khera N, Bonfim C, Atsuta Y, Saber W. Biol Blood Marrow Transplant. (2018) Sep;24(9):1928-1935. doi: 10.1016/j.bbmt.2018.03.016. Epub 2018 Mar 19.

Auer Rods and Marked Myelodysplasia Juvenile Myelomonocytic Leukemia with t(3;5)(q25;q35). Li W, Cooley LD, August K. Pathol Res Pract. (2018) Jun;214(6):919-923.

Tisagenlecleucel in Children and Young Adults with B-Cell Lymphoblastic Leukemia. Maude SL, Laetsch TW, Buechner J, Rives S, Boyer M, Bittencourt H, Bader P, Verneris MR, Stefanski HE, Myers GD, Qayed M, De Moerloose B, Hiramatsu H, Schlis K, Davis KL, Martin PL, Nemecek ER, Yanik GA, Peters C, Baruchel A, Boissel N, Mechinaud F, Balduzzi A, Krueger J, June CH, Levine BL, Wood P, Taran T, Leung M, Mueller KT, Zhang Y, Sen K, Lebwohl D, Pulsipher MA, Grupp SA. N Engl J Med. (2018) Feb 1;378(5):439-448. doi: 10.1056/NEJMoa1709866.

Donor Body Mass Index Does not Predict Graft Versus Host Disease Following Hematopoietic Cell Transplantation. Turcotte LM, Wang T, Hemmer MT, Spellman SR, Arora M, Couriel D, Alousi A, Pidala J, Abdel-Azim H, Ahmed I, Beitinjaneh A, Buchbinder D, Byrne M, Callander N, Chao N, Choi SW, DeFilipp Z, Gadalla SM, Gale RP, Gergis U, Hashmi S, Hematti P, Holmberg L, Inamoto Y, Kamble RT, Lehmann L, MacMillan MA, McIver Z, Nishihori T, Norkin M, O'Brien T, Olsson RF, Reshef R, Saad A, Savani BN, Schouten HC, Seo S, Solh M, Verdonck L, Vij R, Wirk B, Yared J, Horowitz MM, Knight JM, Verneris MR. Bone Marrow Transplant. (2018) Jul;53(7):932-937. doi: 10.1038/s41409-018-0100-1. Epub 2018 Jan 30.

Neurocognitive Dysfunction in Hematopoietic Cell Transplant Recipients: Expert Review from the Late Effects and Quality of Life Working Committee of the CIBMTR and Complications and Quality of Life Working Party of the EBMT. Buchbinder D, Kelly DL, Duarte RF, Auletta JJ, Bhatt N, Byrne M, DeFilipp Z, Gabriel M, Mahindra A, Norkin M, Schoemans H, Shah AJ, Ahmed I, Atsuta Y, Basak GW, Beattie S, Bhella S, Bredeson C, Bunin N, Dalal J, Daly A, Gajewski J, Gale RP, Galvin J, Hamadani M, Hayashi RJ, Adekola K, Law J, Lee CJ, Liesveld J, Malone AK, Nagler A, Naik S, Nishihori T, Parsons SK, Scherwath A, Schofield HL, Soiffer R, Szer J, Twist I, Warwick AB, Wirk BM, Yi J, Battiwalla M, Flowers MDE, Savani B, Shaw BE. Bone Marrow Transplant. (2018) May;53(5):535-555. doi: 10.1038/s41409-017-0055-7. Epub 2018 Jan 17. Review.

Using Liver Elastography to Diagnose Sinusoidal Obstruction Syndrome in Pediatric Patients Undergoing Hematopoetic Stem Cell Transplant. Reddivalla N, Robinson AL, Reid KJ, Radhi MA, Dalal J, Opfer EK, Chan SS. Bone Marrow Transplant. (2018) Jan 15. doi: 10.1038/s41409-017-0064-6. [Epub ahead of print].

CD33 Splicing SNP Regulates Expression Levels of CD33 in Normal Regenerating Monocytes in AML Patients. Lamba JK, Voigt AP, Chauhan L, Shin M, Aplenc R, Eidenschink Brodersen L, Gamis AS, Meshinchi S, Loken MR. Leuk Lymphoma. (2018) Sep;59(9):2250-2253. doi: 10.1080/10428194. 2017.1421756. Epub 2018 Jan 10.

