

2018-19

CANCER CARE
ANNUAL REPORT

focus on pediatric cancer genomics



Children's Mercy
KANSAS CITY

LOVE WILL.

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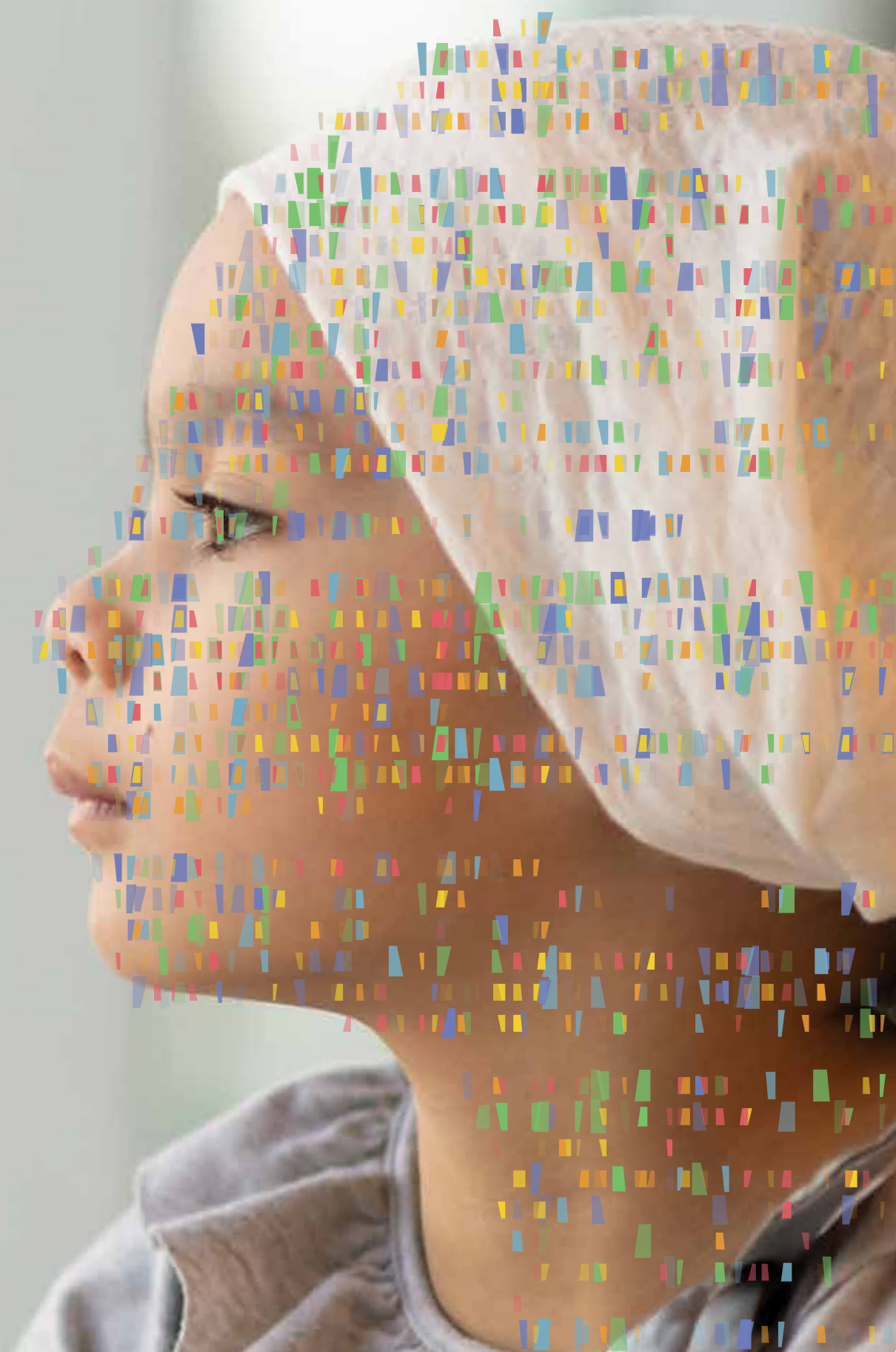
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WELCOME

This year's Children's Mercy Cancer Center Annual Report focuses on what, until now, has been a far-off distant future dream – Cancer Genomics. **IT IS HERE!** And now cancer genomics is rapidly redefining our understanding of cancer, and in turn our treatment of cancer.

It was not too long ago that many thought cancer might be caused by viruses. We now know that cancer is, in fact, the result of one of our own cells gone awry—like a copy machine stuck on copy. The resulting mistakes in our instructions, better known as our genes, are mutations that drive these cancer cells to divide uncontrollably.

The result is these cancer cells take over the space our normal cells and organs need to do their jobs, spreading and wreaking damage throughout the body. Much of our new understanding of this process is being generated by our own researchers here at Children's Mercy. Their work clearly shows that what may appear to be similar between adults and children is not. Cancer has vastly different origins, different mutations, and different paths in children as compared to adults.

In adults, it generally takes decades of cumulative mutations to finally result in enough change in those genes to turn the cell into a cancer cell. But in children, the mutations are few. Sometimes just a single mutation is powerful enough to turn a cell cancerous, and can do so in a child in a much shorter time span, even as young as a newborn.

In my 30-plus years in the field of childhood cancer, I have seen many changes resulting in many improvements for our young patients. Yet, in just the past five to 10 years, with the advent of genomics, there has been an explosion of new discoveries resulting from the critical research labs in cancer centers and universities, like those in the Children's Mercy Research Institute, and from the bedsides of children fighting the battle for their lives.

At times it seems like we are stepping out of a thick, dark forest into a bright, vast clearing that illuminates the causes of, and the therapeutic approaches for, cancer. It is such a bright light that we are still adjusting to it. But we are now seeing our future in the therapy for childhood cancer more clearly. We are so fortunate to have these capabilities here at Children's Mercy. Both the research

focus and clinical application of this new medical approach in our Cancer Genomics program benefits children in our region, and as you'll read, nationally and internationally.

In this journey of better understanding cancer, and particularly childhood cancer, we have entered a new era of discovery that is creating a new era of understanding. With the research and clinical application that is ongoing in the Children's Mercy Cancer Genomics Program and worldwide, we will be, in the coming few years, learning how to better apply this understanding with more precise and rational therapy.

We are already seeing in select cancers that this is proving to be a safer way to achieve higher cure rates for our children. Join us in the following pages as we describe these research discoveries and how we are starting to apply them for our children who have cancer. But stay tuned, this is only the beginning.

ALAN S. GAMIS, MD, MPH

Associate Division Director, Section of Oncology; Professor of Pediatrics, University of Missouri-Kansas City School of Medicine; Clinical Professor of Pediatrics, University of Kansas School of Medicine



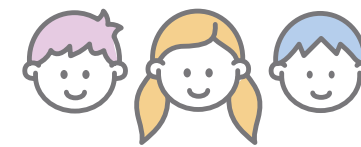
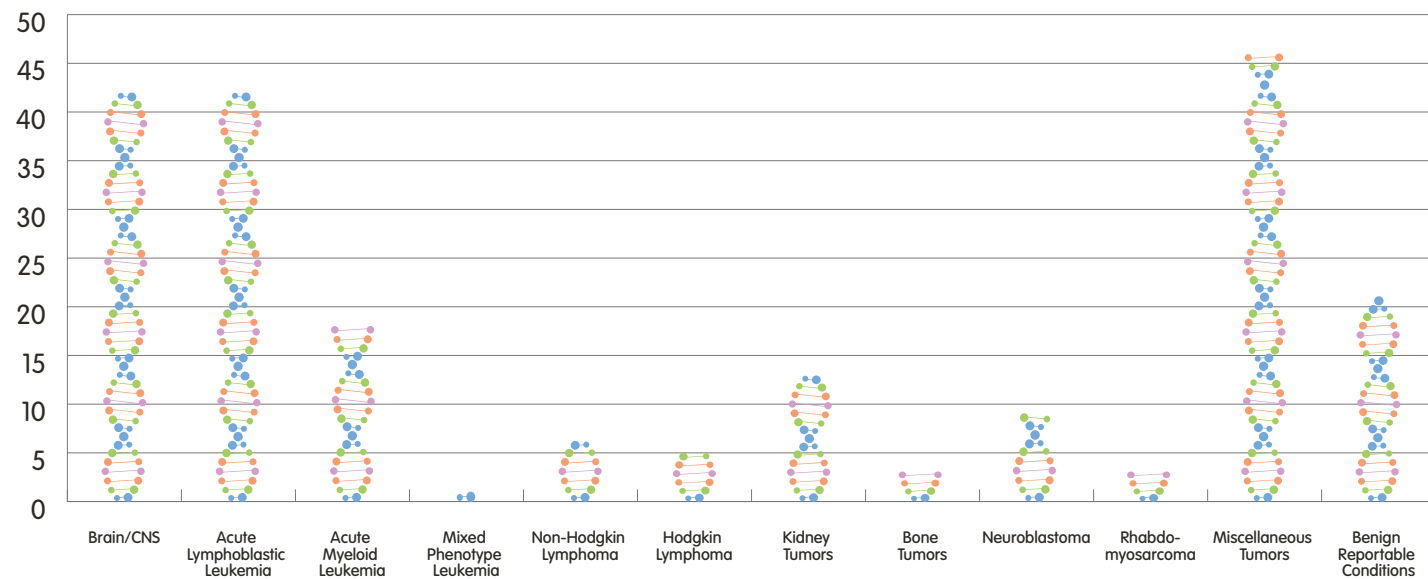
CANCER REGISTRY 2018

The Cancer Registry at Children's Mercy Kansas City plays a vital part in the surveillance of cancer in our 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 2018, the Cancer Registry added 209 patients to the database. Of these patients, there were 188 patients who were diagnosed with malignancies and benign central nervous system tumors. There were 21 patients added to the registry as having 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
2018 PATIENTS



209

Patients added to the Cancer Registry database during 2018.



