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2010 Cancer Care Annual Report

Children's Mercy Hospital

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REDEFINING PEDIATRIC MEDICINE | **ONE CHILD AT A TIME**



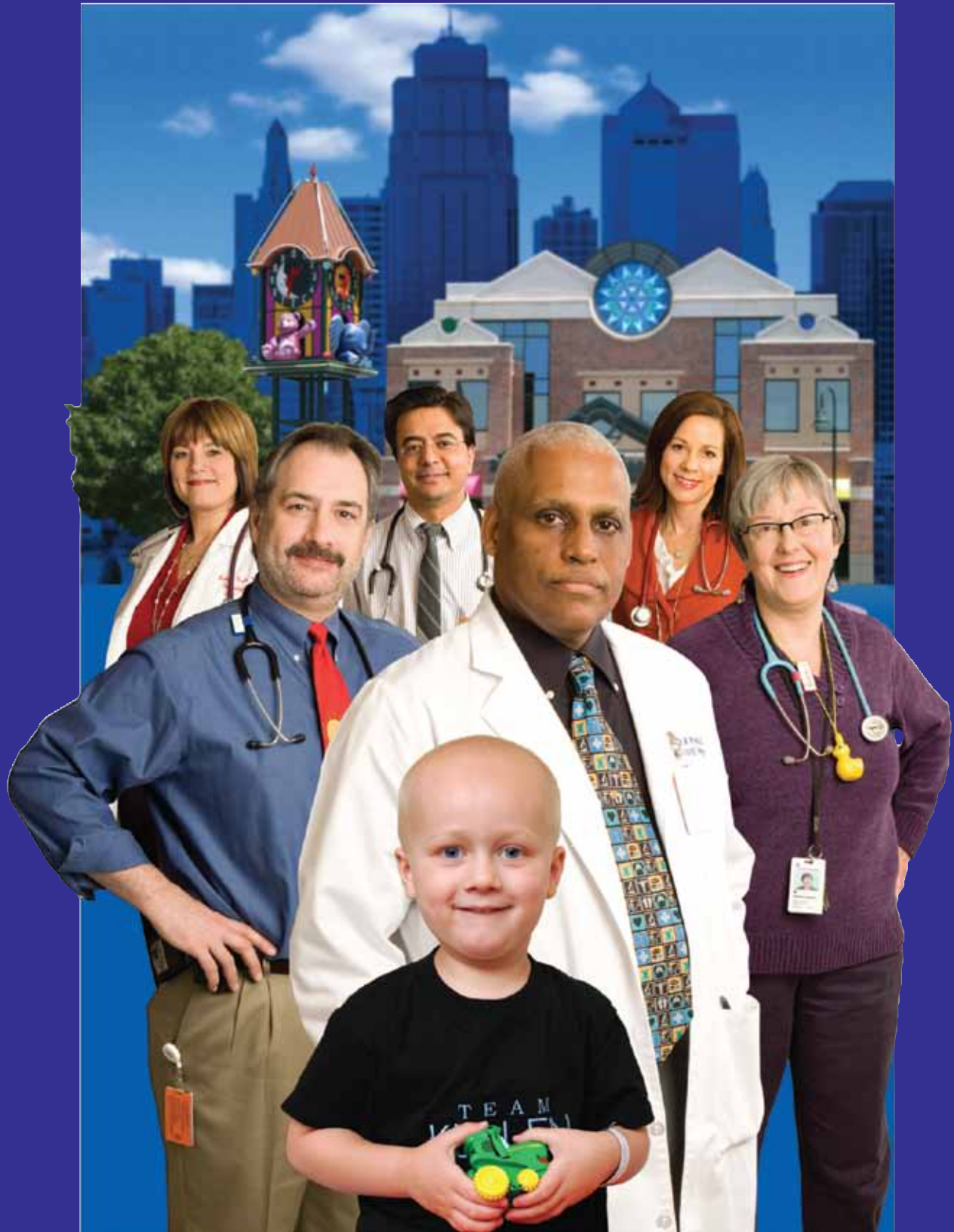
2010

Cancer Care Annual Report



Children's Mercy
HOSPITALS & CLINICS

Kansas City



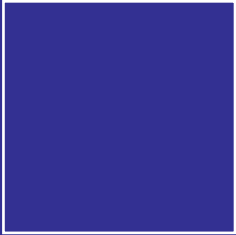
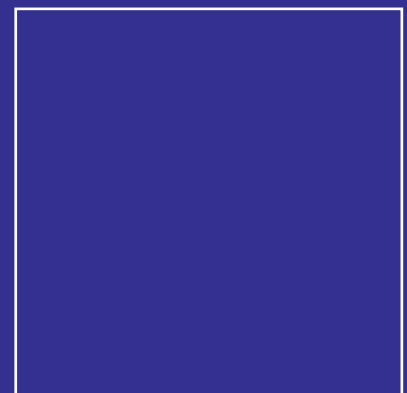


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Dear Friends and Colleagues,

Fifty years ago, less than 10 percent of children diagnosed with cancer survived into adulthood. Now, through 50 years of cooperative research, that number is nearly 80 percent. Today, there are about 350,000 adult survivors of childhood cancer in the United States. This number gives hope to the families of the 13,500 children diagnosed with cancer every year in the United States.

Children's Mercy is honored to have an active role in advancing research in pediatric cancers. As a member of the Children's Oncology Group, we participate in the largest cooperative research group in the world. With more than 7,500 experts in more than 200 children's hospitals, universities and cancer centers worldwide, Children's Oncology Group members treat more than 90 percent of American children with cancer. Children's Mercy Hospital is proud to be classified as one of the larger childhood cancer centers within that group and the only one in our area.

Children's Mercy Hospital also participates in other cooperative research groups. These include The Pediatric Blood and Marrow Transplant Consortium,

the Pediatric Oncology Experimental Therapeutics Investigators Consortium, Neuroblastoma and Medulloblastoma Translational Research Consortium, and Therapeutic Advances in Childhood Leukemia and Lymphoma. Our Drug Discovery and Pediatric Testing program evaluates the efficacy of experimental cancer agents in children. At any one time, we have close to 100 clinical trials available for children with cancer

Our newly established Experimental Therapeutics in Pediatric Cancer Program utilizes the strength of the Children's Mercy Pediatric Clinical Pharmacology Program, which is the largest in North America, and combines it with ground-breaking cancer research. We also lead our own research in areas like infant leukemia, newly diagnosed leukemia, relapsed leukemia, Down syndrome associated leukemia, experimental drug discovery, pediatric drug formulation, pharmacokinetics and pharmacodynamics, bone marrow transplantation, adoptive immune and gene therapies, infectious complications, supportive care, and survivor quality of life.

In recent years, Children's Mercy has experienced tremendous growth. We are currently building a new Bone Marrow Transplant Unit which will accommodate up to 15 pediatric bone marrow transplant patients. The unit is anticipated to open in late 2012. Over the past four years, we have doubled the number of oncologists treating patients. We now have 20 oncologists who each lead a multidisciplinary and multispecialty patient care team.

This year's annual report for the Children's Mercy Cancer Center focuses on the most common liver cancer in children in the United States, hepatoblastoma. Hepatoblastoma affects mostly infants and young children. Successful treatment of hepatoblastoma requires a multidisciplinary team, including medical and surgical subspecialties, all with the knowledge and skill to handle every aspect of care.

