Focus on the HOPE Clinic
(Clínica de Hematología/Oncología: Puente de Esperanza)
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.

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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!
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.
Overall Survival Acute Lymphoblastic Leukemia Diagnosed 2007-2017 by Race

Kaplan - Meier

Percent Surviving

Months After Diagnosis

Caucasian (N=268)
African American (N=33)
Hispanic (N=51)
American Indian, Aleutian (N=1)
Asian/Pacific Islander (N=11)
Other/Unknown (N=13)

13.6 months, 95.82%
15.97 months, 95.54%
60 months, 91.14%

Overall Survival Any Leukemia Diagnosed 2007-2017 by Race

Kaplan - Meier

Percent Surviving

Months After Diagnosis

Caucasian (N=343)
African American (N=44)
Hispanic (N=66)
American Indian, Aleutian (N=3)
Asian/Pacific Islander (N=13)
Other/Unknown (N=16)

8.15 months, 95.29%
15.97 months, 85.99%
60 months, 83.99%
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.
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
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.”
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.
**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 ALL4 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**


**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.

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.

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.

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.”
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.”

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.

Blood tests and a biopsy confirmed that Miqueas had stage IIIB 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.”

“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.

“‘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.”

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.

“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.
“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.

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

A presentation to medical staff in Mexico.

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

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

Terrie Flatt, DO, MA, leading a lecture 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.
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 as 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.

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.
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 dietician 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.

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 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.
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.
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.

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.

Kara Hoolehan, RN, and Theresa Torres, APRN


CHAPTERS


ABSTRACTS/PRESENTATIONS


A Case of Dermatomyositis 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, September 2017.


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