188

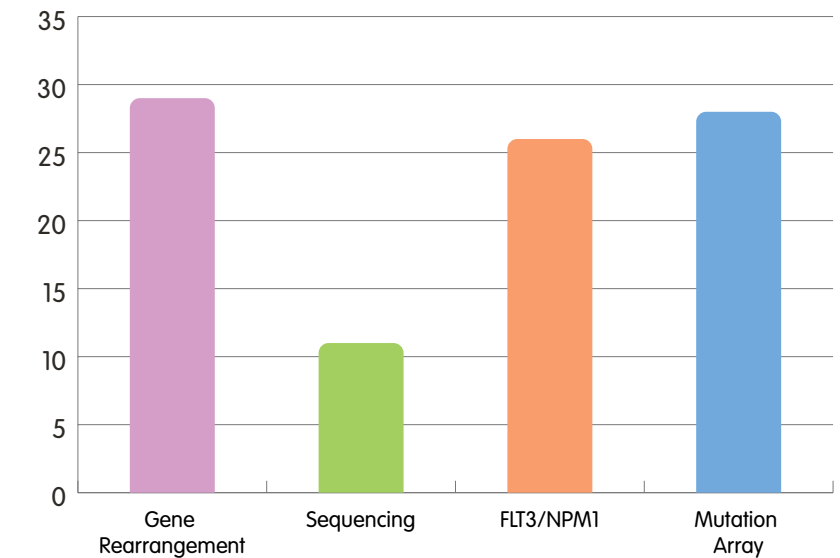
Patients diagnosed with malignancies and benign central nervous system tumors during 2018.



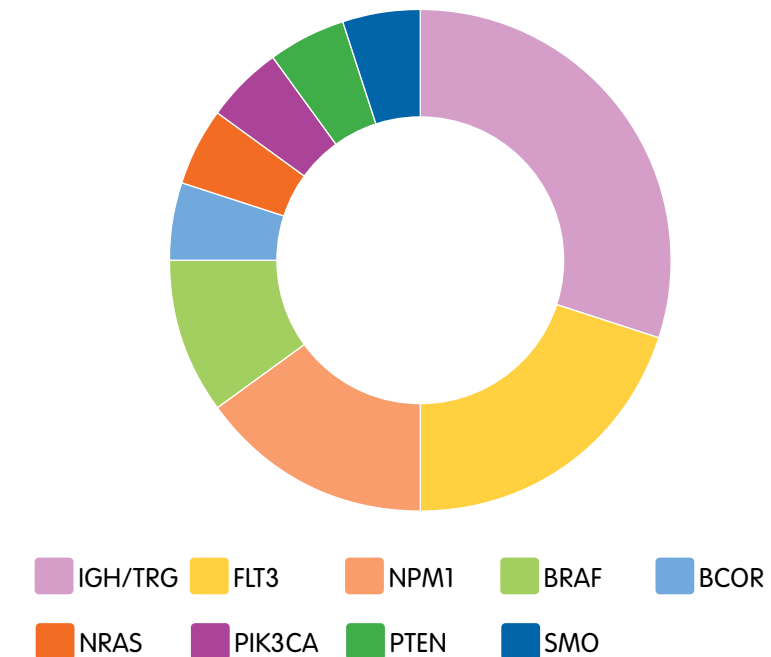
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Patients added to the Cancer Registry as having benign reportable conditions during 2018.

CASES WITH MOLECULAR TESTING



GENES WITH MUTATIONS FOUND



Nearly 100 molecular tests were performed on cancer samples in 2018. Testing revealed important molecular changes in many genes including *FLT3*, *NPM1*, *BRAF*, *BCOR*, *NRAS* and *SMO*. This information helped guide patient diagnoses, prognoses and therapies.

FORGING THE PATH OF PEDIATRIC CANCER GENOMICS



Erin Guest, MD

When it comes to cancer, as with many pediatric diseases, children are not simply little adults. Unlike adult cancer, childhood cancers are not typically associated with numerous genetic alterations. As a result, the molecularly targeted therapies designed to treat adults with cancer are not often beneficial to children. Further, childhood cancer is rare and many of the mutations discovered in the cancer cells are actually in the germline, within all cells in the body.

In addition, genomic research has taught us that pediatric cancers are diverse and that each patient's case is unique. This presents a major challenge in breaking down the data in a meaningful way to guide and individualize treatments. The Children's Mercy Cancer Center Genomics Program, established in 2014, consists of a team of clinicians and researchers with the common goals of incorporating genomics into our everyday clinical treatments and research programs to improve the outcomes for our patients.

The Cancer Genomics Program serves as a bridge between the Genomic Medicine Center and the Division of Hematology/Oncology/Blood and Marrow Transplant at Children's Mercy. Program members include pediatric oncologists, molecular and anatomic pathologists, cytogeneticists, clinical geneticists, genetics counselors, bioinformaticians, and other subspecialists with particular interests in cancer diagnostics and research.

Genomic medicine traverses many different disciplines and the Cancer Genomics Program is designed to intertwine with and support the genomics needs of all of the other cancer center programs, including the Leukemia and Lymphoma

Program, the Brain Tumor Program, the Adolescent and Young Adult Program, Experimental Therapeutics, Stem Cell Transplant, and many more.

The Cancer Genomics Program supports clinical genomics testing for direct patient care, a variety of research efforts in genomics, and translational projects that tie patient outcomes to genomic testing. In its research functions, the program relies upon the Children's Mercy Research Institute (CMRI) for support. In addition, the Children's Mercy Cancer Center, the CMRI and the Cancer Genomics Program are all fortunate to have incredibly generous philanthropic donors who have made this work possible.



We have grown our clinical cancer genomics capabilities extensively, and we now perform most sequencing testing in our on-site Genomic Medicine Center lab. It's important to note that the interpretation of cancer genomics test results is challenging and requires extensive knowledge and skill.

Genetic mutations, also known as variants, that are specific to cancer cells are often not present uniformly within the cancer. Sometimes variants are at such a low level that it can be difficult to distinguish a real mutation from the background error rate inherent to the sequencing process.

Our specialized team of molecular oncologists interprets each child's cancer sequencing result in the context of his/her cancer diagnosis and germline sequencing data. Next, we review the results in our multidisciplinary molecular tumor board. The child's oncologist discusses the clinical diagnosis and the team of experts reviews the sequencing findings to determine if other therapies might be beneficial. In doing so, we take an individualized approach to every patient and we incorporate all available data into the treatment recommendation.

As mentioned above, germline mutations play an important role in the development of childhood cancer. Germline mutations may be inherited or may occur *de novo*, during the child's early development. For this reason, genetic counseling and testing are especially important to determine if a germline mutation contributed to the child's risk of developing cancer, and to discuss the risk to other family members, including siblings.

Certain germline mutations are associated with known risks for specific, often very rare types of cancer. For example, germline mutation of the TP53 gene results in Li Fraumeni syndrome, with increased risks for solid tumors, brain tumors, and leukemias throughout life, from early childhood to adulthood. Li Fraumeni and many other



Erin McBride

childhood cancer predisposition syndromes have established guidelines for cancer screening and early detection, which have been shown to result in better chances of survival.

We work closely with our clinical genetics providers to accomplish testing, counseling, and screening when appropriate. Our Surveillance for Predisposition to Tumors (SPoT)

the Children's Mercy Oncology Biorepository, also known as the Tumor Bank, to sequence every single cancer case in the bank.