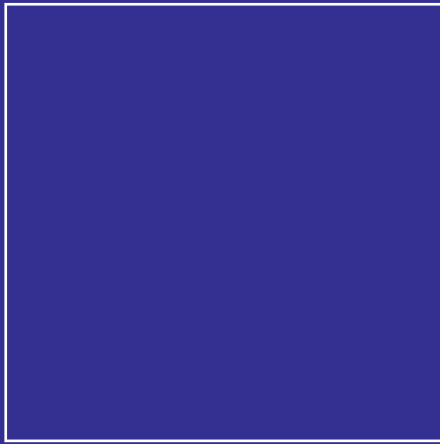
At Children's Mercy Hospitals and Clinics, we are fortunate to have many dedicated professionals who are focused on providing the best possible care for children with cancer. This report highlights all of the people who are involved, and emphasizes the role each one plays in treating children with hepatoblastoma. We hope that this report will serve as an introduction to our team and will illustrate the resources we can provide to help children diagnosed with cancer. We invite you to contact us with any questions that you might have.

Our best wishes to you and the families of our patients,

A handwritten signature in black ink, appearing to read "Alan S. Gamis, MD, MPH". The signature is fluid and cursive.

Alan S. Gamis, MD, MPH
Chief, Section of Oncology

Professor of Pediatrics, UMKC School of Medicine



Dear Friends,

I am pleased to share with you this annual report from the nationally-renowned Hematology/Oncology Division at Children's Mercy Hospitals and Clinics. I hope you will take a few moments to read through this report, which this year focuses particularly on our work with hepatoblastoma, but also provides an overview of the many innovative ways in which we are helping children with cancer.

First, we recently learned that our program has been ranked as one of the Best Children's Hospital Cancer Programs in the nation by US News and World Report. In addition, earlier this year we became only the 11th institution in the nation invited to become a part of the POETIC Network, one of only two consortia that provide treatment alternatives for children with relapsed cancer of all types in North America. We also serve as the clinical pharmacology core for this network. In addition, we are the only program within a 200-mile radius to be a member of the prestigious Children's Oncology Group.

In the past year, we also have developed an Experimental Therapeutics Unit in Pediatric Cancer to conduct early phase studies of promising new pediatric cancer drugs and treatment regimens. We have joined with other area hospitals to form The Midwest Cancer Alliance, bringing together cutting-edge clinical trials and the latest prevention and screening tools to provide the latest advancements in cancer diagnosis and treatment to the Kansas City region. We are also fully supportive of the University of Kansas' pursuit of National Cancer Institute designation as its Pediatric Partner.

One of the highlights this year was our first-ever Survivor Day celebration at Children's Mercy, celebrating the lives of hundreds of former patients who are now healthy, cancer-free children, teens and young adults. What a wonderful reminder it was of why our outstanding hematology/oncology staff members do what they do every day. In the following pages, you can learn more about why everyone at Children's Mercy is exceptionally proud of our cancer program and the many ways in which they are giving children a bright future.

Sincerely,

Randall L. O'Donnell, PhD
President and Chief Executive Officer



THE DIVISION OF HEMATOLOGY/ONCOLOGY

The Division of Hematology/Oncology is not only about doctors treating children. It is about the case management model that ensures that the needs of the child and family are taken care of along with the illness. It is about the Child Life specialists who use activities and distraction to lessen the pain and make treatment time seem to pass more quickly. It is about a chaplain who is there to reflect during hard times and celebrate during joyful. It is about the volunteers who share their time, their skills, their pets, all to bring a smile to a patient's face. It is about the community members who support us each and every year and help us make our program one of the best in the United States.

There have been many changes within the Division over the past few years. Along with a patient population that continues to expand, the staff has grown considerably. Nineteen physicians now make up the Division – each teamed with an advance practice nurse and social worker. In 2011, five fellows actively worked on their three years of specialized training within the Division. The Research/Data Management staff has grown to support both the outside studies from cooperative groups and industry, but also the growing number of research studies designed and initiated by our own clinicians.



With growth has come the opportunity to create areas of special focus within the Division. Leading the charge is our Survive & Thrive Clinic that sees patients for at least two years after their cancer treatment has ended. The mission of the clinic is to guide the patient in their follow-up care based on the kinds of therapy that they received. The hoped for outcome of this will be the long-term health of survivors of childhood cancer.

Also being initiated are special focus areas in leukemia, brain tumors, and adolescent and young adult needs. The Experimental Therapeutics Program continues to grow and offer the most cutting edge therapies to patients who no longer have to travel elsewhere to receive them.

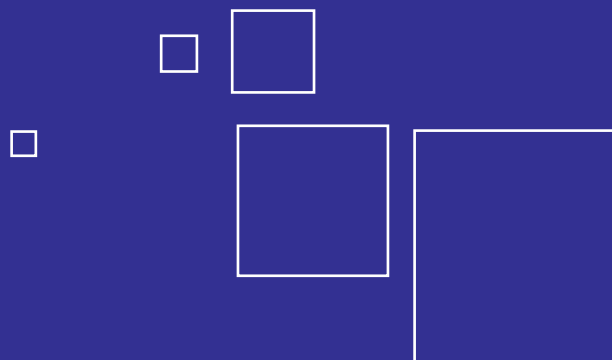
Our success is evidenced by national recognitions. Our cancer program continues to be one of the few pediatric programs to earn a three-year Accreditation Award with Commendation and the Outstanding Achievement Award through the American College of Surgeons accrediting body. US News and World Report ranked us as one of the top 30 pediatric cancer programs in 2011. Our stem cell transplantation program is accredited by the national accrediting body, and recently was chosen to be part of a national public health initiative to create centers of response in the event of a national emergency that would lead to bone marrow failures.

Taking care of children does not stop at the end of the day. Each year, the doctors, nurses and support personnel use their time to reach out. Our staff serves on community boards like the Make-A-Wish Foundation, and Leukemia & Lymphoma Society. The hemophilia, sickle cell, and cancer camps that happen during the summer would not be possible without the doctors and nurses who make time to be there to support our kids away from the hospital.



Division of Hematology/Oncology Retreat
Staff members of the Division took part in a biannual retreat at Paradise Park in Lee's Summit.

The years ahead are exciting ones for the Division of Hematology/Oncology. We recently moved into a new expanded clinic in 2011. We also will be expanding our inpatient area in 2012. This addition will allow us to keep our patients in dedicated areas for their care.



MADLINE'S MIRACLE

As told by Maddie's Mom and Dad

Madeline was our first child. We are a military family and were stationed at Fort Leavenworth at the time of her cancer diagnosis. Madeline has a very large extended family, but they almost all live in the Minnesota area.

Just before the Memorial Day weekend in 2010, Mike had noticed that Madeline's abdomen was sticking out more on the right side than the left side. Although her stomach felt hard where her liver should be, it was hard to believe that anything was wrong. She didn't seem sick. She had just been to her grandparents' for a week and no one noticed anything unusual. However, we were still concerned and brought her in to see the doctor.

After Madeline was examined, the doctor ordered labs and an ultrasound. The radiologist brought us into his reading room. He explained that the ultrasound showed a large mass in Madeline's liver. It was most likely hepatoblastoma. The doctors arranged an evaluation at Children's Mercy that included a CT scan and an evaluation with the liver specialists. When all of this happened, there was a never a question as to where to go. All of us, including our doctors, knew that Children's was the place to go.

That weekend was the hardest weekend in our lives. We knew that the mass in Maddie's liver was likely cancer, but because of the holiday, we wouldn't get any further answers until Tuesday. We did our best to try to have fun and enjoy Maddie. I remember that we had a hard time sleeping and we cried many tears. The fear of the unknown was horrible and the thought of our 23-month-old baby being sick and in pain was almost too much to bear.

When Tuesday finally came, our fears were confirmed. Our daughter had cancer. Dr. Manalang from the Oncology team

was consulted and saw us that day. From that moment on, the wheels to treatment and recovery were set in motion.

