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2011

2011 Cancer Care Annual Report

Children's Mercy Hospital

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2011
**CANCER
CARE
ANNUAL
REPORT**



Children's Mercy
HOSPITALS & CLINICS | Kansas City

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Letter from the Director



Alan Gamis, MD

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

Non-Hodgkin lymphoma is truly a success story. Through cooperative research, survival rates have improved by more than 40 percent since the 1970s. In fact, cure rates for all types of childhood cancers have also improved. From 1975-77, survival rates for all types of childhood cancers combined was 58 percent. Today, overall survival rates are greater than 80 percent for all childhood cancers.

Because childhood cancer is relatively rare, physicians and scientists have had to join forces to achieve the excellent cure rates we see today. The doctors and nurses at Children's Mercy are members of the Children's Oncology Group, the largest international research consortium. As a large childhood cancer center within the COG, Children's Mercy sees approximately 180 new oncology patients each year, while following an additional 1,500 patients during and after treatment. And, we are currently participating in 80-100 clinical trials at any given time.

The Division of Pediatric Hematology/Oncology/Bone Marrow Transplantation at Children's Mercy has seen some amazing changes in the past few years. We have grown from five Pediatric Hematologists/Oncologists in 1995 to a current staff of 22 physicians. With this incredible growth, we have been able to create a dedicated Leukemia/Lymphoma program. This program, led by Keith August, MD, allows us to bring together a group of providers that are focused on administering the latest and best care for patients with leukemia and lymphoma.

We continue to expand our Experimental Therapeutics in Pediatric Cancer Program. This program brings novel therapies

to our relapsed or refractory patients and currently has 15 open protocols. In addition, we are expanding our inpatient unit by opening a new Bone Marrow Transplant Unit with 15 beds, making a total of 38 beds dedicated to our patients. With Magnet recognition and specially trained pediatric oncology nurses, we provide excellent inpatient care.

Successful treatment of childhood cancer does not end with curing the patient. Childhood cancer survivors need specialized care even after they have been cured of their disease. To this end, Children's Mercy has developed a Survive and Thrive Clinic, led by Joy Fulbright, MD, and coordinated by nurse Wendy McClellan, to help survivors with late effects and to ease the transition from pediatric care to the adult health care setting.

This report focuses on non-Hodgkin lymphoma, a cancer that, while it may often present as a medical emergency, is now highly curable through the availability of our multidisciplinary team for accurate diagnosis, staging, treatment and supportive care.

We also use this report to highlight other aspects of our Hematology/Oncology Division, which is proud to be ranked by U.S. News and World Report as one of the top comprehensive children's cancer centers in the nation. We hope to highlight some of the many ways we are working wonders to help treat and cure childhood cancer.

A handwritten signature in black ink, appearing to read 'AGamis MD'. The signature is stylized and cursive.

Letter from the President and CEO

Dear Friends,

Few things tug at the heart as strongly as the thought of children with cancer.

We are fortunate at Children's Mercy to have one of the leading programs in the country to help children and their families cope with this devastating disease. Our team of physicians, nurses, support staff and researchers are committed to providing the highest level of care to these families, while also working toward improving treatments and finding cures for childhood cancers.

Our Experimental Therapeutics in Cancer program continues to grow and achieve national prominence. Working in collaboration with national consortia, we are utilizing our world-renowned pediatric clinical pharmacology expertise to make cancer medications safer and more effective for children here and around the world.


In addition, our Hematology/Oncology staff is leading innovative research to better understand cancers such as mixed lineage leukemia (MLL) and improving how patients respond to bone marrow transplants. We continue to expand services for children with liver tumors, brain tumors and other types of childhood cancers.

We treat nearly 90 percent of all newly diagnosed pediatric cancers in our region, and our outcomes rank among the best in the nation. Through our Adolescent and Young Adult program, highlighted in this report, we are now working to extend that same success to older teens and young adults who could benefit from the same aggressive treatments and protocols.

We are pleased to note that many of the efforts highlighted in the follow pages are collaborative, in particular, our role in the KU Cancer Center. We are committed to working with others to advance pediatric medicine and do whatever it takes to help improve the health and well-being of children here and around the world.

It is no wonder we are ranked by U.S. News and World Report as having one of the best children's cancer programs in the country. As highlighted by the patient success stories in this report, our Hematology/Oncology staff is working wonders every day.

Sincerely,



Randall L. O'Donnell, PhD

President and CEO
Children's Mercy
Hospitals and Clinics

The Division of Hematology/Oncology/Bone Marrow Transplantation

Children's Mercy is the region's leading pediatric cancer program, caring for nearly 90 percent of new pediatric cancer diagnoses in the area. We offer 10 times more pediatric cancer specialists than any other hospital between St. Louis and Denver. Our unique case management system provides every patient with the highest level of care throughout the course of their disease. Plus, our role in several national research consortia helps make sure your patients have access to the most recent advances in treatment.

- › We operate one of the larger childhood cancer centers in the country, with 22 pediatric specialists on staff, and have received Accreditation with Commendation from the American College of Surgeons Commission on Cancer.
- › Our survival rates for nearly every type of cancer we treat are at or above national averages.
- › Your patients have direct access to more than 80 pediatric clinical trials — including several national trials led by our own investigators, as well as trials through the National Cancer Institute's Children's Oncology Group and several other national research consortia.
- › Our Experimental Therapeutics in Pediatric Cancer program, working with our internationally recognized Clinical Pharmacology program, is helping make cancer treatment safer and more effective for children here and around the world.
- › As the primary pediatric cancer provider and only NCI Children's Oncology Group institution in the Midwest Cancer Alliance, we were instrumental in bringing National Cancer Institute designation to the region.
- › We are the only accredited pediatric cancer program by the American College of Surgeons Commission on Cancer in the region and the only pediatric cancer program to have received the "Outstanding Achievement Award" from this organization in the past two three-year survey cycles.
- › Our pediatric bone marrow transplantation program is a regional center for Missouri, Kansas and Iowa, performing 35 transplants a year, including unrelated and related donor transplants for both malignant and non-malignant diseases. ●



Cancer Registry

Cancer registrations begin with the identification of patients who have been diagnosed or treated for malignancies, or other certain benign/borderline conditions, at Children's Mercy or other clinics. The Cancer Registry is operated under the guidance of the Cancer Care Committee and maintains the data standard requirements of the American College of Surgeons Commission on Cancer and the State of Missouri. A complete summary of the data elements concerning diagnosis, histology, site, treatment and disease status is captured. The patients are also followed annually to evaluate treatment methods, outcomes and other patient needs. By having access to such data the impact of disease can be analyzed at Children's Mercy and also at the state and national levels.