Patients and their parents are given the opportunity to donate blood, bone marrow and tumor tissue remaining after a biopsy to the Tumor Bank. The specimens are taken to the CMRI for isolation of DNA, RNA, live cells and other components, and then portions are transferred to the Genomic

Medicine Center for sequencing. The patient's personal identifiers are removed. The result is a broad data set that includes most of the cancers diagnosed

of Tumor Bank clinical samples, our Cancer Genomics Program supports a variety of other cancer-specific research projects. Our largest project so far has involved orthogonal sequencing of leukemia samples from infants with acute lymphoblastic leukemia (ALL).

This sequencing work has identified mutations gained at relapse in infants with ALL who are enrolled in a Children's Oncology Group clinical trial. Ongoing work with additional infant ALL samples is looking at epigenetic changes within the patients' cells before and after treatment with azacitidine. To date, we have collaborated with researchers at Johns Hopkins University, Children's Hospital of Philadelphia, The University of Kansas, Children's National Medical Center, among other institutions, and we welcome new research partnerships.

Our vision for the Cancer Genomics Program is that every child with cancer is given the opportunity to participate in clinical testing and to contribute to research. Although the field of cancer genomics is still relatively new, this information-gathering phase is a critical step and we consider it important to broadly study and compare sequencing results across all childhood cancer types. Our program is poised to lead the way in generating and sharing data, improving outcomes for our patients now and in the future.

OUR VISION FOR THE CANCER GENOMICS PROGRAM IS THAT EVERY CHILD WITH CANCER IS GIVEN THE OPPORTUNITY TO PARTICIPATE IN CLINICAL TESTING AND TO CONTRIBUTE TO RESEARCH.

clinic is dedicated to providing a home for patients to coordinate the recommended screening tests. We see patients annually for visits and work closely with their primary care doctors and other subspecialists to ensure that each child receives the recommended care based on his/her diagnosis.

Research is critical to gain understanding of the significance of sequencing results. To build a robust foundation of new knowledge, the Cancer Genomics Program has partnered with

at Children's Mercy, giving us the ability to compare changes in the cancer cells from diagnosis to relapse, if relapse occurs.

Investigators can utilize the data to design and test new treatment approaches on the banked cells. The de-identified sequencing data will soon be shared in an online public database, empowering collaborative world-wide sharing of cancer genomics data toward a common goal of improving molecularly targeted treatments. In addition to our sequencing

ADVANTAGES OF LOCAL SEQUENCING



Midhat Farooqi, MD, PhD

The Human Genome

Project—an international scientific research collaboration that undertook sequencing of the entire human genome—took 13 years, 20 laboratories across the globe, and roughly 3 billion dollars to complete. In this context, it is astounding to consider that “local” genome sequencing performed by a hospital laboratory could even be a possibility, but, amazingly, less than a decade after completion of the Human Genome Project, it became very much a reality!

Today, multiple human genomes can be sequenced by a single laboratory in just a few days at a technical cost of about \$1,000 per genome. Of course, this cannot be done in just any laboratory. It requires investment in a state-of-the-art facility, the presence of special sequencing equipment, availability of significant computational resources, and hiring of specialized personnel to manage the entire process.

We are fortunate that Children’s Mercy Kansas City was at the forefront of this movement, investing in the Genomic Medicine Center a decade ago. We are even more fortunate that the hospital has supported it strongly ever since. The Genomic Medicine Center is a world-wide leader in genomic medicine and has received international recognition for providing whole genome sequencing and clinically relevant results for critically ill infants, all

within a few days. The Genomic Medicine Center is now bringing genomic medicine to every cancer patient at Children’s Mercy, both clinically and through its research initiatives via the Tumor Bank and the Children’s Mercy Research Institute Biorepository.

By utilizing the Genomic Medicine Center’s existing infrastructure, we are easily able to perform whole genome sequencing for pediatric cancer patients in-house. For such

patients, this includes sequencing the genome of both their cancer cells (to look for changes that drive tumors), as well as their healthy cells (to look for inherited changes that increase the risk of developing cancer).

Testing patients in-house allows us to not only offer this dual sequencing but also to do it via the most comprehensive method of sequencing available, whole genome. Many other laboratories offer sequencing of a few cancer-related genes and sequence only the tumor sample by itself. Such testing makes it difficult to identify which genetic changes are truly specific to a tumor versus those that may be inherited and increase risk of cancer for a patient and their family.

Making this distinction is critically important since: 1) tumor-specific genetic changes can be used to match tumors to precision therapies that attack only cancer cells and spare healthy cells (unlike traditional chemotherapy which affects both cell types) and 2) inherited changes that confer predisposition to cancer are necessary to examine in the pediatric setting because these mutations are found in 5-15% of children with disease, much higher than what was previously believed.

Finally, in-house sequencing allows us to have much more control over the quality of sequence data that is generated. This is essential for clinical sequencing where strict quality control and validity of results is the highest priority. In-house sequencing also supports local researchers because they can drop by, ask questions, and see the process first hand. In turn, this fosters additional stronger research collaborations. Overall, in the end, doing local sequencing brings us closer to the goal of precision medicine: “finding the right drug for the right patient at the right time,” as informed by genetic results.

IDENTIFYING THE DIFFERENCES IN CANCER CELLS

Other than identical twins, all individuals have a unique genetic makeup. This is due to certain sequence differences in their DNA, specific to them, that are carried by all of their body’s cells. Cancer cells, in addition to carrying all of the genetic variants seen in normal cells, have additional genetic changes that differentiate them from normal cells and which help define such cells as cancerous.

In clinical cancer sequencing, it is critical to distinguish genetic variants carried only by cancer cells (“somatic” changes) versus those carried by all cells (“germline” changes) because somatic changes can help guide precision therapy. In other words, this information can help find a drug or agent that specifically targets the genetic differences found in cancer cells, and ultimately does not affect normal cells.

Most clinical cancer sequencing assays looking for these changes in a cancer’s genetic makeup test only the tumor sample, making it difficult to differentiate “somatic” changes from “germline” ones. We recently questioned how many genetic variants found by clinical cancer sequencing tests done at outside laboratories for pediatric cancer patients that had been seen at Children’s Mercy actually found changes that were truly tumor-specific (somatic) versus in all cells (germline).

We did this by resequencing both tissue from the patient’s tumor, along with normal cells found in the same patient’s peripheral blood. We found that only 11 of the 41 variants (27%) found by outside laboratories were actually somatic, which would imply that only certain therapies would truly be precise and specifically target tumor cells. This study’s importance was recognized when it was one of a few selected to be presented as a poster and as a talk at a large international scientific meeting held in Washington, D.C. by the Association for Molecular Pathology.



CANCER GENOMICS RESEARCH

Erin Guest, MD
Midhat Farooqi, MD, PhD

LEUKEMIA/LYMPHOMA

Acute lymphoblastic leukemia in infants

Sadly, only about one in three infants less than 1 year of age with acute lymphoblastic leukemia (ALL) survives despite intensive therapy. Erin Guest, MD, is leading an international clinical trial with the Children's Oncology

Group (COG) to test the safety of the addition of azacitidine, an epigenetic demethylating agent, to chemotherapy for infants with ALL.

Blood and bone marrow samples from infants enrolled in this trial and in a prior COG trial for infants with ALL are being studied in the Genomic Medicine Center at Children's Mercy. In collaboration

with researchers at Johns Hopkins University, we are performing in-depth sequencing analyses to discover biomarkers that better predict response to treatment and to determine the biological basis of resistance to chemotherapy after relapse. We presented our early findings in abstract form at the annual meeting of the American Society of Hematology.

Measuring response to epigenetic treatment

Epigenetic medicines are designed to alter the expression of genes by turning them off or on, thereby leading to cancer cell death and/or vulnerability to chemotherapy. The Children's Mercy Cancer Center partnered with the Therapeutic Advances in Childhood Leukemia & Lymphoma consortium to

study samples from patients enrolled in a trial for treatment of relapsed leukemia. Samples were sequenced to determine the pharmacodynamic changes in DNA methylation and histone acetylation. The results show evidence of potent anti-leukemia effects by the epigenetic drugs. This work has been submitted for publication in conjunction with the overall trial results.

Single-cell sequencing in infantile and T-cell acute lymphoblastic leukemia/lymphoma

Not all cancer cells are alike. One patient's cancer can contain multiple distinct sub-clones. This makes cancer difficult to target with a single approach because some sub-clones may be resistant to certain therapies. At Children's Mercy, we are utilizing powerful

sequencing strategies that analyze individual cancer cells for changes in gene expression. We are taking this innovative approach with all of our patients with newly diagnosed or relapsed leukemia, and we are particularly focused on determining the sub-clones that explain resistance to treatment in infant ALL and childhood T-cell ALL, because both of these cancers are extremely difficult to cure after relapse.