Because Maddie was so young, she really didn't know what was going on. We said prayers with her and we brought blankets from home that were familiar to her. Winnie the Pooh and Eyore were also comforts to her. She liked to "rock-a-bock" a lot (rock-a-bye), and when things hurt, she would count to 10 to keep herself distracted. Around the time of her liver transplant and the last two rounds of chemo, she loved to sing songs on her child radio. Her favorites were "Father Abraham," "Twinkle, Twinkle Little Star," "The Ants Go Marching," and "Baby Bumblebee" – actions included in the performance.



Although Maddie can't tell us what the hardest part of her treatment was for her, we suspect it was the feeling of being ill all the time. The chemotherapy made her really sick and she had a lot of complications.

For us, there were several things that were equally hard. We often had feelings of guilt for not noticing something sooner. We worried that Maddie wouldn't understand what was going on. We always wondered if she

would question (in her own way) why we didn't stop the pain or feelings of not feeling well. Maddie had an extremely complicated first round of chemotherapy and for a while, she didn't even talk. We wondered if our child would ever be normal again and if we would ever hear her talk again in her sweet way. It was also very hard for us to see her lose her long hair (down to almost the middle of her back at the time).

During the months of therapy, our family and friends were amazing. We were so touched and amazed by the loving kindness of people. Our neighborhood took care of our house, yard and flowers. Our employers were supportive, and Mike and I were allowed to take care of Maddie and be there for



each other 100 percent of the time. We were so thankful to be able to stay in the room with Maddie. We don't know what we would have done had we not been able to do that – it was so comforting. Children's Mercy

was our "home away from home" from June to January. On Maddie's birthday, even though she was in renal failure and didn't really know what was going on, Children's Mercy made Maddie a birthday cake and had gifts, cake and ice cream. It was as good as it could have been given the circumstances.

We have learned that kids are so adaptable. They just figure out a way to do things and drive on. When Maddie had nerve issues from the chemotherapy which affected her ability to walk, she used a wheeled walker. On the very first day of having the walker, it was like it was the most natural thing in the world.

For us, reality hit. Life changes in an instant. You don't know the full impact of this statement until it hits you personally. Hearing stories about other people going through difficulties does not even begin to prepare you for when it happens to you. We have truly learned how precious life and health are. These are blessings and each day that you are given is truly a gift. One day you can have everything and the next day your world is upside down in every way.

We will always have a soft spot in our hearts for our Children's Mercy Oncology and Liver Transplant Teams. What wonderful health care providers and people! They were always just a phone call away if we had questions about anything and we always felt like they cared so much for Madeline. From discharge to outpatient follow-ups, tube feeds, medication administration at home – it was all seamless.

We were truly thankful for our caregivers. The nurses and care assistants were wonderful. We had one care assistant who knew exactly how we liked to set up our room and would do this for us prior to our arrival. It made the hospital scene so much better. The nurses were always so kind and understanding and patient with our emotions. They never made us feel rushed or like we were intruding on their time.

We ALWAYS felt like they truly cared for us as a family. We have so much faith and trust in our Oncology Team and Transplant Team. They are awesome!

We met so many wonderful families through our journey – each with different, yet similar stories. It was therapeutic talking with others. All of us share the underlying theme of having a child with cancer, yet our stories and experiences are so different.

If I had advice for other parents going through this, it would be don't be afraid to ask questions – you are your child's best advocate. Make sure you understand what is going on and give your input to the health care team. You are with your child everyday and truly know certain things about your child that they don't have the opportunity to observe. With the expertise of the medical staff and the small day-to-day things you

know about your child, you can create a tremendous partnership with your health care team.

In the beginning of Madeline's diagnosis, it was a terrifying feeling not knowing what the future held for Madeline or our family. We never knew if our child would be normal again like other kids. Because of the wonderful care of our Children's Mercy teams, Madeline has a wonderful life ahead of

her. If you didn't know about her diagnosis and subsequent liver transplant, you would never know how sick she had been. Despite the chemotherapy and the need for lifelong monitoring secondary to her liver transplant, she is a normal child in every way who just happens to have a new liver and is a cancer survivor!

We have moved to Minnesota to be closer to family. Madeline will get to know her cousins, aunts, uncles and grandparents even better. Additionally, Madeline is going to be a big sister! She has a new little brother on the way!



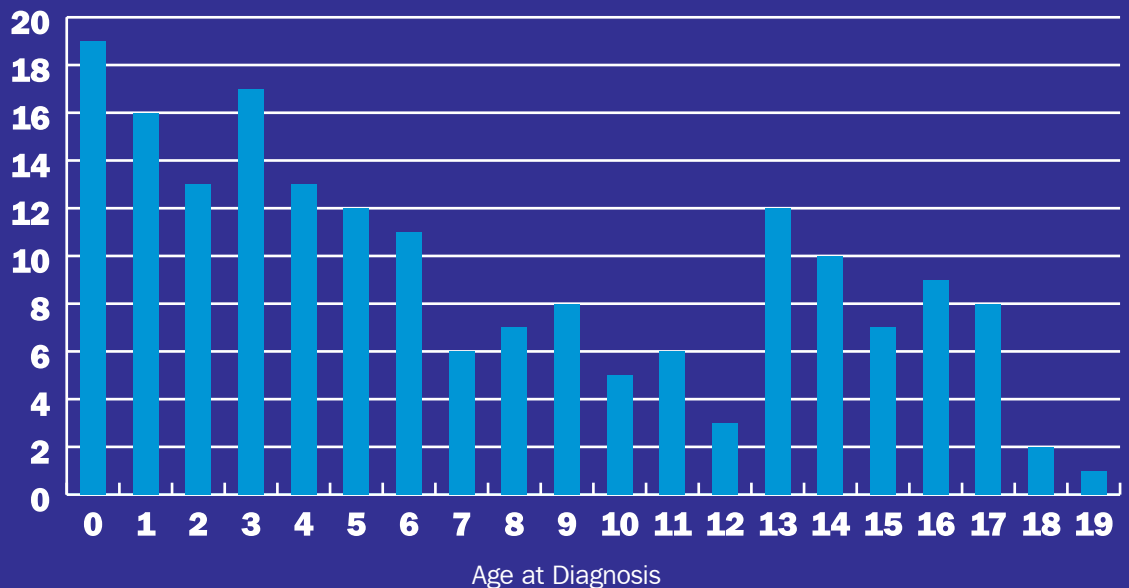
CANCER REGISTRY - 2010 REVIEW

During 2010 the Cancer Registry added 185 patients to the database. Of these patients, there were 174 patients who were diagnosed with malignancies and benign central nervous system (CNS) tumors. There were 11 patients added to the registry as reportable conditions. These conditions allow the Cancer Care Committee and other hospital staff to follow patients that have a propensity for malignant conditions. In 2010, as in past years, the CNS and leukemia conditions were the most frequent to be diagnosed.

Children's Mercy Hospital is required by state and federal law to report basic information about cancer cases and benign brain tumor cases. Data is sent to the Missouri Cancer Registry located in Columbia, Mo. The state registry is under the direction of the Missouri Department of Health and Senior Services. Data also is sent to the National Cancer Data Base which is an entity of the Commission on Cancer and the American College of Surgeons. Data collected by the Children's Mercy Registry is available as study information for Children's Mercy staff and also allows for the impact of cancer to be analyzed on a state and national level. Cancer incidence, site and histology of tumors, age, gender, race and treatment administered make up some of the data that is analyzed. All operations follow the strict patient confidentiality guidelines according to HIPPA privacy regulations.

The cancer patients who are treated at Children's Mercy are followed annually by the Cancer Registrar. By following our former patients we can evaluate treatment methods and patient outcomes. Successful follow-up must be maintained to provide optimal patient care into the future.