Increasing Rates of Thrombosis in Children with Congenital Heart Disease Undergoing Cardiac Surgery. Silvey M, Hall M, Bilynsky E, Carpenter SL. Thromb Res. (2018) Feb;162:15-21. doi: 10.1016/j.thromres. 2017.12.009. Epub 2017 Dec 13.

Donor Experiences of Second Marrow or Peripheral Blood Stem Cell Collection Mirror the First, but CD34(+) Yields Are Less. Stroncek DF, Shaw BE, Logan BR, Kiefer DM, Savani BN, Anderlini P, Bredeson CN, Hematti P, Ganguly S, Diaz MA, Abdel-Azim H, Ahmed I, Maharaj D, Seftel M, Beitinjaneh A, Seo S, Yared JA, Halter J, O'Donnell PV, Hale GA, DeFilipp Z, Lazarus H, Liesveld JL, Zhou Z, Munshi P, Olsson RF, Kasow KA, Szer J, Switzer GE, Chitphakdithai P, Shah N, Confer DL, Pulsipher MA. Biol Blood Marrow Transplant. (2018) Jan;24(1):175-184. doi: 10.1016/j.bbmt.2017.09.013. Epub 2017 Sep 25.

Neurocognitive Dysfunction in Hematopoietic Cell Transplant Recipients: Expert Review from the Late Effects and Quality of Life Working Committee of the Center for International Blood and Marrow Transplant Research and Complications and Quality of Life Working Party of the European Society for Blood and Marrow Transplantation. Kelly DL, Buchbinder D, Duarte RF, Auletta JJ, Bhatt N, Byrne M, DeFilipp Z, Gabriel M, Mahindra A, Norkin M, Schoemans H, Shah AJ, Ahmed I, Atsuta Y, Basak GW, Beattie S, Bhella S, Bredeson C, Bunin N, Dalal J, Daly A, Gajewski J, Gale RP, Galvin J, Hamadani M, Hayashi RJ, Adekola K, Law J, Lee CJ, Liesveld J, Malone AK, Nagler A, Naik S, Nishihori T, Parsons SK, Scherwath A, Schofield HL, Soiffer R, Szer J, Twist I, Warwick A, Wirk BM, Yi J, Battiwalla M, Flowers ME, Savani B, Shaw BE. Biol Blood Marrow Transplant. (2018) Feb;24(2):228-241. doi: 10.1016/j.bbmt.2017. 09.004. Epub 2017 Sep 20. Review.

Tandem Thiotepa with Autologous Hematopoietic Cell Rescue in Patients with Recurrent, Refractory, or Poor Prognosis Solid Tumor Malignancies. Osorio DS, Dunkel IJ, Cervone KA, Goyal RK, Steve Lo KM, Finlay JL, Gardner SL. Pediatr Blood Cancer. (2018) Jan;65(1). doi: 10.1002/pbc.26776. Epub 2017 Sep 14.

Precision Medicine in Pediatric Cancer: Current Applications and Future Prospects. Ahmed AA, Vundamati VS, Farooqi MS, Guest E. High Throughput. (2018) Dec 13; 7, 39.

The Molecular Landscape of Pediatric Acute Myeloid Leukemia Reveals Recurrent Structural Alterations and Age-Specific Mutational Interactions. Bolouri H, Farrar JE, Ries RE, Triche T, Lim EL, Alonzo TA, Ma Y, Moore R, Mungall A, Marra MA, Guidry Auvil JM, Davidsen TM, Gesuwan P, Salhia B,Capone S, Ramsingh G, Hermida LC, Kolb EA, Gamis AS, Smith MA, Gerhard DS, Meshinchi S. Nature Medicine, (2018) 24:103-112.

CHAPTERS

Careers in Quality Improvement and Patient Safety, in Patient Safety and Quality in Pediatric Hematology/Oncology and Stem Cell Transplantation, Hord J, Hays A, Dandoy CE, Hilden J, Billett AL, Mueller BU. (Eds.), Springer 2017.

ABSTRACTS/PRESENTATIONS

Phototoxic Dermatoses in Children Undergoing Treatment for Acute Leukemia (poster). McCarthy L, Gamis A, Goyal R, Guest E. American Society of Pediatric Hematology/Oncology, Montreal, Quebec, May 2017.