CENTRAL NERVOUS SYSTEM TUMORS

Genomics of high-grade gliomas of the brain

Brain tumors are the most common solid tumor in children, as well as the most common cause of solid tumor-related deaths in childhood. Why they arise and what predisposes them to be “high-grade” and aggressive versus “low-grade” and more benign in nature is not completely understood. This study is comprehensively analyzing genomic changes found in high-grade glial brain tumors, such as copy number changes, chromosomal abnormalities, expression differences and genetic sequence alterations, and correlating such findings to specific patient characteristics,

therapy responses and outcomes. This project aims to reveal novel genomic changes in these tumors, as well as novel associations between genetic alterations and specific clinical findings.



SOLID TUMORS

Genetic and epigenetic targets for treatment in solid tumors

Children with solid tumors that do not respond to standard therapy or relapse despite standard therapy, have a very poor prognosis. This is largely due to the limited number of treatment options available. This project supports a national clinical trial where children with relapsed/refractory solid tumors, including neuroblastoma, osteosarcoma and Wilms tumor, among others, are treated with a novel immune therapy that works to help control disease. Unfortunately, not all patients respond to this treatment.

This study aims to comprehensively profile the genomes of tumors being studied by the clinical trial, both before and after immune therapy, to look for specific genetic markers that correlate with therapeutic response. The project has a special emphasis on detecting certain chemical changes to DNA (epigenetic modifications) that are known to play a key role in tumor response to immune-based cellular therapies. Overall, the study's goal is to use genetic information to guide and support use of a

novel targeted therapy for pediatric patients with relapsed/refractory solid tumors.

Exosomes in Ewing sarcoma

Exosomes are tiny particles that are released by tumor cells, which contain components of the original cancerous cell. Because they can be found in blood, the hope is that exosomes can be used to monitor tumor burden and serve as a valuable biomarker for disease. This study has found that exosomes produced by Ewing sarcoma cells are detectable in the blood of patients with disease. It is currently working to develop this finding into a clinically-available

blood test that would be used to detect the presence of Ewing sarcoma cells earlier than an MRI or other radiology scans.

Rhabdomyosarcoma

Rhabdomyosarcoma is the most common type of soft tissue sarcoma found in children with about 400 to 500 new cases occurring in the United States each year. More than half of rhabdomyosarcomas are diagnosed in children younger than 10 years old. What causes these tumors to arise is not clearly known. This study is looking for pathological changes, chromosomal abnormalities, expression differences and genetic sequence alterations in these tumors, correlating them to specific patient characteristics, therapy responses and outcomes. The goal of this project is to reveal novel genomic features in these tumors

that can help explain disease biology and also be specifically tied to relevant clinical findings.

ETHNICITY AND GENOMICS

Hispanic and Native American children diagnosed with Acute Lymphoblastic Leukemia (ALL) in the United States have the poorest outcome when compared to whites, Asians and African-Americans. Some studies have demonstrated that the higher the percentage of Native American (Pre-Columbian) ancestry among children with ALL portends worse overall and event-free survival as well as a less favorable response to end of induction therapy. The term Hispanic, as it is used in the United States, is very broad and is not specific or descriptive of actual ethnic and racial admixture. The term does not account for individual ancestry such as

Mexican, Guatemalan, Peruvian, Puerto Rican ancestry or the various combinations of ancestry. As a result, knowledge regarding which Hispanic groups have the worse outcome remains unknown. The term Hispanic as used in the United States does not account for the vast diversity of European and Pre-Columbian ancestry. The vast majority of the population is an admixture of European and Native indigenous populations (Pre-Columbian ancestry) which is referred to as the Mestizo. Mestizo genetic ancestry is associated with a higher incidence and poorer outcome of ALL. Analyzing ethnic profiles of children diagnosed with ALL may be crucial to improving outcome among Hispanics in Mexico and the United States.

Terrie Flatt, DO, along with collaborating institutions in Mexico, is conducting research studies to look into genetic links between ethnicity and how children respond to treatment. By partnering with international hospitals, Dr. Flatt has established both research and clinical links that provide benefit to all.



Terrie Flatt, DO



TARGETING TEO'S CANCER

Teenagers are famous for burning the candle at both ends, and Teo Rosales was no exception to that rule. In May 2018, he was busy with his classwork and involved in the school's robotics team, a typical sophomore at Olathe Northwest High School.

But one Monday morning before school, he had a nosebleed—a nosebleed that lasted for almost two hours. Later that week, his mother, Ameerah, began noticing that when her son got home from school, he would sleep all afternoon, eat dinner, then go back to sleep again. He also was experiencing lots of bruising.

So when Teo's father, Ruben, took him to the pediatrician, he was referred immediately to the Children's Mercy Emergency Department.

After performing a series of blood tests, doctors delivered some devastating news to Teo and his parents. He had a rare form of leukemia called acute promyelocytic leukemia, a cancer of the blood-forming tissue, or bone marrow.

"When I first heard the news, I froze. My entire world stopped," Teo said. "I looked over at my parents, and there was a moment of silence."

TEO'S TREATMENT

Teo was admitted to the hospital that night and treatment began immediately.

"We knew from Teo's blood work that he was at extremely high risk for internal bleeding," said Erin Guest, MD, Director of the Cancer Genomics Program and the Cancer Center Biorepository. Teo received 6 units of blood in the first 24 hours, and 36 units of blood

products in the first seven days he was hospitalized to reduce his white blood cell count and stabilize his blood's ability to clot.

Working with Dr. Guest on Teo's case was Oluwaseun "Kemi" Olaiya, MD, pediatric hematology/oncology fellow.

"The type of cancer Teo had has a very specific molecular rearrangement that we can test for and target with treatment," she explained. The Children's Mercy Genomic Medicine Center performed the initial testing that determined the molecular rearrangement for Teo's cancer.

Thanks to that information, Teo qualified for a special Children's Oncology Group phase III trial for patients with newly diagnosed APML, study number AAML1331. Children's Mercy is the primary pediatric cancer provider and the only NCI Children's Oncology Group



institution in the Midwest Cancer Alliance.

"This is a very targeted approach for this type of leukemia," Dr. Guest said. "We have been learning a lot more about genetics and the genes that are in each type of cancer. Those are really important markers for how easy or difficult it will be to treat the patient's cancer, and in Teo's case, it guided us toward this study protocol."

Teo also was fortunate he was referred to a pediatric hospital for his care versus an adult hospital. "Not only do we have access to these COG protocols, but research has shown that adolescents have better outcomes when treated in a pediatric hospital, and benefit from all the resources and services we have to offer, like child life, pediatric subspecialists, pharmacists, nutritionists and social work support," Dr. Guest said.



Dr. Guest gets nothing but love from Teo and Mom, Amee.

A UNIQUE STUDY FOR A UNIQUE CANCER

Though chemotherapy is the traditional treatment for APML, this study took a different approach.

"Teo did have a small amount of chemotherapy initially," Dr. Guest explained. "But the primary drug used in this trial was arsenic, plus all-trans retinoic acid (ATRA)."

Arsenic is a poison, but it also can be an effective treatment for cancer, and it doesn't cause the typical side or late effects associated with traditional chemotherapy. The arsenic was delivered via IV, and ATRA via an oral pill.

"It kind of weirded me out that the arsenic was in my body," Teo said. But he responded quickly to the therapy and went into remission.

While in the hospital, Teo passed the time gaming online with his brother, and visiting with friends who delivered lots of fast food to him.

"It's important to still continue with your life as normal as you can, even when the crazy stuff is happening," he said.



Kara Hoolehan, RN, BSN

Teo marked his 17th birthday at Children's Mercy, and even got to meet several of the celebrities who were in town for the Big Slick fundraising event in 2018.

"I talked with Charlie Day from It's Always Sunny in Philadelphia, Paul Rudd from Antman, and Angela Kinsey from the Office," he said. "It was great to talk with Angela because my friends and I are into the Office."

HOME AT LAST

After spending 28 days on the Children's Mercy Oncology Unit, Teo was released to go home.

He continued treatment in the outpatient Oncology Clinic, having three-hour infusions Monday through Friday for a month, then taking a month-long break, followed by another month on treatment and another month-long break. That cycle repeated until the full COG protocol was finished in January 2019.

"Teo responded great to the trial," Dr. Guest said. "His biggest challenge was actually a fear of needles, which are a necessary part of treatment." The Children's Mercy Child Life specialists helped him deal with that fear, and successfully complete treatment.

"The day my treatments ended was a very emotional moment for me," Teo said. "I did it! It was like a weight had been lifted off my chest. I don't have to worry about the cancer anymore."