2011 Registry Statistics

Numbers: During 2011, there were 185 patients added to the Registry database. Central Nervous System tumors represented 26 percent of the annual caseload with leukemia close behind at 23 percent. There were 13 benign reportable conditions that are required by the cancer care committee to be collected due to propensity to recur and special interest. Please see the frequency table for further breakdown of disease types.

Age at Diagnosis: There were 26 patients less than 1 year of age diagnosed during 2011. The 1-4 age group consisted of 57 patients, the 5-9 age group had 29 patients, the 10-14 age group had 40 patients, and there were 33 patients in the 15-19 age range.

Sex: There were 97 female patients and 88 male patients during 2011.

Analytic Patients: During 2011, there were 165 analytic patients, who are patients diagnosed at Children's Mercy or elsewhere but received all of their first course of treatment at Children's Mercy. The analytic patients are those eligible for inclusion in the registry's statistical reports of treatment efficacy and survival.

Race: There were 149 Caucasians, 25 African Americans and 11 Other races. Within the 149 Caucasian patients, 18 were of Spanish/Hispanic ethnicity.

Geographic Origin: During 2011, our cancer patients came from four different states and 48 different counties. Fifty-one percent of the patients were from Missouri, 48 percent from Kansas and 1 percent from other states. ●

Maxine Hetherington, MD





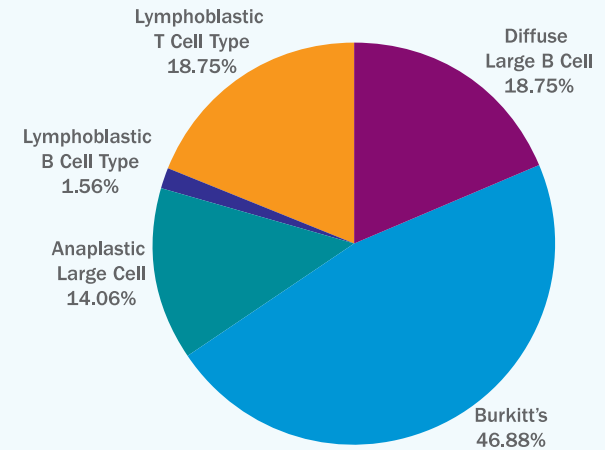
Frequency by Diagnosis 2011

	Totals	Percentage
Central Nervous System	49	26%
Astrocytoma	13	
Glioma	9	
Ependymoma	4	
PNET	2	
Medulloblastoma	1	
Germ Cell	1	
Glioblastoma Multiforme	1	
Benign/Borderline CNS	18	
Leukemia	42	23%
Acute Lymphoblastic Leukemia (ALL)	33	
Acute Myelogenous Leukemia (AML)	9	
Lymphoma	15	8%
Non-Hodgkin	9	
Hodgkin	6	
Neuroblastoma	8	4%
Ewing's Family of Tumors	6	3%
Rhabdomyosarcoma	6	3%
Wilms Tumor	6	3%
Langerhans Histiocytosis	12	7%
Osteosarcoma	8	4%
Retinoblastoma	2	1%
Hepatoblastoma	3	2%
Carcinomas	5	3%
Other Malignant Conditions	10	6%
Benign Reportable Conditions	13	7%

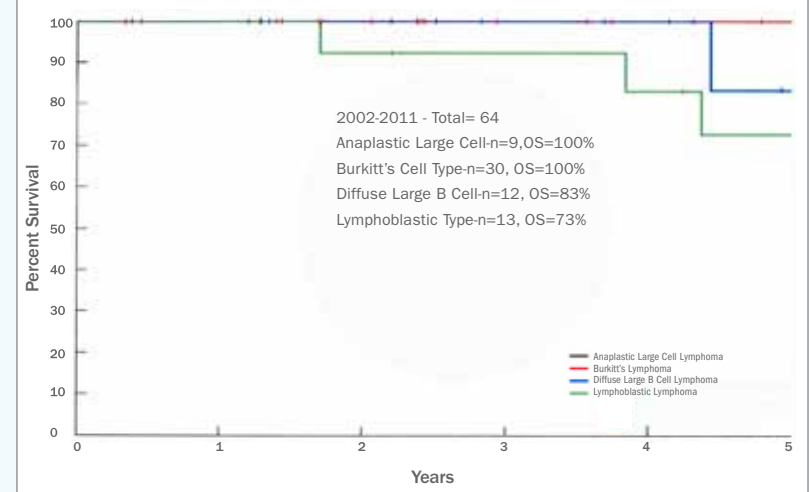
TOTAL 185 100%

Non-Hodgkin Lymphoma Subtypes and Subgroups

Non-Hodgkin Lymphoma Subtype Frequency



Non-Hodgkin Lymphoma Overall Five Year Survival of Subgroups



Staying Positive on the Field—and Against a Daunting Illness

McKenzie Haynes isn't an athlete who puts up with losing. So, in 2010, when the Salina, Kan., high school sophomore earned an admirable eighth place in the 5A state tennis tournament, she made it a priority to finish even better the next year. And, when the threat of leukemia entered her court and threw a wrench in her plans? McKenzie simply shifted her focus from beating her tennis rivals to beating the disease.

McKenzie's superior athleticism was an initial indicator that something wasn't right as the sports seasons evolved that winter. Unusually short of breath for an athlete who excelled at nearly every sport she attempted, McKenzie was initially diagnosed with asthma. Blood tests, however, later proved the condition was much more serious: refractory anemia with excess blasts Type I, a potentially life-threatening illness that can lead to leukemia.

Treatment at Children's Mercy Hospital included blood transfusions, chemotherapy and an eventual bone-marrow transplant. Despite those challenges, McKenzie's positive attitude and competitive spirit never wavered. In fact, McKenzie cited the illness for making her "a lot stronger."

"It made me realize that all the little things aren't such a big deal," she said. "You take a step back and

realize there are things more important than sports and school and all that kind of stuff."

Maintaining that positive attitude led to McKenzie getting back on the court less than 60 days after leaving the hospital. Within eight months of her first, tentative practice strokes, she was ready for the tennis season to start. And by tournament time? McKenzie was once again in top form. With her partner by her side, she placed fourth in the state. Today, she's considering scholarship opportunities to determine where she'll attend college in the fall.

Her physician at Children's Mercy, Jignesh Dalal, MD, Associate Division Director, Section of Bone Marrow Transplantation, called her recovery "amazing." He cited her strong positive attitude as a significant factor in putting her back at the top of her game – both literally and figuratively.

In fact, "All bone marrow transplant patients should follow her lead," he said.

"You need to do what you need to do," he said, referring to the various treatments such serious illnesses require. "But, then, once it is done, move on. Move on with your life. Be positive. Don't let the past affect your present," he emphasized.

