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2001 Cancer Care Annual Report



Focus on Wilms' Tumor

Dear Colleagues,

Wilms' tumor, a cancer of the kidney unique to children, is the topic of this year's Annual Report. This type of kidney cancer is unrelated to the cancer most often seen in adults. This tumor and the discussion that follows highlight the advances that have taken place in childhood cancer and the origins of that success. The National Wilms' Tumor Study Group (NWTSG) was a collaborative effort of pediatric specialists in Oncology, Surgery, Radiation Therapy, and Pathology from institutions throughout North America. These institutions sequentially designed clinical trials based on prior research findings. This collaboration was the most effective way to study and improve outcomes of such a rare tumor. Children's Mercy Hospital patients did participate in the studies designed by this group.

Increased cure rates with minimal or no long term complications is the focus of all cancer treatment. The outcomes of the NWTSG research have made it possible to depart from the concept of an "all out war at all costs" which focused primarily on eradicating the disease and give more attention to the prevention of long term complications. Pediatrics

specialists in the field of endocrine, cardiology, and psychology have joined the battle collectively to treat children diagnosed with Wilms' tumor, as well as other forms of childhood cancer. The treatment of Wilms' tumor and all childhood cancers continues to be a multidisciplinary endeavor.

The diagnosis of Wilms' tumor continues to carry risks of mortality and morbidity which is the rationale for continued research and clinical trials. The Children's Oncology Group (C.O.G.) has taken the baton from NWTSG and continues the work to improve cure rates while systematically developing methods to reduce or alleviate long term side effects of the treatment. Children's Mercy Cancer Center contributes to improved patient outcomes at a national level as a participant of C.O.G. The Children's Oncology Group is one of the largest organizations supported by National Cancer Institute. Our participation ensures our patients have the most advanced, up-to-date treatment options available to them and our physicians and nurses take part in the design and oversight of these studies.

The wide array of pediatric specialists at Children's Mercy Hospital, partnered with



the advanced diagnostic and treatment resources, allows multidisciplinary care to be available to the children of eastern Kansas and western Missouri. Children's Mercy Hospital continues to strive to improve the care and well-being of children in Kansas City and the surrounding region. The Children's Mercy Cancer Center Annual Report will detail how the cancer program contributes to this initiative.

Alan S. Gamis, MD, MPH
Director of Oncology
Chair, CMH Cancer Care Committee

Dear Colleagues,

The number of children cared for by Children's Mercy Hospitals and Clinics continues to grow at a significant pace. In 2001 we had 11,297 inpatient admissions and more than 305,000 outpatient clinic and emergency department visits; both totals represent a nearly 10 percent increase over the previous year.

The Children's Mercy Cancer Center has certainly been an integral part of this growth. Although Wilms' tumors represent a relatively small percentage of the pediatric cancers we see at Children's Mercy, they do represent a cancer in which we have experienced great success in cure rates. Our Cancer Center is accredited by the American College of Surgeons.

This Cancer Care Annual Report is very important in our efforts to keep community physicians and others

informed of our progress regarding the diagnosis and treatment of childhood cancer. It's essential that this treatment involves the support of the entire family, which we accomplish through a multidisciplinary approach where each discipline plays an important role in the outcome of each patient's treatment. Children's Mercy is nationally recognized for the unique, family-centered environment which we provide to meet each child and family's individual needs through innovative, creative venues.

In addition to providing information on the specific programs available at Children's Mercy, this report also features how our activities relate to other centers across the country. I believe our cancer center continues to be one of the best in the nation, and I am pleased to share with you this year's Cancer Care Annual Report.



Sincerely,

A handwritten signature in blue ink that reads "Randall O'Donnell". The signature is fluid and cursive.

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

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MISSION

Patient Care Services:

“Patient Care Services is dedicated to providing pediatric care that is safe, evidence-based and family centered.”