"Everyone at Children's Mercy was wonderful," Teo's mom said. "The nurses, social workers and doctors were very good to us. Teo is really needle-phobic so it took a lot to get him infused and used to the needles, but his psychologist and child life helped with that."

Today, Teo is doing great. He visits Drs. Olaiya and Guest every three months to monitor his blood for the gene rearrangement. So far there are no signs of relapse.

Throughout his therapy and follow-up, data about Teo's response to treatment has been submitted to the COG study investigators as part of the protocol.

"The investigators are looking for a treatment that may be better than the standard treatment," Dr. Olaiya said. "We were excited about the clinical trial and how Teo responded. These aren't new drugs, but they hadn't necessarily been used in this combination and without further traditional chemotherapy to treat this type of cancer before. Our hope is that this research will help change the standard of care for other children diagnosed with APML."

LOOKING TO THE FUTURE

As he completes his senior year of high school, Teo readily admits this experience has changed his life.

"I don't take anything for granted," he said. "I really appreciate waking up to a beautiful Kansas sunrise and admiring the beauty of the earth."

He looks forward to tomorrow, and has been accepted at Kansas State University where he plans to major in anthropology.

"I have been given a second chance at life," Teo added. "I want to be able to do something that I love, that can make other people appreciate the world and the people in it, and that can create a more sustainable future."



Teo poses with Dr. Guest and members of the Hematology/Oncology/BMT nursing staff



MOLECULAR GENETICS LAB

The Molecular Genetics Lab is a specialty testing area of the Department of Pathology and Laboratory Medicine that assesses samples from patients diagnosed with cancerous and non-cancerous conditions to look for specific genetic differences via traditional molecular techniques. In doing so, the Molecular Genetics Lab compliments the Genomic Medicine Center by offering a wide variety of additional methodologies to look for these genetic changes, including DNA amplification, fragment analysis and sequencing. The lab can also perform testing on a range of sample types such as blood and bone marrow specimens, buccal swabs, fresh tissue and tissue that has been fixed in formalin, allowing testing to be done on a wide variety of cases and for nearly all patients.

CANCER CYTOGENETICS PROGRAM

The Children's Mercy Clinical Cytogenetic Laboratory performs genetic analysis of tumor samples from all children with new diagnoses of leukemia, lymphoma or a solid tumor. Study of tumor cells at diagnosis reveals genetic changes that define the tumor type and subdivide tumors into genetic subgroups. This information is used to personalize care and determine optimal therapeutic protocols for that child's specific tumor. The genetic information is especially critical for stratifying patients enrolled in Children's Oncology Group (COG) protocols for the treatment of new diagnosis leukemias. Solid tumor genetic analysis facilitates pathological diagnosis and subtyping, selection of therapy, and predicting outcome. The laboratory utilizes gold standard methods, such as chromosome analysis and fluorescence in situ hybridization, as well as front-line technologies such as microarray and somatic mutation analysis.

FLOW LAB

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. Our test menu includes leukemia/lymphoma immunophenotyping, DNA ploidy, lymphocyte subsets including naïve and memory T/B cells and recent thymic emigrants, ALPS screening and CGD screening.

One of our important tasks is classifying childhood leukemias and lymphomas. The testing panels contain antibodies specific for T-cells, B-cells, monocytic, myeloid, blasts and other cell types. Additionally, we have 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. Our lab is the only one in Kansas that is approved to perform COG testing panels for B-ALL MRD. DNA cell cycle and ploidy measurements are useful to exhibit abnormal genetic material content. Besides providing leukemia lineage classification and DNA ploidy, our lab is developing an assay for CRLF2 expression. A high level of CRLF2 expression is seen in BCR-ABL1-like B lymphoblastic leukemia/lymphoma, which can benefit from treatment with tyrosine kinase inhibitors.



GENETICS AND GENETIC COUNSELING

In some cases, pediatric cancers are associated with inherited mutations in cancer-causing genes. There are several genes that are known to increase the risk of cancer in children. Children with a strong family history of cancer or a cancer type that is associated with a known cancer syndrome can especially benefit from genetic counseling.

Genetic counselors are trained to elicit a detailed multi-generation family history and perform a risk assessment, as well as explain the benefits, limitations and implications of genetic testing to both medical providers and families. For example, a child with

a sarcoma should be evaluated for the possibility of Li Fraumeni syndrome, which can cause sarcomas, along with a wide variety of other cancers both in childhood and adulthood. If a hereditary cancer syndrome is identified, at-risk relatives including parents, siblings and extended family members, can be tested for the familial mutation.

Individuals with hereditary cancer syndromes frequently need increased lifelong surveillance that is tailored to their particular cancer risks. Genetic testing can identify which individuals in a family need increased surveillance, which may be lifesaving. The Children's Mercy

Division of Clinical Genetics has a genetic counselor who specializes in evaluating for pediatric hereditary cancer syndromes and is regularly involved with families in which hereditary cancer is suspected.

We also have a Surveillance for Predisposition to Tumors (SPoT) Clinic that is designed to follow children who have tested positive for a hereditary cancer syndrome and need individualized tumor surveillance. For more information about genetic counseling and genetic testing for pediatric oncology patients, contact Genetic Counselor Caitlin Schwager, MS, CGC, or the Division of Clinical Genetics.



Caitlin Schwager, MS, CGC



CLINICAL RESEARCH

In 1948, Sidney Farber published results of a new treatment for children with leukemia. Farber's article was one of the first that showed promise for any possible therapy for a disease that killed every child diagnosed. Today, the cure rate for childhood acute lymphoblastic leukemia is around 90%. Since Farber's article, it has been clinical research trials and the willingness of parents to enroll their children on these trials that has made this remarkable progress.

For decades, Children's Mercy has been an active member of the international pediatric cooperative groups funded by the National Cancer Institute. Every child diagnosed with cancer is treated on a clinical trial, or is treated according to the most up-to-date standard therapy vetted by research.

As cure rates have risen, the focus of the research and new therapies have changed. We now look into the elements of the disease that may only be seen at the genetic level. Several of the studies that Children's Mercy participates in have biological components that seek answers to questions about what triggers disease and response. A team of clinical research professionals work with Children's Mercy physician researchers to bring research studies to our families. They work behind the scenes to prepare study documents, seek the necessary regulatory approvals, collect data, and collect biology specimens. With the growth of the Cancer Genome program, the scope of our research will continue to evolve to include the capabilities of this expertise.

CHILDREN'S MERCY RESEARCH INSTITUTE

The Children's Mercy Research Institute is creating an integrated research environment where no boundaries exist between science and medicine. In our quest to find answers to pediatric medicine's most challenging questions, we are collaborating with physicians, scientists, academic colleagues, philanthropic partners and others within our community, and around the world.

To accomplish our goals, we're performing the highest quality research using the latest medical technologies. The hospital's leadership in pediatric genomic medicine and clinical pharmacology is driving research and innovation in nephrology, heart care, cancer treatment and other subspecialties to provide answers for the most difficult cases and challenging pediatric conditions.

Integral to our efforts is our focus on applied informatics, the use of cutting-edge computational capabilities. Informatics helps us provide answers to children and their families by accelerating the process of research, improving the quality of research, making it possible to share data with other researchers, and even making new methods of research available.



FaCT

Multidisciplinary care is integral to the overall outcomes and well-being of our patients. Outside of medically directed care, patients and families have many other needs that are addressed by our Family Care Team (FaCT). Regular FaCT rounds and collaboration ensures that all the physical, developmental, emotional, educational and spiritual needs are met for our 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. Child life specialists are child development experts who work to ensure life remains as normal as possible for children in health care settings through preparation, coping and normalization. Preparation is provided by child life specialists who 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 the patient's home school.

Music therapists provide opportunities for self-expression and development of positive coping skills to promote increased comfort, and to support

developmental growth. 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.



Shelbi Polasik, MME, MT-BC



Sara Donnelly, MSW, LCSW, LCSW, OSW-C

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.

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

The Parent-to-Parent Program (PTP) continues to offer support and comfort to all of the families within our 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 our current parents/caregivers; two stocked parent rooms that offer weekly dinners, breakfasts, therapeutic and educational activities and a safe

place to unwind while a child is an inpatient; "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. We have successfully introduced social media into our bereavement follow-up program and have been able to offer additional support. 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 our inpatient families. The Parent-to-Parent Program has been innovative in establishing this program model and was highlighted at the Association of Pediatric Oncology Social Workers conference in 2017.



The **Adolescent and Young Adult (AYA)** program is designed to support patients receiving treatment for cancer or blood disorders. The team of providers includes a clinical social worker and child life specialist who work in collaboration with other disciplines toward the goal of improving the quality of care for the AYA population. Recent accomplishments include the development of a teen unit and teen room on our inpatient floor; a formalized peer mentoring program; additional programming and education around fertility preservation; and improvements to the process around transitioning to adult care. Ongoing projects include the Hematology/Oncology Teen Advisory Board; Teenapalooza events to promote peer interaction; and ongoing education and support.