Or, in McKenzie's case, take advantage of your past to make you stronger for the future. ●



Non-Hodgkin Lymphoma

Non-Hodgkin lymphoma (NHL) is a diverse group of malignancies originating from cells of the immune system.

NHL is tied with Hodgkin lymphoma as the sixth most common type of cancer in children aged infant to 14, accounting for 4 percent of cancers in this age group.¹ The annual incidence is 1.3 cases per 100,000 children in this age group, and 1.8 cases per 100,000 children, ages 15-19.² A disproportionately high incidence is seen in males, with a male to female ratio of 3:1.²

As opposed to the typical low or intermediate grade lymphoma seen in adults, nearly all childhood lymphomas are high grade. Four types of NHL are routinely seen in children:

- › Burkitt's lymphoma, (BL, formerly small, non-cleaved cell lymphoma [SNCCCL])
- › lymphoblastic lymphoma (formerly precursor T-cell lymphoblastic lymphoma, [T-LL])
- › diffuse large B-cell lymphoma (DLBCL)
- › anaplastic large cell lymphoma (ALCL)

Although the etiology of NHL is unknown, suppression of the immune system has been related to the development of NHL in some patients. Children with inherited (Wiskott-Aldrich, X-linked agammaglobulinemia, ataxia-telangiectasia) and acquired (EBV infection, HIV infection) immunodeficiencies are at increased risk for developing NHL. Lymphoma cells are believed to arise from a single damaged cell, with genetic mutations that influence cell growth, differentiation and/or cell death.

Clinical Presentation

NHLs may present in various ways, depending on the subtype.

In general, patients with NHL present with enlarged lymph nodes and may have systemic symptoms such as fever, fatigue or weight loss. Typical sites of disease include the abdomen for BL and mediastinum for T-LL.

NHL often has a much more sudden onset than HL or adult types of NHL. This is a result of rapid growth of the cancer cells, which are typically higher grade tumors in childhood. Because of the propensity for rapid growth, children with NHL are more likely to present with emergent complications than any other tumor type.

Complications may include airway compression from a mass in the chest, obstruction of the bowel from abdominal masses and metabolic derangements from rapid cell turnover.

Work-Up

Evaluation of the patient with suspected NHL includes baseline laboratory work to assess renal function, liver function, coagulation and hematologic status. A chest X-ray should be performed prior to any procedures to evaluate for a mediastinal mass. CT scans are often the initial imaging study to identify the sites of disease. Positron emission tomography (PET) scans have gradually replaced gallium scans and are now considered an essential tool in the initial evaluation of patients with NHL. Whenever clinically feasible, an incisional lymph node biopsy is recommended to make

the diagnosis. Fine needle aspirations are not recommended, as they do not provide adequate tissue for accurate subtyping. If the patient is critically ill, alternative methods of diagnosis may be needed, such as sampling of pleural effusions. Additional diagnostic tests, such as bone marrow exams or lumbar punctures, are typically needed to complete the work-up.

Surgery

The role of the surgeon in the treatment of NHL is generally relatively limited. Initial incisional biopsy for diagnosis is usually required. In children with rapidly progressing lesions such as Burkitt's lymphoma, this can assume some urgency. The next step is often multi-agent chemotherapy, with the exception of small, easily resectable lesions.

Even initial biopsy can be challenging in children with extensive thoracic and mediastinal disease, in whom induction of general anesthesia and the attendant loss of airway tone in conjunction with myocardial depression may result in catastrophic respiratory or circulatory collapse. The most common tumor type with mediastinal involvement is usually lymphoblastic lymphoma. Alternative diagnostic techniques (needle biopsy by interventional radiology, local anesthesia) may be helpful. Rarely, treatment must be instituted presumptively prior to diagnosis.

Generally, tumor burden is the most important prognostic factor in predicting outcome, and there is no role for aggressive attempts at primary resection. However, in disease that can be easily and completely resected, it may improve EFS and prevent complications.

Transplant surgeons may be involved in the care of their patients who develop Post-Transplant Lymphoproliferative Disorders (PTLD). The risk of developing this disorder after solid organ transplantation (TP) depends on the type of transplant (renal TP is the lowest risk, heart-lung TP the highest) and the intensity and duration of immunosuppression. EBV seronegative patients and young age at TP are risk factors.

Staging

The well-established St. Jude's Staging System is utilized for patients with NHL. Approximately 60 percent of children with NHL will present with advanced stages of disease (III or IV).

Pathogenesis and Pathology

The diagnosis of NHL requires biopsy of involved sites. Biopsy samples are submitted to pathology, examined and samples of the biopsy are routinely submitted for light microscopy, flow cytometric immunophenotyping, cytogenetic testing and molecular genetic analysis. Additional portions of the biopsy sample may be frozen for potential treatment or research related studies. Results from all the studies confirm the diagnosis, establish the subtype of NHL, and provide useful cytogenetic and molecular genetic information for establishing prognosis and guiding therapy.

Childhood NHLs are sub-classified on the basis of size and pattern of cells under the microscope to distinguish them from Hodgkin lymphomas and type them as Burkitt's lymphoma, lymphoblastic lymphoma or one of several types of large cell lymphomas.

The most frequent large cell NHL is Anaplastic Large Cell Lymphoma. Accurate subtyping often requires the use of ancillary testing and special immunohistochemical stains to establish T or B lymphocyte lineage and the particular stage of maturation. Though any one of these types of lymphomas may occur in adults, they are much more common in children and have a distinctly different

prognosis and treatment strategy. The types of NHLs also differ from adult lymphomas in that they are more aggressive, more frequently arise in extra nodal site such as abdominal mesentery or mediastinum, proliferate extremely rapidly and are often associated with systemic symptoms.

Genetics & Molecular Biology

The genetic changes that occur in the lymphoma cells help to establish the sub-type of the lymphoma. Commonly, the tissue sent to the cytogenetics lab is broken up and put into tissue culture to encourage cell growth. Usually the cells are 'harvested' the next day. Dividing cells show the chromosomes of the lymphoma.

Genetic changes that characterize lymphoma can be seen by looking at all the chromosomes in a cell using a microscope. Often the genetic changes are specific to the diagnostic subtype of lymphoma.

Fluorescence in situ hybridization analysis (FISH) is another way to examine the involved tissue to look for specific genetic changes that can contribute to the diagnosis. FISH uses small pieces of DNA specific to a gene. These DNA pieces are tagged with color that can be seen under the microscope. The pieces are very specific and can be used to confirm that a particular gene is affected in the lymphoma.