Hematology/Oncology:

To provide comprehensive care to children with cancer and blood disorders in a family-centered care environment in an effort to promote health and well-being. This mission is accomplished in the following ways:

- Treatment of patients and their families with compassion in a family-centered atmosphere that recognizes the physical, emotional, financial, social, and spiritual needs of each individual case.
- Delivery of specialized pediatric medical, nursing, and psychosocial services through an interdisciplinary team approach.
- Education of patients, families, health care students, and providers, and the community about childhood cancer and blood disorders and the impact these diseases have on daily living and long term survival.
- Support of the advancement in the field of pediatric hematology and oncology through medical/nursing research.
- Collaboration with the local, regional, and national organizations to support our mission and service the community at a local and regional level.
- Foster an atmosphere of mutual respect and support in the workplace to enhance the spirit of teamwork and personal and professional growth.
- Foster a leadership model that commits the “person” with the “worker.”

VISION

Patient Care Services:

“Patient Care Services will be recognized as the leader in pediatric health care services through a collaborative approach to evidence-based clinical practice, education, and research.”

Hematology/Oncology:

To be the premier hematology/oncology center in providing extraordinary care for children and families.



HEMATOLOGY/ONCOLOGY SECTION STRATEGIC PLAN

GOALS FOR BEST PRACTICE ENVIRONMENT

- Facilitate seamless care through improved communication between staff and other departments.
- Improved quality of care by education, psychosocial support, community involvement, and clinical practice.
- To have shared ownership by all members focusing on improving the effectiveness of the section.
- Increase community awareness through outreach, education and research participation.
- Improve efficiency and productivity of the entire Hematology/Oncology section.
- To retain experienced and competent staff by creating a program of rewards/incentives and staff education.

2001 Registry Statistics: (January 1, 1990 Reference Date)

- ❖ 1,001 patients are abstracted in the cancer registry since 1990.
- ❖ 108 patients were added to the registry in the year 2001.
- ❖ Frequency of Diagnosis for 2001: (see Fig.1)
 - Five most frequently occurring diagnoses for 2001
 - Leukemia
 - Brain Tumors
 - Neuroblastoma
 - Lymphoma
 - Wilms' Tumor
- ❖ 30 cancer related deaths were recorded in 2001: (see Fig.2)
 - 4 deaths had disease diagnosed in 2001, the remaining were diagnosed prior to 2001.

Class of Case (ACOS-COC Classification) Mortality Data - Figure 2	
Leukemia	9
Lymphoid Leukemias	7
Myeloid Leukemias	2
Central Nervous System	4
Astrocytoma	1
Medulloblastoma	1
PNET	1
Rhabdoid/teratoid tumor, atypical	1
Neuroblastoma	4
Lymphoma	3
Hodgkins	1
Non-Hodgkins	2
Osteosarcoma	3
Hepatocellular Carcinoma	2
Rhabdomyosarcoma	2
Germ Cell Tumor	1
Desmoplastic Small Round Cell Tumor	1
Malignant Round Cell Tumor	1
Total Number of Mortalities in 2001	30

Children's Mercy Hospital Cancer Registry 2001 Frequency of Diagnosis - Figure 1

Leukemia	32 (30%)	Neuroblastoma	9 (8%)
ALL	28	Wilms Tumor	6 (5%)
AML	4	Osteosarcoma	3 (3%)
Central Nervous System	32 (30%)	Retinoblastoma	3 (3%)
Astrocytoma	13	Other	15 (14%)
Glioma	3	Ewing's Sarcoma	2
Primitive Neuroectodermal Tumor	2	Hepatoblastoma	2
Ependymoma	2	Rhabdomyosarcoma	2
Medulloblastoma	1	Adenocarcinoma	1
Pineoblastoma	1	Papillary Carcinoma	1
Atypical Teratoid Rhabdoid Tumor	1	Melanoma	1
Choroid Plexus Carcinoma	1	Yolk Sac Tumor	1
Benign/Borderline	8	Synovial Sarcoma	1
Lymphoma	8 (7%)	Neuroendocrine Tumor	1
Non-Hodgkin's	4	Misc. Reportable Conditions	3
Hodgkin's	4	Total Number of Cases for Year	108

Objective: To Contribute to Cancer Surveillance and Control

- ❖ By collecting and maintaining data on all patients diagnosed and / or treated with malignancy and selected benign/borderline tumors at Children's Mercy Hospitals and Clinics.
 - Abstract data includes information on cancer type and location, stage or extent of disease at diagnosis, treatment received, recurrence, and follow-up information.
- ❖ By providing data to the National Cancer Data Base, the Missouri Central Cancer Registry, and physicians to improve the prognosis for cancer patients.
- ❖ By following our cancer patients annually throughout their lifetime to check on their health status.
 - 95 percent of all CMH cancer registry patients had their disease status updated by the end of 2001.
- ❖ Participate and organize the approval process for accreditation from the American College of Surgeons Commission on Cancer (ACOS). Accreditation was granted in July 1999.