AGE OF PATIENTS AT DIAGNOSIS 2010



2010 CANCER REGISTRY FREQUENCY BY DIAGNOSIS

Central Nervous System	48
Astrocytoma	9
Glioma	8
Medulloblastoma	7
Glioblastoma Multiforme	4
Atypical Teratoid Rhabdoid	3
Ependymoma	2
N.G. Germ Cell	2
Choroid Plexus Carcinoma	2
Benign/Borderline CNS	11
Leukemia	48
ALL	37
AML	11
Lymphoma	15
Non-Hodgkins	8
Hodgkins	7
Neuroblastoma	7
Ewings Sarcoma	6
Germ Cell Tumors	6
Rhabdomyosarcoma	4
Wilms Tumor	2
Osteosarcoma	2
Retinoblastoma	4
Hepatoblastoma	1
Carcinomas	7
Sarcomas	13
Other Malignant Conditions	11
Benign Reportable Conditions	11
TOTALS	185



HEPATOBLASTOMA SURVIVAL RATE COMPARISON

**CHILDRENS MERCY HOSPITAL (CMH)
VS
SURVEILLANCE EPIDEMIOLOGY AND END RESULTS
(SEER) OF THE NATIONAL CANCER INSTITUTE**

5-Year Relative Survival (Percent), 2001-2007

	Ages 0-19
CMH	88.9%
SEER	73.5%

CMH based on follow-up into 2010

SEER based on follow-up into 2008- SEER Cancer
Statistics Review 1975-2008



Curesearch Walk

In April 2011, the first Kansas City Curesearch walk was held and Arrowhead Stadium and raised money for Children's Oncology Group research. Children's Mercy staff joined in on the festivities.

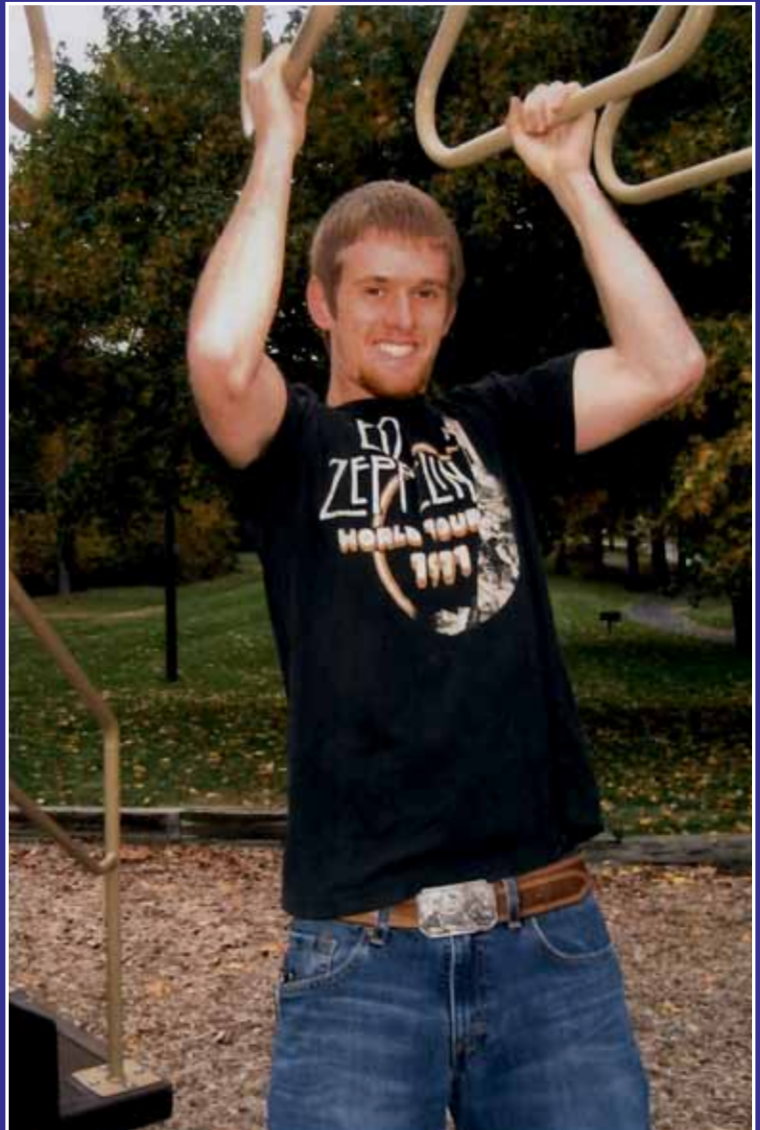
JASON'S JOSTLING JOURNEY

In November 2000, Jason Spengel went on a bike ride that saved his life. It had been raining and there were leaves on the road that made the pavement slippery. Hitting a particularly slick spot, his bike slipped and he flew over his handlebars and landed hard. The scratch on his face seemed to be the only injury to show for the accident, but it wasn't.

A week later Jason ran hard during a basketball game. Afterwards, his mother was worried about how pale and lethargic he was, so she took him to an urgent care clinic. From there, they sent him to Children's Mercy thinking that he was going into diabetic shock. Examined and scanned at once there, the diagnosis was very different than anything they had imagined. Jason had lacerated his liver and was bleeding internally. One of the reasons that his liver may have been so injured was the large tumor that was in it. If Jason hadn't had the accident that injured his liver, they may not have found his tumor until it was too late.

Now that he is a 21-year-old sophomore at Kansas State University, he can smile when he talks about the nine months of harsh chemotherapy that were capped off by an 11-hour surgery where 83 percent of his liver was removed. Back then, there were few laughs. Instead there was the shock of the diagnosis of Stage IV hepatoblastoma, the life change of being a family with a very sick child, and the roller coaster of emotions. At Christmas his tumor was 50 percent smaller and responding to chemotherapy, but then it was not responding and growing by Valentine's Day. Even with setbacks, the attitude that Jason heard from his father became his own: "Always positive." After the "Valentine's Day Massacre," as Jason calls it, he switched to tougher chemotherapy that "turned everything red." The "red devil" worked. He was in remission and finished chemotherapy in July 2001.

In the years since Jason first came to Children's Mercy, he has never been away too long. He still comes in at least yearly for follow-up. When his original doctor moved, he began to see Dr. Richard Shore. Last year, when Jason was going to be seen in regular clinic, he was asked if he would want to go to the new Survive & Thrive clinic that Dr. Shore was directing. Jason was excited about the concept and it turned out to be more than he even hoped. Visiting with Dr. Shore, the Nurse Coordinator, Social Worker and Nutritionist, Jason got information not only on how he was doing, but also things he needed to pay attention to as he got further away from his diagnosis.



All of it was based on the type of treatment that he received. Aside from just his physical health, they also addressed how other aspects of his life were going. They even gave him information about scholarships that he could apply for. When Jason transitions from Children’s Mercy to adult care, he will have these tools to help him in his health care for years to come.

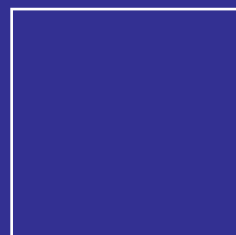
Along with his own care, Jason has devoted himself to the care of the children who have been diagnosed after him. Since he was a boy, Jason has loved nature. Being a Boy Scout allowed him to get out in nature, camp, hunt and work towards Scouting recognitions. As the final step in his Scouting career, Jason planned his Eagle Scout project with his own history in mind. He wanted to give the kids who came to the Hematology/Oncology Clinic toys they could play with while being treated. He talked to one of the Child Life staff members who told him that it was a good idea, but that he could not just collect toys – toys had to be new to prevent unwanted germs. That made Jason’s job harder, but not impossible. In December 2008, Jason delivered a giant \$2,700 check to Children’s Mercy.