Four Versus Five Chemotherapy Courses in Patients with Low Risk Acute Myeloid Leukemia: A Children's Oncology Group Report (oral presentation). Getz KD, Alonzo TA, Sung L, Meshinchi S, Gerbing RB, Raimondi S, Hirsch BA, Kahwash SB, Choi J, Kolb EA, Gamis AS, Aplenc R. American Society of Clinical Oncology, Chicago, Ill., June 2017.

Efficacy of ALL Therapy for WHO 2016-Defined Mixed Phenotype Acute Leukemia: A Report from the Children's Oncology Group (oral presentation). Orgel E, Alexander TB, Wood B, Kahwash S, Devidas M, Dai Y, Alonzo TA, Mullighan CG, Inaba H, Hunger SP, Gamis AS, Carroll III AJ, Heerema NA, Berman J, Woods WG, Loh ML, Zweidler-McKay PA, Horan JT. American Society of Hematology, Atlanta, Ga., December 2017.

Bortezomib Combined with Mitoxantrone, Vincristine, Peg-Asparaginase and Dexamethasone for Children with Relapsed Acute Lymphoblastic Leukemia. August KJ, Gamis AS, Hays JA, Lewing K, Guest E. American Society of Hematology, Atlanta, Ga., December 2017.

Occurrence of Cardiotoxicity and the Impact on Outcomes Among Children Treated on the AAML0531 Clinical Trial: A Report from the Children's Oncology Group (poster presentation). Getz KD, Sung L, Ky B, Gerbing RB, Leger KJ, Barz A, Sack L, Woods WG, Alonzo TA, Gamis AS, Aplenc R. American Society of Hematology, Atlanta, Ga., December 2017.

Clinical Implications of Detection and Clearance of Post-Induction Residual Disease in 2119 Children and Young Adults with AML: Children's Oncology Group Studies AAML0531 and AAML1031 (poster presentation). Brodersen LE, Alonzo TA, Gerbing RB, Kolb A, Gamis AS, Aplenc R, Meshinchi S, Loken MR. American Society of Hematology, Atlanta, Ga., December 2017.

Outcomes Based on CNS Disease Status in Pediatric Acute Myeloid Leukemia and the Role of Peripheral Blood Contamination in Diagnostic Lumbar Punctures: A Report from the Children's Oncology Group Studies AAML0531 and AAML1031 (poster presentation). Kutny MA, Alonzo TA, Gerbing RB, Wang YC, Aplenc R, Gamis AS, Feusner J, Woods WG, Meshinchi S, Johnston D. American Society of Hematology, Atlanta, Ga., December 2017.

Functional Evaluation and Clinical Implications of FLT3 Juxtamembrane Domain Short Variants in Pediatric AML (poster presentation). Tarlock K, Alonzo TA, Wang YC, Gerbing RB, Hylkema T, Ries RE, Hansen ME, Kolb EA, Gamis AS, Meshinchi S. American Society of Hematology, Atlanta, Ga., December 2017.

CD33-Single Nucleotide Polymorphism (CD33-SNP) Score Predicts Gemtuzumab Ozogamicin Response in Childhood Acute Myeloid Leukemia: Report from Children's Oncology Group AAML0531 Trial (poster presentation). Lamba J, Chauhan L, Shin M, Loken MR, Pollard JA, Wang J, Aplenc R, Hirsch BA, Raimondi SC, Walter RB, Bernstein ID, Gamis AS, Alonzo TA, Meshinchi S. American Society of Hematology, Atlanta, Ga., December 2017.

Drug Transporter ABCB1 SNP Predicts Outcome in Patients with Acute Myeloid Leukemia Treated with Gemtuzumab Ozagamicin: A Report from Children's Oncology Group AAML0531 Trial (poster presentation). Chauhan L, Alonzo TA, Wang J, Loken MR, Pollard JA, Aplenc R, Raimondi SC, Walter RB, Hirsch BA, Bernstein ID, Gamis AS, Meshinchi S, Lamba J. American Society of Hematology, Atlanta, Ga., December 2017.