There are two dedicated **psychologists** to assist patients and families with coping with the diagnosis and treatment of cancer. They are available to meet with patients and their families, both while hospitalized and when outpatients. In addition to clinical therapeutic services, the psychologists are also able to complete neuropsychological evaluations to assess any impact of medical treatment on brain functioning, and to assist with school re-integration and planning.

As a member of the Hematology/Oncology/BMT team, the **chaplain** regularly provides spiritual and emotional support to patients and families during the course of a child's illness, as end-of-life discussions are necessary, 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 contacts 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 Sunday worship, concerts and celebrations from various faith traditions, and other activities in the Lisa Barth Chapel. The chaplain participates in team meetings. Providing support to the staff is another important role of the chaplain.



*Tracey Woods,
Chaplain*



The Black & Veatch Building, on the Children's Mercy Adele Hall Campus in Kansas City, Mo., houses the Division of Hematology/Oncology/Blood and Marrow Transplant.



Wearing glittery pink sneakers and hugging a fluffy pink and white leopard print blanket, when 2-year-old Clara Jensen looks at you with those big brown eyes, all you see is an adorable, happy, healthy toddler. But that's not how life started for this child.

A full-term infant, Clara's parents and doctors were caught completely off guard when she was born Sept. 21, 2017 at AdventHealth (formerly Shawnee Mission Medical Center). That's because she had a tumor on the back of her tongue—a tumor the size of a golf ball. In fact, it was so large Clara couldn't close her mouth, or eat.

Immediately, doctors transferred Clara to the Neonatal Intensive Care Unit at Children's Mercy for a higher level of care. Initially, no one was sure what the growth was, but doctors placed a gastrostomy, or G-tube for feeding. As an added precaution, they also placed a tracheostomy, or breathing tube, in case the growth became larger and blocked Clara's airway.

Once those were in place, Clara had an MRI, plus a surgical procedure to collect tissue for a biopsy, and to reduce the size of her tongue.

Based on preliminary test results, doctors determined the growth on Clara's tongue was a malignant tumor. They weren't sure of the exact tumor type though, so they sent the biopsy for more extensive testing.

"It's not routine at most hospitals, but we're actually able to offer every patient who comes to Children's Mercy molecular and genetic testing that may allow us to change their treatment," said Erin Guest, MD, Director of the Cancer Genomics Program and the Cancer Center Biorepository. That additional step turned out to be critical in Clara's case.

RARE DIAGNOSIS

About three weeks after the biopsy was performed, Aaron and Jennifer learned their baby had a rare form of cancer called an inflammatory myofibroblastic tumor.

"It was a bit of a shock when the doctors told us Clara's diagnosis," Aaron said. And the traditional treatment was more than a little scary for this Independence family.

"The doctors said usually with this type of tumor, they remove it surgically, but because Clara's tumor was on her tongue, no one wanted to do that," Jennifer said.

"Clara's tumor was extremely rare," Dr. Guest said. "But with the results of the molecular testing, we were able to identify an abnormality in the ALK gene, which is present in about half of these types of tumors," she explained.

CLARA'S CLINICAL TRIAL





Crizotinib is approved to treat adults with advanced stage lung cancer whose tumors are ALK-positive. It's not a form of chemotherapy, and it has very few side effects.

But the drug had never been used to treat the type of tumor Clara had, and because she couldn't swallow, Clara needed a liquid form of the medication so that she could receive it via her G-tube.

COMPASSIONATE USE

Inspired by this tiny girl with the big brown eyes, the oncology team not only found a liquid form of the drug in development, they applied for a compassionate use trial.

"A compassionate use trial is basically something we can apply for when there are no other good treatment options available for a patient," Dr. Guest explained. Though securing approval for this type of trial can take weeks, the Children's Mercy oncology team received approval in days.

Those findings led Clara's oncology team to search for a drug called an ALK inhibitor. Though they found a medication they thought would work, it wasn't FDA-approved or commercially available to treat the type of tumor Clara had.

"Crizotinib is a molecularly targeted drug that stops cells from growing. The tumor was dependent on that ALK gene rearrangement to grow, and if we could halt that, it would give the tumor an opportunity to shrink," Dr. Guest said.

"This was basically a clinical trial just for Clara," Dr. Guest explained.

Before the Jensens knew it, Clara was receiving the life-saving medicine via her G-tube, and the tumor began to shrink.

"Our other children were sick about the same time Clara started receiving the medication, so I couldn't go see her for a week," Jennifer said. "When I went back to the hospital, I said, 'Wow! Look at her tongue!'"

Clara's tongue was visibly shrinking, and it continued to shrink until the tumor was completely gone.

In all, Clara spent 80 days in the Children's Mercy NICU being closely monitored for any side effects to the medication.

"Other than some mild nausea, Clara didn't experience any side effects," Aaron said.



Lindsey Fricke, RN, MSN



The Jensen family is all smiles during a recent visit.

When the Jensens took her home, they continued the medication, giving it as prescribed, twice a day for an entire year.

COMPLETE REMISSION

"Clara has had a complete remission of the tumor," Dr. Guest said. "She's not had to have any further surgeries or radiation or chemotherapy. Just that single medicine was enough to get rid of the rest of the tumor."

Plus, Clara no longer needs a tracheostomy or G-tube, and because this medication isn't a chemotherapy drug, she won't have to face the late effects of treatment many cancer patients do.

"We had so much anxiety and stress when Clara was sick," Jennifer said. "There were days we

would go to the hospital, watch her struggle and feel helpless."

But those days are long gone. Now 2 years old, Clara sees Dr. Guest every three months for follow-up in the outpatient oncology clinic. Her most recent MRI was all clear.

And even though the tumor could have affected her tongue and

speech development, amazingly, it hasn't. "Clara is very articulate for a 2-year-old," Aaron said.

"We're so grateful for everything that Children's Mercy has done for us and other cancer patients," Jennifer added. "We'll never forget how dedicated they were."



Erin Guest, MD

THE IMPORTANCE OF BIOINFORMATICS AND DATA SHARING IN PEDIATRIC CANCER DIAGNOSIS AND TREATMENT

In a tiny room deep inside the Genomic Medicine Center at Children's Mercy Kansas City is one of the most powerful pieces of technology there is in the fight against pediatric cancer—a super-computer that's home to 3 petabytes of genetic data!

To give you an idea of just how much data that is, it would take 1.5 million CD-ROM discs to store one petabyte of data. The center has three times that! To think of it another way, the super-computer has more than 2,300 compute cores – the equivalent of more than 500 normal desktop computers.

To keep that super-computer humming along, the center has 8 tons of air conditioning, conditioned power and hospital emergency back-up power.

"This computer does much of the heavy computational lifting for us," said Neil Miller, Director of Bioinformatics, Genomic Medicine

Center. "The take-home story is that genomic data are very big, and it takes a lot of horsepower to drive this technology."

Children's Mercy is one of the few hospitals in the nation dedicated to generating its own genomic sequencing data and performing all analysis on site.

"By providing sequencing for our patients right here, we can turn results around quickly," Miller said. "Plus, we have a very skilled and knowledgeable team focused on delivering the highest quality results for our patients, and giving clinicians the best possible insights into the conditions they treat."

Cancer is just one of the many diseases and conditions this super-computer helps diagnose and treat.

"The vision is to be able to provide detailed molecular profiling for every patient," Miller said. "By identifying the mutations in the patient's cancer, our doctors can better personalize and target their treatment."

To do that, the center also utilizes a variety of software tools that characterize the genetic information that's relevant to the clinician.

"This technology generates a tremendous amount of information," Miller said. "In the end, what we try to do is give the oncologist the

tools they need to sort through this data and find the information they need to tailor the treatment to the individual child," Miller said.

The center also is working on pharmacogenomic testing that looks at the patient's genes and helps clinicians determine which medications will generate the best clinical response.

CHILDREN'S MERCY IS ONE OF THE FEW HOSPITALS IN THE NATION DEDICATED TO GENERATING ITS OWN GENOMIC SEQUENCING DATA AND PERFORMING ALL ANALYSIS ON SITE.

And, to assist with cancer research, the center is performing retrospective tumor bank sequencing, and working to share this data with researchers outside Children's Mercy.

"Our goal is that by sharing this database with the broader scientific community, researchers will be able to find patients with the same genetic mutations, and they can use that information to better inform treatment or develop research protocols," Miller said.

Plus, patients and families can bank their tumor information for use in future research that may one day help other children facing a cancer diagnosis.