St. Jude's (Murphy) Staging System for Childhood Non-Hodgkin Lymphoma

Stage	Definition
I	Single tumor (extranodal) or single anatomic area (nodal), excluding mediastinum or abdomen
II	Single tumor (extranodal) with regional node involvement On same side of diaphragm: a) Two or more nodal areas b) Two single (extranodal) tumors with or without regional node involvement Primary gastrointestinal tract tumor (usually ileocecal) with or without associated mesenteric node involvement, grossly completely resected
III	On both sides of diaphragm: a) Two single tumors (extranodal) b) Two or more nodal areas All primary intrathoracic tumors (mediastinal, pleural, thymic) All extensive primary intra-abdominal disease; unresectable All primary paraspinal or epidural tumors regardless of other sites
IV	Any of the above with initial central nervous system or bone marrow involvement (<25 percent)

Treatment

Substantial progress has been made in treating NHL. Five-year relative survival rates for children with NHL have improved from 43 percent in 1975-77 to 86 percent survival rates in 2001-2007.¹ Patients with localized disease will typically have survival rates exceeding 90-95 percent. Historically, treatment regimens have been focused on intensifying therapy to improve cure rates. With improved outcomes, more recent trials are attempting to reduce therapy in certain subgroups of NHL patients, in attempts to reduce toxicities.

NHLs, with their propensity for rapid growth, are very chemosensitive. Therefore, chemotherapy is the major modality used in treating NHL. The excellent cure rates we see today are the result of many cooperative trials and improvements in diagnosis and supportive care. A variety of chemotherapy regimens are used, which are highly dependent on the subtype of NHL. Length of therapy also varies greatly between subtypes. Treatment of BL or DLBCL is typically short and intense (approximately six months in length) as compared to T-LL where chemotherapy is given for approximately two years. Radiation is rarely needed in the initial treatment of NHL. As previously noted, surgery's critical role is in obtaining tissue at diagnosis.

While outcomes have improved dramatically over the years, there is still room for improvement. Novel therapies are being evaluated

to treat refractory or relapsed patients. These therapies include targeted therapies, such as antibodies, where the goal is for the medication to attack the tumor cells more specifically and cause less harm to the surrounding normal tissues.

Treatment of the patient with NHL requires the expertise and collaboration of the surgeon, radiologist, pathologist, cytogeneticist and pediatric oncologist to achieve such excellent outcomes. By participating in collaborative trials, oncologists at Children's Mercy continue to help improve the outcomes for patients with NHL. In addition, patients with NHL need long-term care and evaluation for late effects or side effects caused by the treatments used in NHL. With the development of our Survive and Thrive Clinic, Children's Mercy has a dedicated group of providers that are specifically trained in monitoring and treating late effects.

Children's Mercy Outcomes

From 2001-2010, 64 patients have been diagnosed with NHL at Children's Mercy, with a mean of 6.4 new cases/year for the past 10 years. Overall survival is 89.7 percent with a median follow-up of 225 weeks. The male:female ratio is 2.4 : 1.0. Overall survival of patients at Children's Mercy is compared to national data in the adjacent graphs. Children's Mercy survival (89.7 percent) compares favorably to national results (86 percent survival). ●

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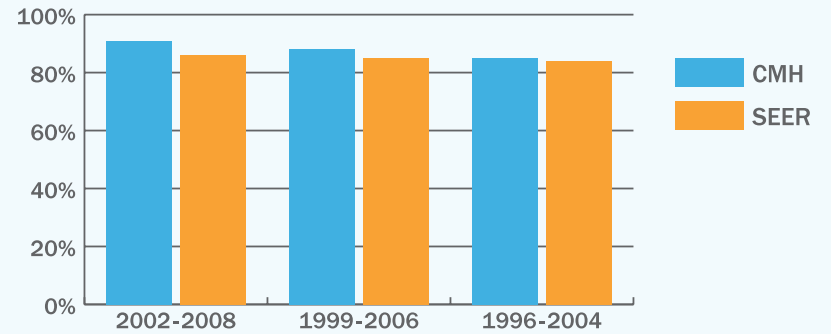
Tristan Flatt, DO



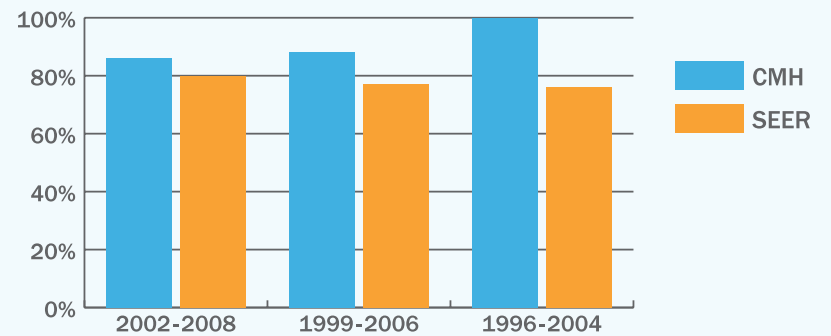
Non-Hodgkin Lymphoma Survival Rate Comparison

Children's Mercy Hospital (CMH) vs Surveillance Epidemiology and End Results (SEER) of the National Cancer Institute

NHL Overall Survival (Ages 0-14)



NHL Overall Survival (Ages 15-19)



A High School Routine Interrupted Twice

The local doctor thought **Josh Carroll's** "crumminess" might be attributed to pancreatitis. So, as the Lamar, Mo., teenager's condition at Barton County Memorial Hospital continued to get worse throughout that first week he was there, he was transferred to Children's Mercy Hospitals and Clinics for further testing.

Josh entered Children's Mercy as a Gastroenterology patient on Dec. 20, 2009. And, on the morning of Jan. 1, 2010, he was officially diagnosed with non-Hodgkin lymphoma.

"The suspected pancreatitis was eventually part of it," says Josh. "I actually had a cancerous tumor in my pancreas."

Immediately, Josh began treatment in the Children's Mercy Division of Hematology/Oncology/Bone Marrow Transplantation. Assigned to Karen Lewing, MD, Pediatric Hematologist/Oncologist and an Assistant Professor of Pediatrics at the UMKC School of Medicine, Josh continued treatments through April 2010.

"At that time, we thought we were past it," adds Phillip Carroll, Josh's father.

Unfortunately, Josh relapsed on Aug. 25, 2010, just four months later. It was the summer before his junior year of high school.

"I woke up paralyzed from the waist down at 4 a.m. – just couldn't move," says Josh, adding that he was then life flighted back to Children's Mercy, where the Carroll family learned that the cancer was back.

"Not again," he remembers thinking that day.

This time, the tumor was growing on Josh's spine, which explained the paralysis. For three weeks, he couldn't move and the family didn't know if Josh would ever walk again. Dr. Lewing asked for a more aggressive treatment protocol and Josh didn't leave the hospital for 70 days as he fought the cancer for the second time.