Revised Risk Stratification Criteria for Children with Newly Diagnosed Acute Myeloid Leukemia: A Report from the Children's Oncology Group (oral presentation). Cooper TM, Ries RE, Alonzo TA, Gerbine RB, Loken MR, Brodersen LE, Raimondi SC, Hirsch BA, Aplenc R, Gamis AS, Kolb EA, Meshinchi S. American Society of Hematology, Atlanta, Ga., December 2017.

Functional Properties of Exon 17 KIT Mutations in Pediatric CBF AML Predict for Inferior Outcome and Enhanced Response to Tyrosine Kinase Inhibition: A Report from the Children's Oncology Group (oral presentation). Tarlock K, Alonzo TA, Gerbing RB, Wang YC, Ries RE, Hylkema T, Joaquin J, Raimondi SC, Hirsch BA, Kolb EA, Gamis AS, Meshinchi S, Pollard JA. American Society of Hematology, Atlanta, Ga., December 2017.

Evaluation of Cancer Testis Antigens (CTAs) As Immuno-Therapeutic Targets in Pediatric AML (oral presentation). Ries RE, Smith JL, Triche T, Farrar JE, Alonzo TA, Ma Y, Wei L, Auvil JG, Gerhard DS, Marra MA, Gamis AS, Kolb EA, Bolouri H, Meshinchi S. American Society of Hematology, Atlanta, Ga., December 2017.

A Case of Dermatotoxicity Secondary to Skewed 6-mercaptopurine Metabolism Improved with Allopurinol (poster presentation). Goubeaux D, Tolbert J, Chastain K, Hetherington M. American Society of Pediatric Hematology and Oncology, Montreal, Canada, April 2017.

Improving Patient Care for Hispanic Pediatric Oncology Patients with Limited English Proficiency (poster presentation). Torres T, Flatt T, Society for International Pediatric Oncology, Washington, D.C., October 2017.

The Scope of Practice for Advance Practice Nurses Working with Short Term Global Health Programs (poster presentation). Johnson P. Congress of the International Society of Paediatric Oncology, Washington, D.C., October 2017.

Development of a Pediatric Oncology Nursing Curriculum in Cambodia (roundtable presentation). Sniderman E, Johnson P, Saith S. Congress of the International Society of Paediatric Oncology. Washington, D.C., October 2017.

Ki-67 Proliferative Index as a Prognostic Marker for Therapeutic Response among Pediatric Patients with De-Novo Acute Lymphoblastic Leukemia (poster presentation). Reddavallia N, Li W, Sherman A, Santa-Olalla Tapia J, Flatt T. American Society of Pediatric Hematology and Oncology, Montreal, Canada, April 2017.

The Role of Hispanic Ethnicity on Outcomes in Pediatric Hematopoietic Stem Cell Transplantation at a Single Institution (poster presentation). Garcia Rodriguez, L, Jefferson M, Radhi M, Sherman A, Chignola B, Flatt T. American Society of Pediatric Hematology and Oncology, Montreal, Canada, April 2017.

Hodgkin Lymphoma: Characteristics and Overall Survival at a Single Institution in Mexico (poster presentation). Garcia Rodriguez L, Juárez Villegas L, Flatt T. American Society of Pediatric Hematology and Oncology, Montreal, Canada, April 2017.

Not Everyone is the Same: Understanding Acute Lymphoblastic Leukemia among Hispanic Children (keynote speaker). Flatt T. First International Pediatric Oncology Conference, Mexico City, Mexico, May 2017.

Pediatric Leukemia: When to Suspect it and What to do (invited speaker), Flatt T. XVI Congreso de Medicina General, Pachuca Mexico March 2017.

Coming to Terms with Errors and the Price if You Don't: Error Prevention Primer (keynote speaker). Flatt T. Hospital de Nino, DIF, Keynote Speaker. State Nursing and General Medical Seminar. (2) Pachuca Mexico, January 2017.

Genomic Analysis and Pathway Characterization of Genes with Somatic Variants in Infant Acute Lymphoblastic Leukemia (poster presentation). Fry J, Farooqi MS, Yoo B, Kostadinov R, Farrow E, Kelley S, Gibson M, Miller N, Johnston J, Brown P, Guest EM. American Society of Hematology, Atlanta, Ga., December 2017.

Genomic Breakpoint and Fusion Transcript Analysis of KMT2A Rearrangement in Infant Acute Lymphoblastic Leukemia (oral presentation). Guest E, Yoo B, Farooqi M, Miller N, Johnston J, Kostadinov R, Farrow E, Kelley S, Gibson M, Brown P. International Society of Paediatric Oncology, Washington, D.C., October 2017.