Class of Case (ACOS-COC Classification) - Fig. 3

- ❖ During the abstracting process a class of case is assigned according to the criteria set forth by the ACOS. The class of case determines whether a case must be included in the registry
 - Class 0 includes patients diagnosed at CMH but received all of their first course of treatment elsewhere. In 2001- 0 Cases met this criteria.
 - Class 1 includes patients diagnosed at CMH who received all or part of their first course of treatment at CMH. In 2001- 81 Class 1 patients were recorded.
 - Class 2 includes patients diagnosed elsewhere and received all or part of their first course of treatment at CMH. In 2001 - 15 Class 2 cases were reported.
 - Class 3 includes patients diagnosed elsewhere who receive their first course of treatment at another facility. These patients later have recurrence and come to CMH for subsequent treatment. In 2001- 1 Class 3 case was reported.

- ❖ Class of Case 0-2 are followed annually to determine survival and disease status.

Benign and Borderline Tumors

- ❖ These tumors are included in the registry by agreement of the Cancer Care Committee.
- ❖ Determination for inclusion is the location of the tumor (e.g. central nervous system) or its propensity to recur and/or progress to malignancy.
- ❖ Eleven Benign and Borderline Tumors were reported for 2001 (see Fig. 3)

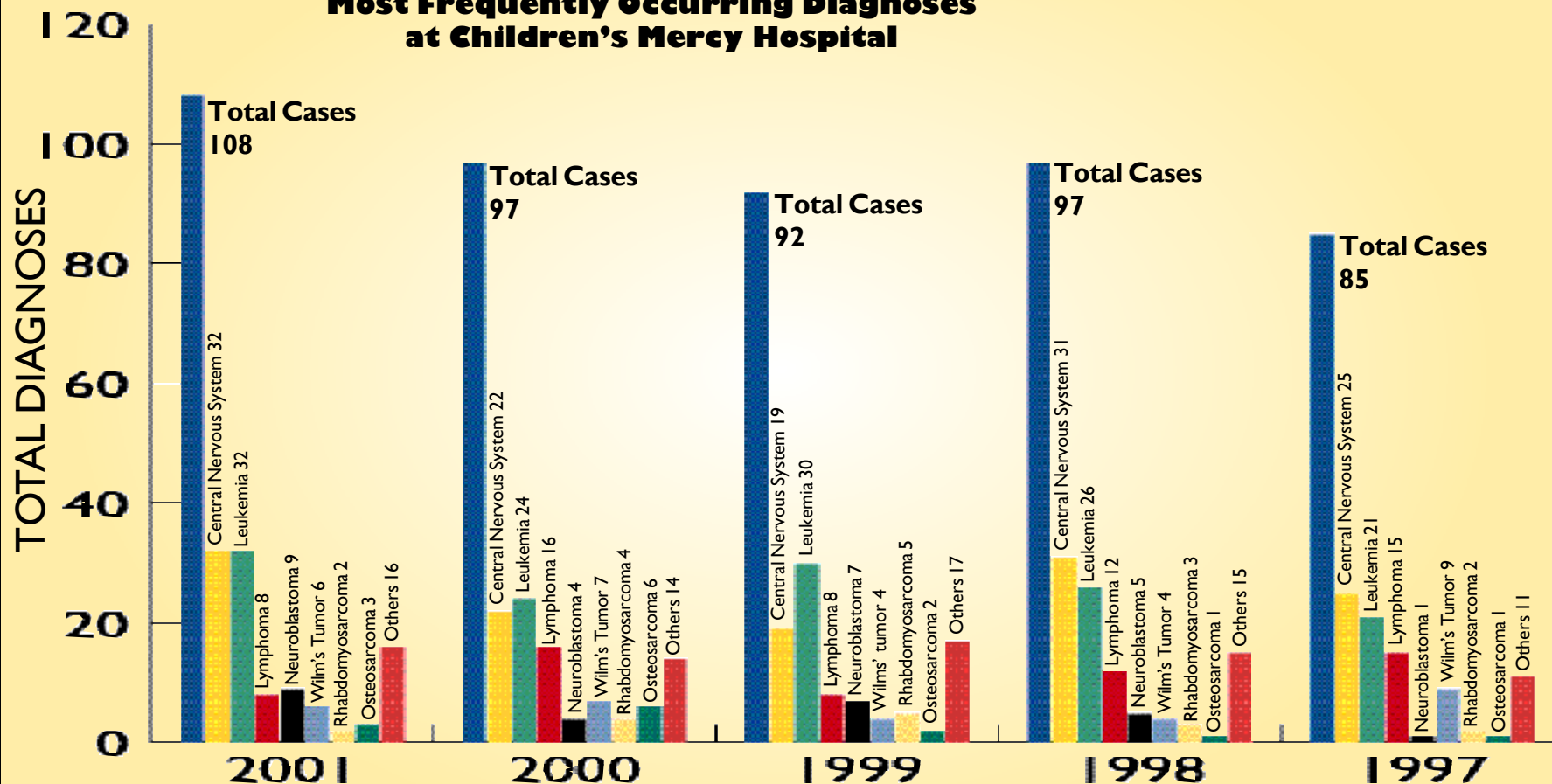
Reference Date

- ❖ The Commission on Cancer (COC) of the American College of Surgeons requires a start date for data collection to begin. This date is controlled by the facility through the guidance of the Cancer Care Committee and is approved by the COC.
 - January 1, 1990 is the reference date for the Children's Mercy Hospital effective April 17, 2001.

Class of Case (ACOS-COC Classification) - Figure 3

Class 0	0	(0%)
Diagnosed at CMH - received all of first course of treatment elsewhere.		
Class 1	81	(75%)
Diagnosed at CMH - received all of first course of treatment at CMH.		
Class 2	15	(14%)
Diagnosed elsewhere - received all or part of first course of treatment at CMH.		
Class 3	1	(1%)
Diagnosed elsewhere - received all of first course of treatment elsewhere.		
Benign/Borderline	11	(10%)
Included in the Registry due to location (tumor of central nervous system), or because of its propensity to recur.		

A Five-Year Comparison of Most Frequently Occurring Diagnoses at Children's Mercy Hospital