Through the chemotherapy treatment, Josh slowly regained feeling in his lower half. And, working with the Occupational Therapy and Physical Therapy Departments at Children's Mercy, he began to walk again.

"He basically missed his entire junior year as he worked his way back and through chemotherapy," adds Phillip, admitting that the relapse was hard for the entire family. But, turning to Dr. Lewing and their cancer team at Children's Mercy, Josh and his family found the support and expertise they needed to get through the aggressive treatment plan.

After the second long bout of treatment, Josh was again declared cancer-free, joining his high school classmates to attend prom in the spring of 2011 and graduating the following year.

Now, Josh is in his first year at Pittsburg State University in Pittsburg, Kan., and, because of his experiences with Children's Mercy, he has plans to study pre-medicine in hopes of becoming a doctor. ●



Karen Lewing, MD 

Nutrition

Supportive therapy for non-Hodgkin lymphomas often requires early intervention by nutritionists. Pain and limited stomach capacity from rapidly growing abdominal tumors often render patients acutely malnourished at diagnosis, as they're simply unable to eat anything until the tumor can be reduced.

This is typically a medically and emotionally intense time period requiring rapid interventions and frequent interruptions in eating/feeding which further compromise nutritional status. Once treatment is initiated lymphomas can shrink rapidly, which can help relieve some pain and stomach compression. Initially the large amount of destroyed lymphoma cells can overwhelm vital organs, making the child extremely ill, which further complicates feeding.

Early interventions with tube feedings or IV nutrition are often not an option due to medical complexity. Once the child's tumor burden is reduced and vital functions stabilized, nutrition therapy focuses on support with tube feedings or IV nutrition until appetite returns after chemotherapy. However, the intensive treatment schedules required for NHL can damage the stomach and intestinal lining as well as cause significant nausea, continuing to render the child unable to meet their needs by eating. Feeding tubes are often used to deliver consistent nutrition until side effects decrease.

Developments in supportive medications and nutrients have improved children's recovery time after chemotherapy, allowing them to eat naturally with the support of their families and medical team. Nutrients targeted to support the stomach and intestines at the cellular level can increase resilience to chemotherapy damage, which allows for shorter recovery time after chemotherapy. Medications to stimulate a child's appetite often help reduce the amount of time they require supportive nutrition, allowing them to eat naturally which is a significant emotional comfort to the child and their family.

Registered dietitians specializing in nutrition, support and assess children with NHL daily while in the hospital, recommending adjustments to feeding regimens and IV nutrition prescriptions. Once out of the hospital, dietitians continue to work with the child and parents on transitioning to a diet high in calories, protein and food-derived vitamins and minerals to improve quality of life and intestinal health. ●





Radiology

Although tissue sampling is still required to make a diagnosis of the non-Hodgkin lymphomas, imaging plays a vital role in the workup, staging and monitoring of this disease.

Chest X-rays, abdominal ultrasounds, Computerized Tomography (CT) scans of the chest and abdomen, and Magnetic Resonance Imaging (MRIs) are all valuable modalities used to evaluate and follow this disease. Cross-sectional imaging (CT/MR) serves as the primary way of determining the distribution, severity and staging of the disease. In recent years, PET/CT has become a workhorse for evaluation of NHL because of its ability to not only detect tumor sites, but also to see if they are metabolically functional.

Positron emission tomography (PET) works by attaching a radioactive particle to glucose, which is then taken up by the metabolically active tissue. This modality is particularly useful on post treatment examinations when a residual mass may persist, but may not represent active disease. The anatomical (CT) and functional (PET) components are performed at the same time, and by fusing them together it can show if certain areas are active tumor or just residual soft tissue mass.

PET/CT may also be useful in the localization of a site for biopsy ensuring adequate tissue is obtained in a manner least invasive to the patient.

Although not always appreciated, there is the radiation risk associated with the ongoing use of diagnostic imaging. During treatment and for several years afterward, imaging is performed to detect disease recurrence, disease progression and development of second malignancies. Although small, the long-term risks of exposure to medical radiation are real. One of the primary roles of the pediatric radiologist is to keep radiation dose to a minimum in these patients, whose tissues are not only more radiosensitive, but are getting more CT scans than other children.

At Children's Mercy, we work hard to ensure the children who receive diagnostic imaging receive the lowest amount of radiation necessary to provide the needed results. With state of the art equipment, special pediatric dose calculators, certified technologists and board certified pediatric radiologists, we are proud to work with the excellent team of providers at Children's Mercy to provide optimal care for the children with non-Hodgkin lymphoma. ●

Inpatient Unit

The course of treatment for a pediatric oncology patient of any age, and with any cancer diagnosis, includes an inpatient hospital stay.

While a patient is in the hospital undergoing treatment, the cancer care team works to make the child and family's transition to daily hospital life as seamless as possible. The nurses that staff the Hematology/Oncology/Bone Marrow Transplantation Unit are typically the front line of daily care for the patient and family.

These inpatient nurses are at the bedside administering chemotherapy as well as other supportive medications to handle the effects of the treatment. Aside from chemotherapy, the nurses also assist with surgical biopsies or removal of the lymph nodes, as well as procedures that require sedations, such as lumbar punctures that can be done on the floor.

Clinical work aside, inpatient nurses are provided more resources and education to assist families at the time of diagnosis. While the physicians and residents are responsible for all aspects of diagnosis, nursing input is welcome and valued. It is usually the inpatient nurse's responsibility to coordinate care between the multi-disciplinary care teams. Inpatient nurses also alert the care team to changes in patient status and assist the social workers with psychosocial care during a stressful time. ●

Outpatient Clinic

The Hematology/Oncology Clinic provides a multi-disciplinary approach in caring for all oncology patients, including the non-Hodgkin lymphoma patients and their families.

The clinic includes experienced, highly skilled registered nurses, many of whom are certified pediatric oncology nurses. Nursing staff provides a vast range of nursing services including coordination of patient care, assessment, obtaining laboratory specimens, chemotherapy, biotherapy, medication administration, sedations and transfusions in a safe and nurturing environment. Patients and their families are treated in the Hematology/Oncology Clinic with compassion in a family-centered environment that recognizes their physical, emotional, spiritual and social needs. The clinic nurse advocates and provides support to patients and their families during their treatment of non-Hodgkin lymphoma through answering of questions, listening to their concerns, and educating about medications and their side effects. ●





Advanced Practice Nurses

Advanced practice nurses (APN) are very involved in the care of the patient with lymphoma. APNs are master's prepared nurses who partner with the patient's physician to provide *individualized care*.