Genomic Landscape of Infant Acute Lymphoblastic Leukemia with MLL (KMT2A) Rearrangement (poster presentation). Guest EM, Kostadinov R, Farooqi M, Yoo B, Farrow E, Kelley S, Gibson M, Miller N, Brown P. Pediatric Genomic Medicine and Precision Therapeutics Conference, Kansas City, Mo., April 2017.

Transcriptome and Cluster Analysis of Infant Acute Lymphoblastic Leukemia Cases with and without MLL (KMT2A) Rearrangement (poster presentation). Yoo B, Farooqi M, Kostadinov R, Miller N, Johnston J, Farrow E, Kelley S, Gibson M, Brown P, Guest E. Pediatric Genomic Medicine and Precision Therapeutics Conference, Kansas City, Mo., April 2017.

Antagonizing Prolactin Induced JAK/STAT Signaling in Osteosarcoma (poster presentation). Angulo P, Subramaniam D, Chastain K, Guest E, Fulbright J, August K, Anant S. American Society of Pediatric Hematology & Oncology, Montreal, Canada, April 2017.

Transcriptome and Cluster Analysis of Infant Acute Lymphoblastic Leukemia Cases with and without MLL (KMT2A) Rearrangement (poster presentation). Yoo B, Farooqi MS, Kostadinov R, Miller N, Johnston J, Farrow E, Kelley S, Gibson M, Brown P, Guest E. American Association for Cancer, Washington, D.C., April 2017.

Central Venous Catheter Associated Thrombosis in Congenital Heart Disease Patients: A Preliminary Analysis of the Children's Hospital Acquired Thrombosis (CHAT) Registry (poster presentation). Silvey M, Branchford B, Krava E, Jaffray J, Mahajerin A, Carpenter S. International Society on Thrombosis and Haemostasis Congress. Berlin, Germany, July 2017.

Initial Results from a Cohort in a Phase 2a Study (GBT440-007) Evaluating Adolescents with Sickle Cell Disease Treated with Multiple Doses of GBT440, a HbS Polymerization Inhibitor. (oral) Hoppe CC, Inati AC, Brown C, Wang W, Gordeuk VR, Liem R, Woods WG, Piccone CM, Fong E, Balaratnam G, Dixon S, Tonda ME, Washington CB, Yaron Y, Lehrer J. American Society of Hematology, Atlanta, Ga., December 2017.

Comparison of Surgeries at Hemophilia Treatment Centers and Other Facilities in Children with Hemophilia A: A Retrospective Cohort Analysis Using the PHIS Database (poster). Risal A, Hall M, Silvey M, Richardson T, Carpenter SL. Hemostasis and Thrombosis Research Society Scientific Symposium. Scottsdale, Ariz., April 2017.

Bleeding Disorder Associated Intracranial Hemorrhage as Applied to Alleged Abusive Head Trauma (oral presentation). Anderst J, Carpenter SL, Presley R, Berkoff MC, Wheeler A, Sidonio R, Soucie JM. Pediatric Academic Societies Meeting. San Francisco, Calif., April 2017.

The Association of Bleeding Disorders with Non-traumatic Intracranial Hemorrhage and Spontaneous Subdural Hemorrhage (oral presentation). Anderst J, Carpenter SL, Soucie M, Presley R. Helfer Society Annual Meeting. Denver, Colo., April 2017.

Paying it Forward: The Shared Knowledge of Pediatric Nursing Care from the United States to the West Bank Palestine and Beyond (poster presentation). Bartholomew J, Burks C. SIOP, Boston, Mass., October 2017.

Landscape of Neuroblastoma in COG (oral presentation). Bartholomew J, Fitzgerald W. APHON, Palm Springs, Calif., August 2017.

Patient Management in High-Risk Neuroblastoma–A Look at the Literature (oral presentation). Bartholonew J, Secola R, Armideo E. APHON, Palm Springs, Calif., August 2017.

Medication Timeliness in Emergency Department in Pediatric Sickle Cell Disease Population Presenting with Vaso-Occlusive Episode. Goubeaux DL, Hoch K, Woods GM, Routhieaux J, Guignon M, McDougall Kester V. American Society of Hematology, San Diego, Calif., Dec. 2018.