Neil Miller

SEARCHING FOR GENOMIC ANSWERS

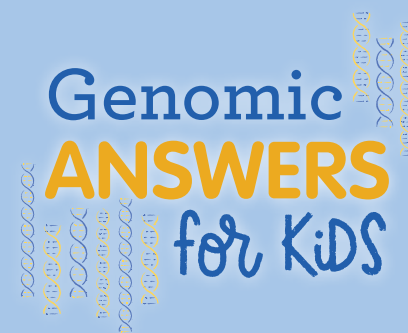
When a child is diagnosed with cancer, the question “Why?” becomes more relevant than ever. Patients, parents, clinicians and researchers all want to know the answer to that one question. Often, there is no answer, but thanks to the Children’s Mercy Genomic Medicine Center, that may one day change.

Established in 2011, the center was the first of its kind with a pediatric focus and has become an epicenter for genomic research at Children’s Mercy, and around the world. Led by Tomi Pastinen, MD, PhD, Director, the center’s focus is to increase the diagnosis rate for rare diseases in pediatric medicine.

“Currently, less than half of kids with rare diseases get an answer from molecular testing,” Dr. Pastinen said. “We want to change that—we want the majority of kids to receive an answer from a molecular test, including children diagnosed with cancer.”

To reach that goal, the Genomic Medicine Center is utilizing several novel technologies, such as third-generation sequencing and single-cell genomics.

“This technology allows us to look at the ‘blind spots’ in current diagnostic sequencing technologies,” Dr. Pastinen explained. “This is achieved by generating much longer sequencing reads than conventional technologies can. We believe that this unexplored space may hold some of the answers we are looking for.”



A flagship initiative of the Children’s Mercy Research Institute and the center is an initiative called **Genomic Answers for Kids**. This initiative is in the early stages of collecting and storing genomic information and biological samples from children and their biological family members who have a rare genetic condition. The resulting database will be a rich resource for researchers studying genetic conditions, potentially leading to answers and new treatments for children.

Tom Pastinen, MD, PhD

“We envision that rare forms of pediatric cancer have a heritable basis in up to 10 to 20 percent of cases,” Dr. Pastinen said. By systematically employing the center’s advanced set of genomic tools, he believes they will uncover more inherited mutations in these patients.

This information could help potentially identify the molecular switch responsible for the cancer.

Armed with that information, clinicians would be able to search for treatments targeted at specific genetic mutations.

While Dr. Pastinen admits this will be a long journey, he’s hopeful Children’s Mercy can accelerate the pace of discovery and advance the field of genomic medicine by sharing the center’s database with the scientific community.

“We are working as fast as we can to implement these novel genomic tools for patients with unsolved rare diseases,” Dr. Pastinen said. “These families can’t wait for answers. They want to know why their child is sick.”



Bryce Munson remembers the very first time he had what he thought was a panic attack. Mom Erryn Westerhold does, too.

“I was in my 7th grade math class when I started having trouble breathing, my chest hurt, I couldn’t focus and my vision was blurry,” Bryce said.

Erryn took Bryce to the family’s pediatrician, who prescribed anti-anxiety medication. For a while, the panic attacks stopped, but over the next three years, they became more and more frequent.

“On the surface, it looked like I had a really, really bad case of anxiety,” Bryce said. But he didn’t.

Erryn and Bryce’s father, Jerald Munson, started to question whether something else might be causing their son’s anxiety attacks and uncontrollable spikes in his blood pressure. Jerald’s mother had had an inherited disorder called von Hippel-Lindau syndrome, or VHL.

VHL is characterized by the formation of tumors and cysts in different parts of the body. These tumors may be cancerous or noncancerous, and often first appear during young adulthood. Though Jerald’s mother had passed away from VHL, he had never shown any signs or symptoms of the disorder.

“We knew in the backs of our minds that it was possible Jerald could have VHL and the boys could have inherited it, but it had never been an issue,” Erryn said. Until Bryce’s anxiety attacks began.

DIAGNOSING VHL

Erryn started researching VHL and found people with the condition commonly develop a type of tumor called a pheochromocytoma. These tumors occur in the adrenal glands, which are located on top of each kidney. Though pheochromocytomas are usually not cancerous, they can cause headaches, panic attacks, excess sweating and dangerously high blood pressure—all symptoms Bryce had.

After discussing Jerald’s family history with their pediatrician, he referred Bryce to an endocrinologist at Children’s Mercy for further testing. Jerald and Erryn recall the day they got the call that Bryce had a pheochromocytoma on his right adrenal gland.

“It was terrifying, actually,” Erryn said. “I was at work when the phone rang and they said we needed to get Bryce to Children’s

THE MUNSONS’ SAFETY NET



Clayton Munson

Michael Munson

Bryce Munson

Mercy immediately. I told them, 'I get off work at 5:30 p.m., and I'll bring him up then,' but they said we needed to get him there NOW."

Erryn and Jerald dropped what they were doing, and rushed Bryce to the hospital. There, doctors removed the pheochromocytoma and his right adrenal gland.

While hospitalized, Bryce said specialists lined up outside his door. "I felt like I had 30 doctors!" he said.

"He was pretty popular," Jerald said. "Endocrinologists, neurologists and oncologists—Bryce had a team of specialists taking care of him at Children's Mercy. That's the kind of care this condition requires."

After a few days in the hospital, he returned home to Warrensburg to recover. "I had lots of medications to regulate," Bryce said. "And I had to take my blood pressure like 100-million times a day."

Mom said it wasn't quite that bad, but she kept a journal of his blood pressure readings that she still has today. "I would send the readings to his endocrinologist every day, and she would adjust his medications accordingly," Erryn said.

A few months later, Bryce returned to Children's Mercy to have a smaller pheochromocytoma removed from his left adrenal gland via a cryoablation procedure. Since then, he's been tumor-free. No treatment other than medication has been necessary.

ON THE SPoT!

When Bryce tested positive for VHL, it generated a whole new level of concern that everyone in the Munson family, except Erryn, could have the disorder.

First, Jerald tested positive for VHL. He discovered he also has several non-cancerous tumors throughout his body. He's had one removed from his kidney, and his doctors are watching him closely.

Though the odds were 50/50 that Jerald had passed VHL on to Clayton, 14, and Michael, 11, they also tested positive for VHL.



So far, neither has shown any symptoms of the disorder, but to be certain the brothers stay healthy, they're now followed in the Children's Mercy Surveillance for Predisposition to Tumors, or SPoT Clinic.

The clinic was developed to follow patients with a variety of hereditary cancer syndromes that predispose them to different types of tumors in all parts of the body. At each clinic visit, the team reviews national screening guidelines specific to the patient's diagnosis, and makes sure the patient is current on all surveillance testing.

"We focus on kids who have complex cancer risks, meaning their risk for tumor development requires more complex screening schedules," explained Caitlin Schwager, MS, CGC, Genetic Counselor for oncology and Manager of the SPoT Clinic.

"That can be a lot for families and primary care providers to manage, especially if there are multiple children involved, like the Munsons."

The SPoT Clinic team includes Caitlin, Kevin Ginn, MD, pediatric neuro-oncologist, and Erin Guest, MD, Director of the Cancer Genomics Program and the Cancer Center Biorepository. They conduct the clinic eight times a year, following approximately 30 to 40 patients.

"The SPoT Clinic is like a safety net for these patients and their families," Caitlin said. "We can improve adherence by following established protocols, reducing the risk that something will be missed, and improving the quality of life for these families."

WE'VE GOT YOUR BACK

Bryce, Clayton and Michael take comfort in knowing the SPoT clinic team is keeping a close eye on their health, allowing them to focus on what's important to three active guys.

"I'm a senior in high school now," Bryce said. "I'm taking college courses and I'm thinking about getting a business degree."

Clayton is the family daredevil. He loves doing tricks on his bike and playing soccer. He's broken several bones, but so far hasn't developed any tumors related to VHL.

And Michael, known to his brothers as Mikey, loves playing football and taking care of his pet rabbit, but has no symptoms of VHL either. All three are followed in the SPoT Clinic annually. Their next imaging and lab tests are scheduled for March 2020.

"To be honest, we dread that time of year," Jerald admitted. "We know there's a risk there could be something we might have to deal with, but so far, we've gotten good news."

Still, the concern is always in the backs of their minds.

"If one of the boys has a headache more than a couple of days in a row, or they don't feel good, we're concerned it might not just be a headache, or a virus, it could be more serious," Erryn said.

Jerald agreed. "We worry that the minor stuff could turn out to be something major."

COUNTING THEIR BLESSINGS ...

Though Erryn and Jerald have had a lot to deal with since Bryce's diagnosis, they're thankful they discovered it when they did, and that Children's Mercy was in their corner.



The Munson family with staff of the Children's Mercy SPoT Clinic, Caitlin Schwager, MS, CGC, Erin Guest, MD, and Kevin Ginn, MD.