This team approach allows for consistent providers for the patient and family as they go through therapy, as well as follow up when the treatment is complete.

APNs provide case management services which encompasses the patients total therapy needs. Patients with lymphoma often require specific labs, chemotherapy, radiology imaging and therapy, inpatient and outpatient treatments, and home health care. All of these needs are well coordinated for the patient with lymphoma by their specific APN.

The APN provides education on the diagnoses of lymphoma and the treatment. She will review the therapy and how it is affecting the patient, perform physical examinations, order laboratory tests and scans, and prescribe medications. They are the point person for phone contact when families are home and have questions or problems. APNs provide support, guidance, education and help to determine interventions that might lessen symptoms and make treatment as easy as possible.

We also have APNs that manage the inpatient chemotherapy service. These APNs oversee the care of patients admitted to the hospital to receive chemotherapy. They see the patients in the morning, do physical exams, adjust medications and then will round on the patient with a physician each day. They are able to provide continuity of care for these patients who are frequently hospitalized. ●

Finding the Support When Your World is Upside Down

Surreal.

That's the first word that comes to mind for Sarah Martinez when she remembers back to her feelings on Jan. 5, 2010 – the day she found out her 4-year-old son, **Jude**, had cancer.

“The Monday prior to diagnosis his left eyelid was swollen, but there was no sign of infection,” says Martinez, adding that Jude had tumbled down the basement stairs of their Lee's Summit, Mo., home a week prior. “We took him into Children's Mercy South for an X-ray and they ended up doing a CT scan. That's when they found the primary tumor.”

When the results came back, Jude was diagnosed with stage IV Burkitt's lymphoma, an aggressive type of non-Hodgkin lymphoma (NHL).

“My first reaction was to whisk him off to St. Jude's,” admits Martinez. “But, after meeting Dr. Lewing, my husband and I knew that Children's Mercy would be the best place.”

Karen Lewing, MD, pediatric hematologist/oncologist at Children's Mercy and Assistant Professor of Pediatrics at the UMKC School of Medicine, began an intensive treatment plan that included the addition of a prescription drug known as rituximab as part of Jude's chemotherapy.

“It's a very aggressive cancer, so we did not have the luxury of time,” added Martinez. “Thankfully, we had faith in Dr. Lewing and Jude's team with this treatment plan.”

In addition to Dr. Lewing, Jude's cancer care team included Jill Anderson, APRN, CPHON, as well as several other oncology nurses and staff members dedicated to his care and treatment.

“When you are faced with losing the most precious thing you have, you are in an indescribable state of mind,” says Martinez. “But, because the staff members at Children's Mercy are part of your team, they have the amazing ability to help you stay sane and get you through every rough patch.”

After nearly seven months of the intense chemo, Jude finished his treatment more than two years ago. Now, a happy, witty, 7-year-old, Jude only visits the Children's Mercy Oncology Clinic for follow-up appointments every four months.

“You know you have an amazing team and hospital when your son, who had just been through so much, is sad after finishing treatment because he wants to still be on 4 Henson (inpatient unit),” adds Martinez. “I also knew that his team was amazing when I had to adjust to not seeing them all of the time, too.” ●



Bre Anne Langel, RN



Understanding the Role of the MLL Gene in Infant Leukemia

The mixed lineage leukemia gene (MLL) is important in human development. It is also a major contributor to the development of infant leukemia. A physician researcher at Children's Mercy wants to know why.

"Our laboratory is especially interested in the MLL gene," says Erin Guest, MD, assistant professor of Pediatric Hematology and Oncology at Children's Mercy. "In some types of leukemia this gene is broken and a piece of it gets attached to other genes. This is extremely common in infant leukemia, where over 80 percent of the babies with leukemia will have this MLL translocation."

Dr. Guest and Ali Shilatifard, PhD, from Stowers Institute for Medical Research, are looking at interactions between proteins and DNA in the nucleus of the cell. These proteins are what tells the DNA which genes should be turned on and which should be turned off.



GET TO KNOW: Erin Guest, MD

Hematology/Oncology; Assistant Professor of Pediatrics, University of Missouri-Kansas City School of Medicine

Just understanding the genetic code may not be enough to really know exactly what makes leukemia tick. Dr. Guest is also working toward knowing why the gene breaks apart and how it translocates to other genes.

“Our lab is trying to figure out what MLL does in both healthy cells and in leukemia,” says Dr. Guest. “When it does break apart and translocates to another gene, what are the resulting changes in the makeup of the resulting proteins? We think that probably changes how all of the DNA gets expressed.”

Sorting this out is a challenge. The MLL gene triggers the production of the MLL protein, which influences other genes to be turned on or turned off. The MLL protein, in turn, can attach itself to others in a protein complex with impacts on many other genes. Finally, what triggers the translocations and the results of that will need to be understood.

The research currently focuses on established leukemia cell lines. These cell lines provide a model to study how MLL functions in living cells. It is hoped that soon the research will be able to study bone marrow cells from Children’s Mercy patients.

“We need to understand what changes brought about by MLL and associated proteins may lead to this type of leukemia developing,” says Dr. Guest. “It may then be possible to identify molecular targets for drug development that might work well for these infant patients.”

This is an especially important goal given the grim prognosis that currently accompanies a leukemia diagnosis with MLL involvement in infants. ●

Just understanding
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Reformulating Cancer Drugs for Children

Two years ago, Kathleen A. Neville, MD, MS, was asked to assume the job of Director of the Experimental Therapeutics in Pediatric Cancer Program (ETPC) at Children's Mercy. The goal was to give children with refractory cancer a local option to pursue treatment with early phase cancer drugs. Since that time, the program has grown in both size and stature and is involved in more than 15 studies of Phase I and Phase II agents.

"We are working with national consortia and have our own investigator-initiated trials," says Dr. Neville. "We also collaborate closely with the Institute for Advancing Medical Innovation at the University of Kansas. The collaboration's main focus is to reformulate older cancer drugs into pediatric-appropriate formulations, as well as to perform drug discovery work relevant to pediatric tumors."

The program was selected to serve as the clinical pharmacology core for The Pediatric Oncology Experimental Therapeutics Investigators' Consortium (POETIC) and the Neuroblastoma Medulloblastoma Treatment Research Consortium.

"When those consortia begin designing a new trial, they look to us for expertise analyzing the pharmacokinetics of a drug, providing mathematical models on how the drug is handled by the body, and

helping design the types of observations needed to measure the drug," she says. "We are dealing with early phase agents and there is not a lot of information available, so we are integrally involved in making sure studies are designed appropriately in order to determine whether a drug is safe and effective before it enters a child's body."