Relationship Between Hemolytic Index Early in Life with Development of Abnormal Transcranial Doppler Velocities in Pediatric Patients with Sickle Cell Anemia. Goubeaux DL, Kalpatthi R, Sherman A, Woods GM. American Society of Hematology, San Diego, Calif., Dec. 2018.

Outcomes of Sickle Cell Integrated Pain Program Clinic in Management of Pain in Pediatric Sickle Cell disease. Goubeaux DL, Robertson G, Kingsley R, Sarcone S, Sherman A, Woods GM. Sickle Cell Disease Research and Education Symposium, Washington, D.C., Jun 2018.

An Unusual Anaphylactic Response to Treatment in a Patient with Severe Type 1 von Willebrand Disease. Goubeaux DL, Carpenter, SL. American Society of Pediatric Hematology/Oncology, Pittsburgh, Pa., May 2018.

Whole Genome Bisulfite Sequencing (WGBS) Robustly Measures the Pharmacodynamics Effect of Decitabine/Vorinostat Epigenetic Treatment in Relapsed Patients with ALL Demonstrating Potent Hypomethylation Associated with Upregulation of PRC2 and TP53 Targets (Oral Presentation). Kostadinov R, Yoo B, Farooqi MS, Kelly MS, Guest E, Burke MJ, Wheelen S, Brown P. American Society of Hematology, San Diego, Calif., Dec. 2018.

Outcomes of Hematopoietic Stem Cell Transplant in Patients with Germline SAMD9/SAMDL Mutations (Oral Presentation). Ahmed I, Schwartz JR, Friehling ED, Vander Lugt MT, Klco JM, Triplett B, Goyal RK. North American Immuno-Hematology Clinical, Education and Research (NICER) Symposium, June 2018.

SAMD9 Mutation Associated Bone Marrow Failure Treated with Bone Marrow Transplant: A Unique Treatment Approach to a Rare Case (Poster). Farooki, S; August, K; Ahmed, I; American Society of Pediatric Hematology/Oncology, Pittsburgh, PA, May 2018.

Outcomes of Hematopoietic Cell Transplantation in Patients with Germline SAMD9/SAM9L Mutations (Poster). Ahmed IA, Schwartz JR, Friehling ED, Vander Lugh MT, Klco, JM, Triplett B, Goyal RK. PBMTC at American Society of Pediatric Hematology/Oncology, Pittsburgh, Pa., May 2018.

Occurrence of Medulloblastoma in Patient with Curry-Jones Syndrome (Case Study Presentation). Porath B, Farooki S, Singh V, Amudhavalli S, Grote L, Cooley L, Ginn, K. Association of Molecular Pathology, San Antonio, Texas, Nov. 2018.

Review of Karotypic Data From Low Grade Glial Brain Tumors (Poster). Cooley L, Smith SC, Gener M, Ginn K. Cancer Genomics Consortium. Nashville, Tenn., Aug. 2018.

Novel Treatment Approach for Patients with Central Nervous System (CNS) Pure Embryonal Carcinoma with Intensive Induction and Consolidation Marrow-Ablative Chemotherapy Followed by Anti-CD30 Antibody-Drug Conjugate, Without Irradiation (Poster). Abu-Arja MH,Conley SE, Abdel-Baki, MS, Osorio DS, Coven S, Abu-Arja RT, Boue D, Ginn K, Leonard J, Finlay J. International Symposium for Pediatric Neuro-Oncology. Denver, Colo., June 2018.

Identifying and Accelerating Potential New Drug Therapies for Pediatric Atypical Teratoid Rhabdoid Tumors (ATRTs) Through Drug Repurposing (Poster). Wood N, Ginn K, Roy A, Boyd CS, Weir S, Ramamoorthy P, Anant S. International Symposium for Pediatric Neuro-Oncology. Denver, Colo., June 2018.

Effect of Dexrazoxane on Left Ventricular Function and Treatment Putcomes in Patients with Acute Myeloid Leukemia: A Children's Oncology Group Report (Oral Presentation). Getz KD, Sung L, Leger K, Alonzo TA, Gerbing RB, Cooper TM, Kolb EA, Gamis AS, Ky B, Aplenc R. American Society of Clinical Oncology, Chicago, Ill., June 2018.