Jason also came to look forward to oncology camp each year. After seven years of attending as a camper, Jason has returned for the past three years as a camper’s companion. Before camp, he gets information about the camper that he will be matched with. During the week of camp, Jason and his camper get to know each other, share their stories, and have fun together. It is an experience that Jason relishes.



Looking back and looking forward are things that Jason can do easily. When thinking of what the diagnosis of cancer did to him and his family, he reflects that he has an appreciation for things that he probably would not have had without the experience. He also knows what his parents went through is more than he can even imagine.

College now is Jason’s focus. He will move into his first apartment as he enters his sophomore year. He will devote himself to his studies in Wildlife and Outdoor Enterprise Management – with minors in business and economics. This should be no problem for the kid who got straight A’s the year he had to miss 69 days of school because he had cancer!



HEPATOBLASTOMA

Hepatoblastoma is the most common liver cancer in children. It affects mostly infants and young children between the ages of 2 months and 3 years. It makes up about 1 percent of all childhood cancers, with about 100 cases of hepatoblastoma diagnosed each year in the United States.

Like most cancers, we do not know exactly what causes hepatoblastoma. It is believed to develop when mistakes (mutations) occur during the normal growth of liver cells. These mutant cells grow without the usual regulation of normal liver cells, and this leads to a tumor.

Some children have certain genetic syndromes that are predisposed to developing hepatoblastoma, such as Beckwith-Wiedemann syndrome, hemihypertrophy, and familial adenomatous polyposis. Premature and extremely low birth weight infants (especially those weighing less than 3 ½ pounds (1500 grams) at birth), have an increased risk of developing hepatoblastoma. Babies who are smaller than average (3 pounds 5 ounces - 5 pounds 8 ounces), have a slightly increased risk of developing hepatoblastoma. The reason for the high risk associated with lower birth weights is not clear. Most children who are born with low birth weight never develop hepatoblastoma and most children that develop hepatoblastoma have no risk factors. Some children are diagnosed with hepatoblastoma so young that scientists believe that the cancer starts before the children are born.

Children with hepatoblastoma usually present with a painless enlarging abdominal mass. Less common symptoms are poor appetite, vomiting, weight loss, and abdominal pain. Many times an ultrasound of the abdomen is done to investigate the specific location of the abdominal mass. Once it is known that there is a mass in the liver, a CT scan and MRI are done. These studies can give very detailed images of the liver and

its blood vessels. In 10-20 percent of children, there already has been spread of the cancer from the liver to the lungs. Because of this, a CT scan looking at the lungs is usually done with the CT scan of the abdomen.

Blood tests also are performed. Many children with hepatoblastoma have anemia and elevated platelet count. Most also have a very elevated serum alpha-fetoprotein (AFP) level. AFP is a protein in the blood that can be high because some hepatoblastoma cells produce it. With effective treatment, the AFP falls to normal levels. This makes AFP a useful clinical marker for monitoring treatment and recurrence.

A diagnostic biopsy is required to make an accurate diagnosis of hepatoblastoma. Sometimes, a complete removal of the tumor may be done if the tumor is small and confined to a single lobe, or section, of the liver. Unfortunately, about 70 percent of tumors are quite large when they are first discovered and are not able to be taken out immediately. Children whose tumors can be completely removed by surgery have the highest cure rates.

After a biopsy or surgical removal of the tumor, a pathologist examines the tumor tissue and can help guide the oncologist about its aggressiveness. This examination also can determine whether the tumor cells resemble those present in a fetal liver (pure fetal histology). This type has an excellent cure rate if the tumors are completely removed.



This process of looking for cancer in other parts of the body is called staging. There are four stages of liver cancer. The hepatoblastoma staging system uses surgery as its focus. The four stages are:

Stage I: The entire tumor was removed with surgery.

Stage II: Tumor cells are found close to the edge of normal liver tissue after the tumor has been removed with surgery. This means that there probably are a few tumor cells still left in the liver, called microscopic residual disease.

Stage III: Some of the tumor was removed with surgery, but some (or all) of the tumor could not be removed. Children who had only a biopsy prior to starting chemotherapy are in this group.

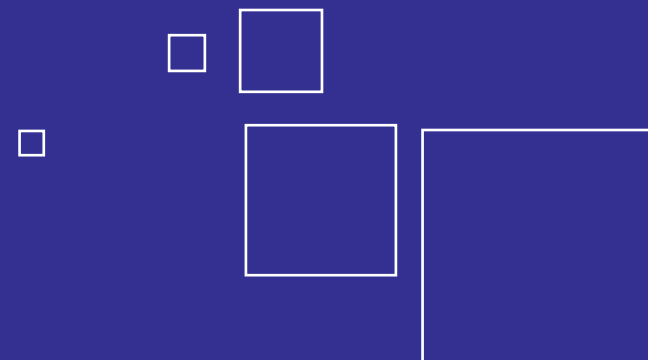
Stage IV: The tumor has spread to the lungs or other parts of the body.

Recurrent: The cancer has come back (recurred) after it has been treated. Liver tumors may recur in the liver or in other parts of the body.

Through cooperative research, we have a better understanding about the features of hepatoblastoma. This knowledge helps us predict how children will respond to treatment and the risk of the tumor coming back. We know that children with hepatoblastoma cells outside of the liver (metastatic spread) have lower cures than children without metastatic disease.



Some children are diagnosed with hepatoblastoma so young that scientists believe that the cancer starts before the children are born.





Liver transplantation is an important component in the treatment of children with hepatoblastoma.

Earlier stage tumors (I or II) are more easily cured. However, 70 percent of liver tumors are late stage (III or IV) when they are diagnosed. Children who have an abnormally high AFP at diagnosis that rapidly decreases when initially treated with chemotherapy may have a more favorable cure rate. Children who have a normal or only slightly elevated AFP do not do as well and may require different treatment. These factors will classify if a child has a hepatoblastoma that is very low-risk, low-risk, intermediate-risk or high-risk.

The cure rate of hepatoblastoma varies greatly between risk groups. Almost all children with very low-risk hepatoblastoma are cured with surgery alone. Children with metastatic hepatoblastoma (high-risk) have a cure rate around 20-40 percent.

Surgical removal of the tumor is the most important part of successful treatment for hepatoblastoma. An operation is performed to remove the tumor and the part of the liver where the cancer cells are found. If the cancer cells have spread to other parts of the body, surgery may also remove the tumors from these areas. The most common places for liver cancer to spread include tissues that surround the liver or the lungs.

If the tumor has spread throughout the liver, or if it is not possible to preserve enough normal liver when surgically removing the tumor, the liver may be replaced entirely with a portion of healthy liver. Liver transplantation is an important component in the treatment of children with hepatoblastoma.

Chemotherapy refers to drugs that destroy cancer cells. Chemotherapy may be used before surgery to shrink the tumor so that it can be surgically removed. This is



done for those tumors that can't be removed at diagnosis. Chemotherapy also can be used after surgery to destroy any remaining cancer cells. Hepatoblastoma usually responds very well to chemotherapy. Different combinations of cisplatin, vincristine, 5-fluorouracil and doxorubicin can be used.

Chemotherapy side effects that are seen after chemotherapy has been completed are called late effects. The potential late effects following treatment for hepatoblastoma depends partly on the therapy received and the age at which it was received. In general, there may be problems with the heart, kidneys, nerves or hearing from the most common chemotherapy used to treat liver tumors. Patients who have a liver transplant need to take medications to suppress the immune system for the rest of their lives.