Dr. Neville is board certified in hematology/oncology and pharmacology, a relatively rare combination. The program's other staff includes Keith August, MD, MSc, Associate Director of the Phase I program, nurse practitioners and research nurses who are also experienced in treating pediatric cancer patients. For trials in children, especially those trials that are focused on treatment in addition to research, there is no other place with the expertise of ETPC in the area.

Dr. Neville says, "For most of our kids, they have run out of standard treatment options and the only remaining choices are treatment with early phase therapy or hospice care. Children's Mercy felt that while contributing to the knowledge was important, giving choices to our patients to be able to pursue treatment and remain close to home was even more so. We are pretty far along in achieving that goal." ●

“The collaboration’s main focus is to reformulate older cancer drugs into pediatric-appropriate formulations as well as to perform drug discovery work relevant to pediatric tumors.”

Kathleen Neville, MD, MS
Experimental Therapeutics
in Pediatric Cancer Program
Director



Pictured:

Front Row (l-r):

Steven Leeder, PharmD, PhD
Uttam Garg, PhD
Kathleen A. Neville, MD, MS
Andrea Gaedigk, PhD
Sara Soliman, RN, BSN, CPHON, CPN
Wendy Haylett

Back Row (l-r):

Keith J. August, MD, MSc
Robin E. Pearce, PhD
Tyce Bruns, BS, MS
Michael Venneman, RN, BSN
Tao Lin, MS

Alleviating Side Effects of Bone Marrow Transplants with Photopheresis Therapy

For the past decade, Jignesh Dalal, MD, has worked to perfect a widely used therapy that reduces bone marrow rejection, making it safe for children.

In 2011, supported by a \$120,000 grant from the Midwest Cancer Alliance, Dr. Dalal and his colleagues designed photopheresis for pediatric patients for treatment of graft-versus-host disease. To date, they have completed this therapy in many patients, demonstrating photopheresis can be tolerated in children.

“We’ve shown we can successfully do this in children,” says Dr. Dalal, Associate Division Director, Bone Marrow Transplantation Section. “Taking blood out of a child’s body can be dangerous. But we’ve done it and alleviated the difficult side effects that come with a bone marrow transplant.”

After mixing a bowl of blood with psoralen, they expose cells to ultraviolet light, killing reactive lymphocytes. Then, they infuse the blood back in to help generate tolerance. The machine designed for children uses a smaller bowl and circuit size, decreasing the time blood is outside the body.



GET TO KNOW: Jignesh Dalal, MD

Associate Division Director, Section of Bone Marrow Transplantation;
Associate Professor of Pediatrics, University of Missouri–Kansas City School
of Medicine

After the procedure, Dr. Dalal and his colleagues monitor patients very closely. For two months post-transplant, they check in with patients twice a week. The frequency falls to twice every 15 days for the following six months.

During this time, our research team monitors B-cells and T-cells at two-month, four-month and six-month intervals. Doing so helps them determine how the body generates tolerance and which immune system cells play the biggest roles in the process. If the cells are imbalanced, putting a child at risk for graft-versus-host disease, the team attempts to push them back into equilibrium.

So far, Dr. Dalal says, the results have been very encouraging.

According to Dr. Dalal, between 50 percent and 60 percent of patients experience positive benefits, including increased energy, skin loosening, decreased eye and mouth dryness, and an overall improved quality of life.

“We’re seeing the positive effect of the photopheresis appear between four to six weeks after transplant, and the peak benefit comes at around four to six months,” Dr. Dalal says. “From what we’ve seen, that positive effect remains.”

Understanding how cells generate tolerance has broader-reaching implications. With this knowledge our team could ultimately reduce rejection rates for solid organ transplants or improve treatments for lupus and scleroderma.

The result of our team’s work is a significant step forward. Successful photopheresis eliminates the need for immune-suppressive drugs, making children less vulnerable to viral, fungal or bacterial infections that can attack their compromised immune systems.

In addition, the team is currently analyzing data for its next challenge – understanding the chemotherapy drug cyclophosphamide.

“This drug isn’t well understood. Currently, we give all patients the same dosage,” Dr. Dalal says. “At Children’s Mercy Hospital, we’re investigating whether genes play a role in how the body metabolizes it and if different doses produce different side effects and desirable effects.”

This continued research strengthens Children’s Mercy’s existing reputation as a world-class pediatric cancer facility bringing cutting-edge therapies to patients. ●

Successful photopheresis eliminates the need for immune-suppressive drugs, making children less vulnerable to viral, fungal or bacterial infections that can attack their compromised immune systems.



AYA Program Focuses on Improving Outcomes for Adolescents and Adults

Every year about 26,000 patients between the ages of 15 and 29 are diagnosed with cancer in the United States and Canada. Unfortunately, outcomes for patients in this age range are not as good as younger patients with the same diagnoses. And, for patients in this age range who are not seen at a children's hospital, the outcomes are even worse.

“There has been a lack of improvement in survival in this age group when compared to patients in other age groups,” says Joy Fulbright, MD, Pediatric Hematologist/Oncologist, and Assistant Professor of Pediatrics. “That lack in improvement is thought to be due to several key issues including low enrollment in clinical trials, lack of appropriate psychosocial support, differences in disease biology, and increased rates of non-compliance to prescribed therapy.”



GET TO KNOW: Joy Fulbright, MD

Pediatric Hematology/Oncology; Assistant Professor of Pediatrics, University of Missouri–Kansas City School of Medicine

Dr. Fulbright is leading the development of an Adolescent and Young Adult (AYA) cancer program at Children's Mercy to address these issues.

Access to clinical trials is one of the highest priorities. In the United States, approximately 10 percent of patients ages 15-19 and 1-2 percent of patients ages 20-39 are enrolled in clinical trials, while 40-70 percent of patients under age 15 are enrolled in clinical trials.

For example, from 2000-09, Children's Mercy saw 194 new oncology patients between the ages of 15-24 versus 1,032 new patients in that age group within the hospital's Missouri region (KC metro/Northwest/Southwest) who were seen elsewhere. Thus, almost 80 percent of the patients in the region are not being seen in a center where they could enroll in or follow Children's Oncology Group protocols.

"In certain cancers such as ALL, AML and Ewing's Sarcoma, research has shown that patients treated at a children's hospital have better outcomes," says Dr. Fulbright. "Patients with certain diagnoses do better when following the pediatric protocols, which in general are more aggressive."

A study conducted by Gupta, Pappo, Saunders, et. al. looking at patients treated with Ewing's Sarcoma (EWS) showed that those treated at pediatric facilities had better outcomes than those treated at adult facilities. The three-year-event-free survival (EFS) for localized EWS was 43 percent in those treated at adult facilities versus 70 percent in those treated at the pediatric facility. Multiple studies comparing AYA patients with acute lymphoblastic leukemia treated on pediatric versus adult protocols have demonstrated improved survival in the patients treated on pediatric protocols.