Proteomic lLandscape of de Novo Acute Myeloid Leukemia. Hoff FW, Qiu Y, Hu W, Qutub AA, Gamis AS, Aplenc R, Kolb EA, Alonzo TA, de Bont ES, Horton TM, Kornblau SM. Amer Assoc Cancer Research, Chicago, Ill., April 2018.

Proteomic Profiling of the Unfolded Protein Response Identifies Patients Benefiting from Bortezomib in Pediatric Acute Myeloid Leukemia. Hoff FW, Qiu Y, Hu W, Qutub AA, Gamis AS, Aplenc R, Kolb EA, Alonzo TA, de Bont ES, Kornblau SM, Horton TM. Amer Assoc Cancer Research, Chicago, Ill., April 2018.

Comprehensive Transcriptome Profiling of Cryptic CBFA2T3-GLIS2 Fusion-Positive AML Defines Novel Therapeutic Options – A COG and Target Pediatric AML Study (Oral Presentation). Smith JL, Ries RE, Santaguida MT, Gekas C, Alonzo TA, Gerbing RB, Gamis AS, Aplenc R, Kolb AE, Hylkema T, Eidenschink Broderson L, Loken MR, Bolouri H, Meshinchi S. American Society of Hematology, San Diego, Calif., Dec. 2018.

RPPA-Profiling Identifies Patients with Low Phosphorylation Levels of HSF1 at Serine 326 As Potential Candidate for Bortezomib Treatment in Addition to Standard Therapy in Pediatric Acute Myeloid Leukemia (Oral Presentation). Hoff FW, Hu W, Qiu Y, Gamis AS, Aplenc R, Kolb AE, Alonzo TA, Qutub AA, de Bont ES, Bruggeman SWM, Kornblau SM, Horton TM. American Society of Hematology, San Diego, Calif., Dec. 2018.

Proteomic Landscape of De Novo Pediatric Acute Myeloid Leukemia (Oral Presentation). Hoff FW, Hu W, Qiu Y, Gamis AS, Aplenc R, Kolb AE, Alonzo TA, Qutub AA, de Bont ES, Bruggeman SWM, Horton TM, Kornblau SM. American Society of Hematology, San Diego, Calif., Dec. 2018.

Enhancement of Eligibility Guidelines for Gemtuzumab Ozogamicin Therapy for Childhood Acute Myeloid Leukemia: A Report from Children's Oncology Group Protocol AAML0531 (Poster). Pardo L, Eidenschink Broderson L, Lamba JK, Alonzo TA, Wang Y, Paine D, Gamis AS, Kolb AE, Pollard JA, Cooper TM, Aplenc R, Meshinchi S, Loken MR. American Society of Hematology, San Diego, Calif., Dec. 2018.

.

ANNUAL REPORT CONTRIBUTORS

Terrie Flatt, DO, MA - Editor

Keith August, MD
Katherine Chastain, MD
Linda Cooley, MD, MBA
Maria Del Pilar Coromina, CHI™ MA
Sara Donnelly, LSCSW, LCSW, OSW-C
Julie Fournier, RN
Joy Fulbright, MD
Kevin Ginn, MD
Erin Guest, MD
Allyson Hays, MD
Wendy Hein, RN, MSN, FNP-BC
Maxine Hetherington, MD
Kristy Hurst, RHIT, CTR
Weijie Li, MD, PhD
Ruth Morgan, BS, SCYM
G. Douglas Myers, MD
Lisa Peters, LMSW, LCSW, OSW-C
Theresa Torres, APRN, FNP, CPHON
Amanda Trout, LMSW, LCSW, OSW-C
Robin Ryan, MPH, CCRP
Kristin Stegenga, PhD, RN, CPON
Jaszianne Tolbert, MD
Cindi Vandedale, RHIT, CTR
Jami Wierson, RN, BSN, MBA, CCRC

Division of Hematology, Oncology, Bone Marrow Transplantation Faculty

DIVISION DIRECTOR

Gerald Woods, MD
Division Director, Division of Hematology/Oncology/BMT; Director, Sickle Cell Program; Professor of Pediatrics, University of Missouri-Kansas City School of Medicine