Because hepatoblastoma is so rare, national and international research studies are extremely important. Current research is investigating how hepatoblastoma cells react to different chemotherapies. We are also identifying developmental genes for hepatoblastoma and understanding its molecular signals. Well-designed research trials are used to help understand if new chemotherapies will help increase the cure of children with high-risk hepatoblastoma. Clinical trials also help researchers understand if decreasing the amount of chemotherapy in children with low-risk hepatoblastoma will decrease their life-long side effects of chemotherapy, while still keeping the cure rate at 85-90 percent.

Because of previous and new research, Children's Mercy oncologists continue to improve outcomes for children with hepatoblastoma. The goal of our team at Children's Mercy is to cure every child with hepatoblastoma with the least amount of permanent side effects.



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HAILEY'S HIGHWAY TO HEALTH

When Hailey and her twin brother, Trevor, went home from the hospital after their premature birth, their parents thought that the days of doctors and nurses were going to slow down. Their respite was short. Just three weeks after Hailey's mother, Donna, had returned to work, a new medical story began for the family.

Fourteen-month-old Hailey was sitting on her dad's lap when he noticed that her stomach was very hard. Hailey had been fussy and not feeling well for about a week, but her parents thought it was because of the recent immunizations she had received. This new change was something different. Concerned, Donna put Hailey in the family van and drove to the emergency room. After being examined at their local hospital near Waverly, Kan., an ultrasound was done. Donna saw what the technician typed on the screen: "Mass." What she feared was confirmed by the doctor who said he thought that Hailey had cancer. They were sending Hailey to Children's Mercy.

It was a Saturday in September when Hailey's grandpa, sitting in the stadium in Manhattan watching the K-State game, got the call. Donna remembers telling him that they were following the ambulance that was carrying Hailey to Kansas City. She told him to stay at the game; everything was going to be okay. Grandpas, grandmas, aunts and uncles weren't taking Donna's advice. They started appearing at the hospital soon after Hailey was settled into her room.

Over the weekend, Hailey's blood was tested and scans were taken of her from top to bottom. They slowly got information about what the doctors knew. There was a tumor that was taking up almost three-fourths of Hailey's liver. She had some nodules in her lungs. A blood test called alpha fetoprotein, which measures protein made by immature liver cells, was measuring over 1 million. Normal results are 0

-15. All of these things made the doctors think that Hailey had hepatoblastoma. One other thing that Hailey's parents found out that added to their surprise – a risk factor for hepatoblastoma is having been born prematurely with a low birth weight.

Hailey was a very sick little girl – her chance of survival with a tumor like hers that had spread outside of her liver was estimated at less than 50 percent. There was a good chance that even if they got the cancer under control, she would relapse. The family prayed for the best, but prepared for the worse. The family's priest came to the hospital and while the family surrounded the bed, Hailey received her last rites.



Monday morning came and the relative quiet of the weekend was replaced by the quickened pace of the new team starting the week on the oncology floor. Dr. Alan Gamis, Section Chief, Oncology, came in and spent several hours talking to Hailey's family about what they thought was the matter and what he thought the plan was going to be. Dr. Andrews came and explained to the family that because Hailey's tumor was so big, taking it out was too risky. He wanted to do a procedure to take a small piece of it so the pathologists could look at it under the microscope and make sure that they were treating it correctly.

When the diagnosis of hepatoblastoma was confirmed, treatment began. Hailey's parents agreed to participate in a research study being conducted by the Children's Oncology Group. One of the things that the study was trying to find out was if changing the drugs given would have any impact on the hearing loss that some of the treatment drugs could result in. Hailey was not assigned to the new treatment, but instead was one of the people in the study who received the standard care. Hailey's mom says that they were very happy to sign up for the study because they had hope that even if it didn't help Hailey, it would help others who might be diagnosed with liver cancer.



Hailey entered the hospital six times to get chemotherapy. Therapy was intense and frequent. Hailey did well and didn't have many problems. After her fourth round, she was admitted for the surgery that was talked about when she was first diagnosed. The chemotherapy had shrunk the tumor and now Dr. Andrews was ready to take out what was left. Over more than 10 hours, the surgical team worked on Hailey. Dr. Andrews came out regularly to tell the family how she was doing. At the end, Hailey was taken back to the room to start

the healing process.

Less than two weeks later, Hailey was out of the hospital and celebrating Christmas at home with her mom, dad, big sister, Jordan, and her twin brother. The family was still holding its breath for what might come next.

The final two rounds of chemotherapy came and went. The last round was notable because during it, Donna celebrated her 30th birthday. She

remembers sitting with Hailey in her room giggling about their "Club CMH" special birthday weekend getaway. The nurses and doctors who were there for both Hailey and her family

during all of her trips to Children's Mercy, made the time away from home filled with caring and kindness. That Children's Mercy spirit made it easy for the family to have hope and a positive attitude each day.

When Hailey's treatment ended, there were blood tests and scans to see if the tumor stayed away. At one point, there was a jump in Hailey's alpha fetoprotein. The fear of relapse returned. Luckily, it was a temporary jump and results normalized. Things seemed to be going well.

It wasn't until five years out from diagnosis, that Donna said it hit her: "It's real – it's over – we made it." Relief and overwhelming gratitude came with her realization.

Today, Hailey is an active and happy 10-year-old. She is a lover of all animals, but her dog, Gibbs is her special buddy. She is also now a big sister to six-year-old Kaitlyn. Her mom says that Hailey loves life and celebrates it every day. Hailey now goes to the Survive & Thrive clinic where she will continue to learn how she can take care of herself and what her special needs may be because of her treatment. Donna says that Hailey doesn't remember much about her treatment. Her parents get to be the holder of that story.



COMPREHENSIVE CARE FOR CHILDREN WITH LIVER CANCER

Children's Mercy Hospital is the only children's hospital in the region to offer a comprehensive care clinic to improve the care of children with liver cancer. This unique approach combines the skills and knowledge of cancer doctors, liver doctors, liver surgeons and liver transplant surgeons, all specialized to treat children. The subspecialists work closely together. Since all of the specialists see the child at the same comprehensive care clinic appointment, they are able to have detailed discussions with the family on all facets of their child's care. The families are able to speak with all of the disciplines at each visit. Not only does comprehensive care improve the child's outcomes, but it is easier for the family to see all physicians at one appointment instead of separate ones.



Liver Care Center

The Children's Mercy Liver Care Center is one of only a few comprehensive treatment and research centers nationwide dedicated exclusively to pediatric liver care. The Liver Care Center brings together pediatric clinical and research expertise in gastroenterology, general and thoracic surgery, critical care medicine, hepatology, nursing, pharmacology and radiology to offer a more integrated, comprehensive approach to liver disease for children from birth to age 18.

Pediatric Liver Transplant

Occasionally liver transplant is the only way to remove the entire tumor and cure the cancer.

Children's Mercy Hospital has an excellent liver transplant program, with outcomes among the best in the nation. Since 1998, our patient survival rate is 89 percent and our graft survival is 83 percent. The liver transplant program

has more than 40 years of experience, with our surgeons having additional training in the area of pediatric liver transplantation as well as other liver surgeries. Our liver transplant program is also one of the participating centers in Studies in Pediatric Liver Transplantation (S.P.L.I.T.) which furthers research in this area.



MULTI-SPECIALTY MANAGEMENT OF CHILDREN WITH HEPATOBLASTOMA

Along with the primary oncologist and nurse practitioner, there are number of other specialties that are important pieces in managing the child with hepatoblastoma.



RADIOLOGY

The first task of the pediatric radiologist in the management of the child with hepatoblastoma is to establish and oversee the proper imaging algorithm. Typically, a child with an abdominal mass is first imaged with ultrasound. Due to the size and extent of many liver tumors, the radiologist often personally supervises or performs the examination to ensure the proper images are acquired. Correct sequencing chosen by the attending radiologist is

radiologist also takes care to minimize the radiation dose. In some cases, the patient may also require MRI for further clarification of tumor type or extent.