"The main issue is that patients in this age group don't get enrolled. The decreased enrollment has not allowed this population to experience the same improvements in survival as the younger population or those patients older than 40," says Dr. Fulbright. Children's Mercy is the only COG provider in a 200-mile radius, meaning that access to COG trials and protocols is limited outside of Kansas City. "Our goal is to develop research specifically to improve adolescent and young adult care and increase participation in COG trials."

Dr. Fulbright received a Hyundai Hope on Wheels grant to help support the development of the program. In addition to providing access to trials, the program will focus on increasing awareness of the unique needs of AYA patients, improving compliance with treatment regimens and follow-up care, and addressing the psychosocial, educational and occupational needs of patients on and off treatment to improve overall quality of life. Dr. Fulbright also has a special research interest in decreasing risk of infertility for these patients and improving medication compliance. Through a collaborative effort at Children's Mercy, smart phone apps are being designed to improve drug compliance which we plan on studying in AYA patients on oral chemotherapy regimens.

"We want to make sure they know these clinical trials are available and to allow other hospitals, if they don't have protocols for this age group, to collaborate with us," says Dr. Fulbright. ●

The comprehensive cancer center at Children's Mercy has an emphasis on clinical innovation and patient-centered care that depends on several different departments and areas of the hospital working together to meet the needs of our patients. When a patient receives a cancer diagnosis, he or she has access to a multi-disciplinary support staff that includes:

- › Pharmacy Department
- › Family Care Team (FaCt) that includes Child Life, Social Work, Chaplaincy and our Parent to Parent Program
- › Survive and Thrive Program
- › Research and Data Management

Learn more about each of these programs and departments in the pages to follow as well as at childrensmercy.org/oncology.

Pharmacy

The Pharmacy department is integral to the complete care of oncology patients. The Children's Mercy Pharmacy staff and facilities have evolved over the past decade with a goal of providing the best pharmaceutical care possible for all our patients, including those with cancer.

The distinct teams within this department include decentralized pharmacists, clinical specialist pharmacists, investigational drug service, home care and outpatient operations. We have two clinical pharmacy specialists who work with patient families and assist the primary team in optimizing patient medications based on drug interactions, disease states and organ function.

In addition to our pharmacy specialists, we have four pharmacists and a technician who are dedicated to the review of chemotherapy orders, and responsible for the safe production and distribution of chemotherapy to all patients within the Children's Mercy system. These additional pharmacists may also spend part of their day educating patient families and/or participating in patient care team activities. Our investigational drug service works with more than 100 open drug trials for our patients including phase I and II oncology drug studies. Our outpatient pharmacy is able to compound many prescriptions that are not commercially available.

Our Hematology/Oncology pharmacists are dedicated to providing education to pharmacy students through clinical rotations and lectures at our local school of pharmacy and our pharmacy department has two nationally accredited post-graduate residency programs. In 2008, Children's Mercy started only the second program in the nation for post-graduate residency training of pediatric hematology/oncology pharmacists, providing pharmacists with focused and intensive training in the care of pediatric patients with cancers. ●





Family Care Team (FaCT)

Music therapy services are offered to patients and families at bedside to address the specific needs of each individual. Music interventions are designed and planned after an assessment of need and generally involve the use of both live vocal and instrumental music. Children are encouraged to take an active role in making music.

The Parent to Parent Program has been working hard to continue providing for our families. There are many services offered through the PTP program, including: trained parent mentors available to share, listen and support our current parents; a stocked parent room that offers weekly dinners, breakfasts, therapeutic activities and a safe place to unwind while a child is an inpatient; “care bags” for the new families upon admission to help ease some burden of a hospital stay.

Child Life Specialists help make the hospital more comfortable, easier to understand and fun for patients and families. Child Life tries to reduce the stress and worry that may come with being in the hospital or from being ill. The trained specialists prepare patients and families for upcoming procedures and help them through the procedures using distraction and comfort positioning. They also empower the patients by giving them realistic choices when choices are available. Child Life helps the patients cope with their feelings, thoughts and questions as well as learn and grow while still in the hospital through normal developmental play and medical play.

Ten **clinical social workers** are a part of the primary team working with patients and their families diagnosed with any form of cancer, including NHL. The social workers understand that any change in a child’s health can alter a family’s life in

many ways. Social workers are licensed professionals trained to address the needs of the patient and their family. Social workers help with therapeutic support including adjustment to illness, bereavement, crisis intervention, parent child interactions and sibling support. Care planning including education on advanced directives, school issues, legal issues and transition to adult care are addressed as well. Finally, social workers can assist with community referrals to assist with financial concerns, transportation issues and mental health referrals. The social workers help the family develop coping skills from the point of diagnosis through the end of treatment and beyond.

The **chaplain** working with Hematology/Oncology is available to meet every new patient and family who are inpatients. The family’s own clergy will be contacted if requested. Chaplains can also assist with locating a local clergy person of their denomination or faith for families outside the area. The chaplain continues to support families throughout treatment.

A pair of **psychologists** assist with the mental health challenges that present when under treatment for NHL or any type of cancer. They are available to meet individually with the patients and their families. The psychologists also complete neurocognitive testing to aid patients in making sure their educational needs are met.

An **on-site teacher** works with patients on the inpatient floor and in clinic to assist with the challenge of keeping up with school work while a patient is undergoing treatment. Our 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. ●





Survive and Thrive Program

The Survive and Thrive Program is available for any patient who is five years off of active treatment. This program offers specialized services for childhood cancer survivors. The focus of the program is comprehensive medical and emotional care along with education on the late effects of childhood cancer therapy, necessary recommendations for ongoing health care follow-up and healthy lifestyle choices. ●

Research and Data Management

The backbone of clinical research in pediatric cancer is the Children's Oncology Group (COG). Through this member organization, more than 200 institutions throughout the world are able to open multi-site clinical trials and enroll the numbers of children necessary to reach the answers to questions about treatment, supportive care and follow-up care of children with cancer.

At Children's Mercy, a dedicated research staff within the Division of Hematology Oncology and Experimental Therapeutics coordinate the studies that enroll children with non-Hodgkin lymphoma.

Besides the COG treatment studies that continue to adjust treatment regimens that get the highest cure rate along with the fewest side effects, children with NHL can participate in a national registry that is available for future contact by researchers, biology studies that bank tumor specimens for scientists to study, and new drug studies available through COG or other channels. Increasingly, Children's Mercy researchers are developing their own studies for our patients.

It is the goal of these researchers to provide families with quality research opportunities led by quality research professionals. ●



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