LEADERSHIP

Shannon L. Carpenter, MD, MS
Associate Division Director, Section of Hematology; Director, Hemophilia Treatment Center; Professor of Pediatrics, University of Missouri-Kansas City School of Medicine

Alan S. Gamis, MD, MPH
Associate Division Director, Section of Oncology; Professor of Pediatrics, University of Missouri-Kansas City School of Medicine

Rakesh K. Goyal, MD
Associate Division Director, Section of Blood and Marrow Transplantation; Professor of Pediatrics, University of Missouri-Kansas City School of Medicine

FACULTY

Ibrahim A. Ahmed, MD, DSc
Associate Professor of Pediatrics, University of Missouri-Kansas City School of Medicine

Keith J. August, MD, MS
Principal Investigator, Children's Oncology Group; Program Director, Leukemia and Lymphoma Program; Associate Director, Experimental Therapeutics in Pediatric Cancer; Associate Professor of Pediatrics, University of Missouri-Kansas City School of Medicine

Margaret A. Boyden, MD
Hospitalist; Assistant Professor of Pediatrics, University of Missouri-Kansas City School of Medicine

Terrie G. Flatt, DO, MA
Director, Spanish-Speaking Program; Associate Professor of Pediatrics, University of Missouri-Kansas City School of Medicine

Joy M. Fulbright, MD
Director, Survive and Thrive Program; Director, Adolescents and Young Adult Program; Interim Director, Bone and Soft Tissue Sarcoma Program; Associate Professor of Pediatrics, University of Missouri-Kansas City School of Medicine

Kevin F. Ginn, MD
Neuro-oncologist; Director, Brain Tumor Program; Assistant Professor of Pediatrics, University of Missouri-Kansas City School of Medicine

Amanda Graul-Conway, MD, MS
Hospitalist; Assistant Professor of Pediatrics, University of Missouri-Kansas City

Erin M. Guest, MD
Cancer Genomics Program Director; Cancer Center Biorepository Director; Associate Professor of Pediatrics, University of Missouri-Kansas City School of Medicine

Erin Hall, MD
Assistant Professor of Pediatrics, University of Missouri-Kansas City

J. Allyson Hays, MD
Histiocytic Program Director; Assistant Professor of Pediatrics, University of Missouri-Kansas City School of Medicine

Maxine L. Hetherington, MD
Associate Professor of Pediatrics, University of Missouri-Kansas City School of Medicine

Gary L. Jones, DO
Hospitalist; Assistant Professor of Pediatrics, University of Missouri-Kansas City

Karen B. Lewing, MD
Fellowship Program Director; Associate Professor of Pediatrics, University of Missouri-Kansas City School of Medicine

G. Doug Myers, MD
Cellular Therapy Program Director; Associate Professor of Pediatrics, University of Missouri-Kansas City School of Medicine

Glenson Samuel, MD
Hospitalist; Assistant Professor of Pediatrics, University of Missouri-Kansas City School of Medicine

Mukta Sharma, MD, FAAP, MPH
Associate Professor of Pediatrics, University of Missouri-Kansas City School of Medicine

Michael S. Silvey, DO
Clinical Assistant Professor of Pediatrics, University of Missouri-Kansas City School of Medicine

Nazia Tabassum, MBBS
Assistant Professor of Pediatrics, University of Missouri-Kansas City School of Medicine

Jaszianne Tolbert, MD
Director, Experimental Therapeutics in Pediatric Cancer; Assistant Professor of Pediatrics, University of Missouri-Kansas City School of Medicine

Melanie A. Villanueva, DO
Hospitalist; Assistant Professor of Pediatrics, University of Missouri-Kansas City School of Medicine

Brian Wicklund, MDCM, MPH
Director, Coagulation Medicine Program; Professor of Pediatrics, University of Missouri-Kansas City School of Medicine

Children's Mercy KANSAS CITY

THE UNIVERSITY OF KANSAS CANCER CENTER

NCI Cancer Center

A Cancer Center Designated by the National Cancer Institute

BEST CHILDREN'S HOSPITALS U.S.News & WORLD REPORT CANCER 2018-19

Children's Mercy Kansas City
2401 Gillham Road | Kansas City, MO 64108
(816) 234-3000 | childrensmercy.org/cancer

MAGNET RECOGNIZED AMERICAN NURSES CREDENTIALING CENTER