Following the performance of and ultrasound, CT, or MRI, the radiologist then establishes a differential diagnosis. Often, it is possible to render a specific diagnosis of hepatoblastoma with a high degree of confidence after careful evaluation of imaging

studies. At times, the diagnosis of hepatoblastoma may be unclear. When this occurs, the radiologist suggests further imaging to continue to help narrow the differential.

Finally, the radiologist plays an important role in the staging of patients with hepatoblastoma. Staging determines if and where the cancer has spread. It is used to guide cancer treatment. Radiologists map the vascular anatomy of the liver to determine the extent of tumor involvement. This is integral for correct PRETEXT classification. PRETEXT is a liver cancer staging system that uses imaging before surgery

to determine where the tumor has spread within each of the four parts of the liver. The radiologist then reports if the tumor has invaded or is in close proximity to important veins, or has otherwise extended beyond the liver and into other parts of the body.



important to help narrow differential diagnoses and clarify tumor extent or invasion. The ultrasound is often quickly followed by a contrast-enhanced CT. The radiologist carefully manages this examination to ensure that the proper images are obtained at certain phases of contrast enhancement. The

PATHOLOGY

The histological confirmation of the diagnosis of hepatoblastoma is best done on a wedge biopsy. A wedge biopsy is done by a surgeon and involves the removal of a chunk of the identified tumor area. While a less-invasive needle core biopsy could provide tissue sufficient to distinguish it from other neoplasms, sub-classifying a hepatoblastoma may be impossible on needle core biopsies.

Sub-classifying the tumor is done by the pathologist. The pure “fetal” type of hepatoblastoma manifests as well differentiated hepatic morphology and has a favorable prognosis. It specifically lacks any other subtype of tumor differentiation.

The other subtypes of hepatoblastoma have a less favorable prognosis. Small cell undifferentiated hepatoblastoma is particularly problematic for pathologists to recognize with confidence since

it looks like so many other childhood blastic tumors under the microscope. This subtype carries an unfavorable prognosis. A battery of immunohistochemical stains may be helpful to confirm the diagnosis and subtype these tumors. Thus, the tissue diagnosis not only confirms the diagnosis but allows for predicting prognosis of the tumor.



Although serum alfa-fetoprotein (AFP) is markedly elevated in more than 80 percent of hepatoblastomas, the small cell undifferentiated hepatoblastoma does not show AFP elevation. During the course of treatment and following resection of AFP positive hepatoblastoma, AFP levels are measured to follow the rate of drop in anticipation of complete resolution for completely resected

tumors. The rate of fall has prognostic value and persistently elevated levels may be an indication of persistent or refractory disease.

CYTOGENETICS

Cytogeneticists study the chromosomes of tumor in order to identify any abnormalities. Chromosome abnormalities have become a useful tool in predicting how patients with particular types of tumor will respond to therapy.

Cytogenetic analysis of hepatoblastoma has been reported in a limited number of cases. Recurrent chromosome abnormalities that have been seen include the gain of chromosomes 1q, 2q, 8q, 17q and 20; and loss of 4q. The most common recurring structural abnormality is an unbalanced t(1;4) that results in a gain of 1q and loss of 4q. Rare genomic and expression profiling studies have confirmed these abnormalities and further refined the regions of gain and loss. Molecular studies have discovered mutations in key genes that are important in the genetic pathways of developing liver. These studies may help elucidate the pathogenetic mechanisms responsible for the development of hepatoblastoma. INI1 testing helps differentiate hepatoblastoma from a more aggressive variant that mimics rhabdoid tumor.

Most cases of hepatoblastoma are sporadic. However, hepatoblastoma is associated with several cancer predisposition syndromes including Beckwith-Wiedemann syndrome, familial adenomatous polyposis, and LiFraumeni syndrome.

Hepatoblastoma can be seen in glycogen storage disease type I. Premature infants, particularly those with low birth weight or very low birth weight, are at increased risk of developing hepatoblastoma.

Familial adenomatous polyposis (FAP), a syndrome of early-onset colonic polyps and adenocarcinoma, results from germline mutations in the APC tumor suppressor gene. One study estimated that 1 in 20 hepatoblastomas is probably associated with FAP. APC mutations, common in patients with hepatoblastoma and FAP, are rare in patients with sporadic hepatoblastomas.

Patients with hemihypertrophy or Beckwith-Wiedemann syndrome should be screened using alpha-fetoprotein (AFP) as a marker to detect hepatoblastoma. AFP monitoring should be performed every three months until the child is at least 4 years old. Loss of heterozygosity of chromosome arm 11p markers occurs commonly in hepatoblastoma associated with Beckwith-Wiedemann syndrome and hemihypertrophy.

Children who survive hepatoblastoma should be considered for evaluation of FAP, and those patients found to carry an APC mutation need close surveillance because of their increased risk for colonic polyps and adenocarcinoma.

RESEARCH

Children's Mercy is a participating institution in The Children's Oncology Group (COG) current clinical trial for hepatoblastoma, COG AHEP0731. Each new study that Children's Mercy participates in builds off of what was learned in the previous study.

In AHEP0731, the hepatoblastoma is categorized within the risk groups shown below. The risk groups may include different stages of the disease because tumor cell characteristics are different as well as tumor markers.

Very Low-Risk: Stage I PFH hepatoblastoma – treatment: Surgery Only

Low-Risk: Stage I non-PFH, non-SCU or Stage II non-SCU hepatoblastoma

Intermediate-Risk: Stage I SCU, Stage II SCU, or any Stage III hepatoblastoma

High-Risk: Any Stage IV or any stage hepatoblastoma with initial AFP < 100 ng/mL hepatoblastoma

Children's Mercy also participates in PLUTO=Pediatric Liver Unresectable Tumor Observatory, as part of the COG AHEP0731 clinical trial. Patients and families choose to be a part of the PLUTO registry. This registry follows young patients who have had liver tumors and, due to extent of disease, need a liver transplant. The goal of the PLUTO registry is to create an international database of outcome information for this rare tumor of childhood.



NURSING

Advance Practice

The Advance Practice (AP) nurse is a first responder to the child diagnosed with hepatoblastoma. In this role, the nurse fills the role of a case manager, navigating the family through their therapy. This includes everything from helping to get insurance approval, working with the psycho-social team to ensure delivery of services, to visiting the child's school to explain what is going on to the diagnosed child's classmates. With the primary physician, the teamed AP nurse is the consistent face of a child's cancer treatment at Children's Mercy.

Inpatient Nursing

A diagnosis of cancer is difficult for anyone. A diagnosis of cancer in a child can seem unbearable. At Children's Mercy, children with hepatoblastoma end up spending several days on the Hematology/Oncology inpatient unit to receive care for tumor and to recover from the side effects of the treatments. For nurses, caring for a child with a new diagnosis of hepatoblastoma goes beyond just giving medications. When a child needs to stay in the hospital for an extended length of time, the inpatient nurse becomes a familiar face. Aside from administering the medications, the nurse is responsible for monitoring side effects as well as supporting the needs of the family. Most of the nurses taking care of children on the inpatient floor have special certification in the area of chemotherapy. For the family with a child with hepatoblastoma, the nurse is the one who is always around to help answer questions about side effects of the medications as well as hold hands and give hugs of encouragement.