"Children's Mercy is a great hospital," Jerald said.

Erryn is grateful their Warrensburg home is only an hour away from the hospital's Adele Hall Campus, and the SPoT Clinic.

"I feel very blessed we live this close to Children's Mercy, and a team of specialists who know what VHL is and how to treat it."



The Munson family



Kevin Ginn, MD



NEURO-ONCOLOGY

The Children's Mercy Cancer Center Neuro-Oncology Program is a multidisciplinary program led by Kevin Ginn, MD. The primary focus of the program is to provide access to advanced cancer therapy and 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 deaths and morbidity and these patients benefit from the individualized care plans developed by multiple subspecialists available at Children's Mercy.

Here, we treat approximately 50 new patients a year and each patient is discussed at our twice-monthly multidisciplinary tumor boards. These tumor boards allow in-depth discussion of new or established patients, ensuring thorough care planning to improve patient care. Our involvement in national consortiums such as Beat Childhood Cancer and the Children's Oncology Group (COG), as well as pharmaceutical industry relationships, allows us to provide access to cutting-edge clinical trials for both new and relapsed patients.

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 comprehensive care and cutting-edge therapy provided close to home for every patient with a central nervous system tumor that enters the doors of Children's Mercy.

LIVER TUMOR

The Liver Tumor Program is a multidisciplinary team, which includes oncology, hepatology, surgery and liver transplant services. They work together to give comprehensive care to children with liver cancer. Every patient's treatment plan is discussed with all of the disciplines. The coordination of care begins prior to diagnosis and continues even after treatment has been completed.

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 that could compromise individual and family well-being. This includes supportive care, symptom management and psychosocial needs for all members of the family. Research initiatives focus on symptom assessment and management for adolescents and young adults with cancer, as well as active engagement with music during hospitalization for young children.

LEUKEMIA AND LYMPHOMA

The Leukemia and Lymphoma Program at Children's Mercy is comprised of experts in the diagnosis and management of hematologic malignancies in children and young adults. Under the direction of Keith August, MD, the Leukemia and Lymphoma Program is a collaborative effort dedicated to delivering state-of-the-art clinical care and to generating innovative and collaborative research efforts. Members are multidisciplinary and include faculty from the Sections of Oncology, Blood and 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.

Keith August, MD



HISTIOCYTOSIS

The Histiocytosis Program at Children's Mercy provides a comprehensive setting for children with a group of rare diseases. The program is led by J. Allyson Hays, MD, pediatric hematologist/oncologist. It 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 orthopedic surgeons, pediatric endocrinologists, pediatric dermatologists and pediatric pathologists familiar with Langerhans cell histiocytosis (LCH), hemophagocytic lymphohistiocytosis (HLH), sinus histiocytosis with massive lymphadenopathy (SHML)/Rosai Dorfman (RD), juvenile xanthogranulomatous disease (JXG) and Erdheim-Chester disease (ECD). 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.



EXPERIMENTAL THERAPEUTICS

The Experimental Therapeutics in Pediatric Cancer Program at Children's Mercy was founded in 2010 with a goal of providing patients with access to early phase clinical trials after relapse and/or progression has resulted in limited remaining options for therapy. Over the years, we have developed relationships with consortiums and pharmaceutical companies, increasing our ability to have open trials available when they are needed. On average, 25 clinical trials are open at any time through our collaboration with Beat Childhood Cancer, Children's Oncology Group, Aflac Cancer Center at Emory Children's Hospital and industry partners. The Experimental Therapeutics team includes three physicians, each with their own specific area of interest including neuro-oncology, solid tumors, blood cancers and cancer genomics (including ethnic diversity and its relation to outcome/response). The team also includes advanced practice nurses and three dedicated clinical research coordinators, who are vital to our mission and help to maintain the trials and monitor study patients.

In a given year, Experimental Therapeutics treats 15 to 20 children. In addition to the Kansas City region, we have received a number of outside referrals from centers in Wichita, St. Louis, Oklahoma, Colorado, Iowa, Arkansas, Illinois and Texas. With the continued development of the Children's Mercy Research Institute and our strong relationship as consortium partner in the NCI-designated University of Kansas Cancer Center, we are poised to become a national leader in innovative cancer treatments for children. Access to early phase clinical trials has made a significant difference for children with cancer in Missouri, Kansas and the region.

BONE AND SOFT TISSUE SARCOMA

Sarcoma accounts for approximately 15% of all childhood cancers. Each year, Children's Mercy treats approximately 15 to 20 children with bone or soft tissue tumors, the most common of which are osteosarcoma, Ewing sarcoma and rhabdomyosarcoma. The Bone and Soft Tissue Sarcoma Program at Children's Mercy (in collaboration with the Sarcoma Center at the University of Kansas Cancer Center) consists of highly-trained specialists in pediatric oncology, orthopedic oncology, radiation oncology, rehabilitative medicine, radiology, pathology and interventional radiology, who focus on providing cutting-edge, family-centered sarcoma care from diagnosis through treatment and post-therapy monitoring. We believe no child should have to leave the Kansas City area in order to receive elite, streamlined sarcoma care, and providing such care is our daily priority. Additionally, with an expanding panel of collaborative research opportunities, we are helping to identify the next generation of sarcoma therapies right here in Kansas City.

The Bone and Soft Tissue Sarcoma Program at Children's Mercy is led by Joy Fulbright, MD, and Joel Thompson, MD. The program consists of orthopedic surgery (Howard Rosenthal, MD, and Kyle Sweeney, MD) radiation oncology (Ronny Rotondo, MDCM, FRCPC), rehabilitative medicine (Kimberly Hartman, MD), pediatric oncology, pathology, interventional radiology and radiology. Our goal is to provide seamless care coordination from radiation oncology to pathology and orthopedic surgery, with a multidisciplinary tumor board and enhanced collaborative research across disciplines.

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% 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 increase 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.

IMMUNOTHERAPEUTICS



The Cancer Immunotherapeutics Program at Children's Mercy promotes innovative basic and translational investigation 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.

ACKNOWLEDGEMENT OF 2019 CANCER CENTER DONORS

The Cancer Center is grateful for the support from our philanthropic donors and granting organizations:



Big Slick hosts and celebrity friends celebrate a record-breaking 10th Annual Big Slick Celebrity Weekend benefiting pediatric cancer research at Children's Mercy.



Paul D. Kempinski, MS, FACHE, President and Chief Executive Officer at Children's Mercy, accepts a check for \$350,000 from Steve Edwards, Chairman and Chief Executive Officer of **Black & Veatch**, at the 2019 Black & Veatch Charity Golf Tournament. The tournament benefited the cancer genomics program at Children's Mercy.



Founded by Deliece Hofen when her son, Braden, was diagnosed with Stage IV Neuroblastoma, **Braden's Hope for Childhood Cancer** funds research into targeted therapies that shut down the activators of childhood cancers. Thanks to Braden's Hope, children and families have real HOPE for long, healthy lives.



Founded by six-year-old Noah Wilson during his cancer journey, **Noah's Bandage Project** provides cool and fun bandages to kids and raises funds for pediatric cancer research. Noah's parents, Deborah and Scott Wilson, continue Noah's Bandage Project to help kids right here at Children's Mercy and all across the globe.

CANCER CENTER PHILANTHROPIC DONORS IN 2019:

- Ann and Matt Anthony
- Big Slick
- Black & Veatch
- Braden's Hope for Childhood Cancer
- C.W. Titus Foundation
- James M. Burcalow
- DeBruce Foundation
- Noah's Bandage Project
- Mr. and Mrs. Henry J. Massman IV
- Laura and Hatch McCray
- Roderick J. and Jo Anne Cyr Foundation
- Lisa and Dolph Simons
- Victor E. Speas Foundation, Bank of America, N.A. Trustee
- Victor E. and Caroline E. Schutte Foundation Trust E, David W. Frantze and Bank of America, N.A., Co-Trustees
- Bret and Christy Wilson
- Ann and Frank Uryasz

CANCER CENTER GRANTING ORGANIZATIONS IN 2019:

- Alex's Lemonade Stand Foundation
- Braden's Hope for Childhood Cancer
- Children's Mercy Cancer Center Auxiliary
- Children's Oncology Group
- Curing Kids Cancer
- Hyundai Hope on Wheels
- Masonic Cancer Alliance
- Noah's Bandage Project
- St. Baldrick's Foundation
- The University of Kansas Cancer Center

We are grateful to all of the incredible donors and granting organizations who are putting children first in the fight against childhood cancer. The donor commitments listed here represent philanthropic gifts of \$50,000+ in fiscal year 2019 and organizations providing research grant funding to the Cancer Center in 2019.

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