Outpatient Nursing

The Hematology/Oncology Clinic employs experienced, highly skilled registered nurses, many of whom are certified pediatric oncology nurses. For outpatient hepatoblastoma patients and their families, the clinic nurse works directly in the primary care. Hepatoblastoma patients receive a wide range of nursing services during visits to the outpatient oncology clinic. This includes reviewing clinical history and performing a physical assessment; laboratory specimen collection; chemotherapy; biotherapy; medication administration; and transfusions.



NURSING

Nursing care provided by all Hematology/Oncology nurses includes the provision of patient and family education related to diagnosis, treatment, medication administration and management of side effects to therapy. The nursing staff performs and assists with advanced technical procedures, routinely consulting with certified child life specialists to reduce stress and pain for patients and families. These same nurses assist families in navigating their way through the Children's Mercy Hospital system. This is an especially important role as Hematology/Oncology patients routinely receive services from multidiscipline subspecialty clinics, such as Radiology, Surgery, Developmental and Behavioral Medicine, Physical Therapy/Occupational Therapy, and Nutrition.

Along with the traditional patient care needs that nursing attends to, Hematology/Oncology nurses are involved in Hematology/Oncology and hospital-wide committees that strive to improve access to and quality of care for patients and families. These nurses attend educational and professional development courses that ultimately improve their ability to provide the highest quality nursing care. Hematology/Oncology nurses are visible in their communities, as well. They participate in fundraising for various organizations and volunteer their time at camps specifically for hematology and oncology patients and their siblings.



NUTRITION

Oncology dietitians at Children’s Mercy Hospital hold specialty certification in nutrition support sciences to better address the challenges of supporting children through chemotherapy, radiation and surgery. Children with hepatoblastoma are often too ill to tolerate enough food to sustain them. Early nutrition support with supplemental tube feedings can improve their tolerance to chemotherapy by keeping their GI tract strong and their bodies nourished. Frequent assessment of eating ability and tolerance is necessary to determine how best to meet nutrient needs. Measurements of height, abdominal girth, arm circumference, and lab values are helpful indicators of nutrition status since weight measurements can be influenced by extra fluid or a large tumor.

The liver is responsible for converting food into the microscopic nutrients that fuel every cell and function of the body. The liver also serves as storage for carbohydrates, vitamins and minerals. Nutrition support for children with liver disease, from any cause, is a delicate task. Liver dysfunction typically leads to inability to digest nutrition effectively, so IV nutrition must be utilized if children are unable to tolerate eating or tube feedings into their stomach. Unfortunately, IV nutrients are less tolerable by the

liver than infusing nutrition by mouth or tube, so great care must be taken to minimize stress on the liver.

Children with hepatoblastoma are at a particular nutritional disadvantage because chemotherapy side effects add to the damage to their GI tract. The stress on the GI tract often brings them to need IV nutrition sooner than children with other types of cancer. Management of IV nutrition requires hospitalization initially, then careful transition to the home setting with caregivers learning the precise infusion of nutrients via pump. Once their GI tract heals from chemotherapy damage they are then able to tolerate tube feedings along with some regular food, allowing for improved rates of growth and gain. Nutrition goals are to maintain normal rates of growth and weight gain, while attempting to minimize the length of time on IV nutrition to limit stress on the liver.

It’s also important for the child to remain a part of the social structure of mealtimes with their families, even if eating isn’t probable or possible at times. Families are encouraged to maintain their typical mealtime routines, which can be a source of familiarity and emotional comfort for the child.

THE PHARMACY TEAM

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 inpatient/clinic operations, clinical specialist pharmacists, investigational drug service, home care and outpatient operations. There are 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 also have four pharmacists and a technician dedicated to the review of chemotherapy orders. They are responsible for the safe production and distribution of chemotherapy to all patients within the Children's Mercy system. Our investigational drug service works with more than 100 open drug trials for our patients. This includes some phase I and many phase II oncology drug studies. Our outpatient pharmacy is able to compound many prescriptions that are not commercially available.



Our Hematology/Oncology pharmacists also are dedicated to providing education to pharmacy students through clinical rotations and lectures at our local school of pharmacy. Our pharmacy department also 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. This residency program provides pharmacists with focused and intensive training in the care of pediatric patients with cancers.

Over the past two decades, use of a standard and consistent regimen of chemotherapy for hepatoblastoma has helped improve survival by increasing the rates of surgical resection of these tumors. In an attempt to further increase survival, the latest treatment protocol from the Children's Oncology Group incorporates the novel chemotherapy agent irinotecan for high risk patients. For both intermediate and high-risk patients, the agent doxorubicin is paired with a drug which has the sole purpose of decreasing doxorubicin's known potential side effect of heart damage.

FAMILY CARE TEAM (FaCT)

Although there have been many advancements in the treatment of childhood cancer, caring for a child diagnosed with hepatoblastoma is a no less



daunting road for parents, siblings, family members and friends. The Hematology/Oncology Family Care Team (FaCT) recognizes that treatment is not merely a series of chemotherapy, clinic appointments and inpatient admissions. It is a process where the most important outcome is that the patient and family are able to redefine their “new normal” after treatment ends. For many patients and families with hepatoblastoma, life will never be the same. This requires continued adjustment with each developmental stage of their life.

Our family care team is composed of highly specialized psychosocial staff members who are equipped to support families through each step of the process, including diagnosis, active treatment, end of treatment, and late effects. The overarching goal of the family care team is to assist each patient and family member by providing support and guidance on an individual basis.

The family care team consists of social workers, child life specialists, music therapists, a psychologist, a chaplain and a school teacher. All members of the family care team are available to provide support to the patient, parents and school staff in order for the patient to stay connected with their peers throughout treatment. Team members can meet with siblings and classmates to provide education on the diagnosis and treatment and facilitate discussion of how they can support the patient in their treatment process.

As part of an ongoing relationship with each patient and family, the family care team considers it a privilege to accompany patients and families on their journey and bear witness to their determination, courage and resilience.

*Above:
Camp Courage brings children with
Sickle Cell Disease a few days of
summer fun with peers and caregivers.*

SURVIVE & THRIVE CLINIC

The Survive & Thrive long-term follow-up program was developed in 2009 to meet the needs of childhood cancer survivors at Children's Mercy. The Survive & Thrive Clinic is held several times a month and is staffed by an oncologist, nurse, social worker, and registered dietician. With the growing number of survivors comes an opportunity to learn more regarding treatment and the late effects of treatment.

One of the goals of the program is to increase survivors' knowledge of their treatment, potential late effects, and healthy lifestyle choices. The Survive & Thrive Clinic follows survivor guidelines established by the Children's Oncology Group. The guidelines serve as a foundation for creating individualized follow-up plans for each cancer survivor.

With the use of Passport for Care, an electronic program developed by Texas Children's Hospital and Baylor College of Medicine, survivors receive a treatment summary and education about potential late effects. Another focus of the program is transition of care from Children's Mercy to the

adult medical community. In preparing survivors for transition, emphasis is placed on insurance coverage, potential late effects, and tests/procedures needed to monitor for late effects.

Survivors of hepatoblastoma who come to the Survive & Thrive Clinic have a comprehensive physical exam, lab work and diagnostic tests (determined by the Children's Oncology Group survivor guidelines), and referrals to specialists if needed. An example of a common test for survivors of hepatoblastoma is an audiogram to evaluate for hearing loss due to chemotherapy.

Survivors receive a treatment summary and education folder containing information about late effects and tips for being healthy after cancer. The social worker meets with survivors to discuss insurance coverage, evaluate for school or work issues, provide support resources if needed, and educate survivors and their families about available scholarships. Survivors are followed annually to monitor for late effects of treatment, provide continue education and support, and prepare for the transition of care from Children's Mercy.



Survivor Day

Celebration

In July, the Survive & Thrive Program sponsored the first Survivor Day Celebration at Crown Center in Kansas City.

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Cancer Center
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