A young girl with blonde hair and bangs is smiling and holding a blue handlebar. She is wearing a white t-shirt with a graphic that says "PROUD TO BE AMERICAN" above a stylized American flag. The background shows a red and blue playground structure and a stone wall.

Elizabeth

Elizabeth is an energetic 6-year-old who enjoys tap dancing, ballet, and crafts. She also likes to sew clothes for her dolls and bears.

Elizabeth came to Children's Mercy in February 2002 and has successfully completed her treatment for Wilms' tumor.

Elizabeth's older sister noticed a strange mass around her stomach while giving Elizabeth a bath one day. After seeing their pediatrician, they arrived at Children's Mercy and Elizabeth had surgery the following day.

"Elizabeth did great after the surgery," says Elizabeth's mother,

Nancy. "She went back to school and finished the year."

Nancy was very impressed with all the attention and support they received at Children's Mercy.

"A lot of people we had met in the hospital came in and checked on us," says Nancy. "Even the nurse that originally checked us in at Emergency came back to see how Elizabeth was doing."

Elizabeth says that she doesn't mind coming back to the Oncology Clinic at Children's Mercy because she likes to do all the crafts.



Epidemiology

Wilms' tumor is the most common primary tumor of the kidney and the third most common solid tumor in children. Approximately 460 new cases are diagnosed per year in the United States. For unilateral Wilms' tumor, the M:F ratio is 0.92:1.00. The tumor is slightly more common in the African-American population, and significantly less common in Asian populations. The mean age at diagnosis is 42 months for males and 47 months for females.

Clinical Presentation

Wilms' tumor often presents as an abdominal mass observed by a parent while bathing the child. Other signs and symptoms include abdominal pain, gross hematuria, hypertension (found in 25% of cases), fever, and anemia. Typically on exam, a large flank mass can be palpated. It is important to document the occurrence of any congenital anomalies such as aniridia, hemihypertrophy and genitourinary abnormalities. Of those patients that present with metastases at diagnosis, the majority (approximately 80%) will have disease in the lungs as the only site.

Work-up

Evaluation of the patient with suspected Wilms' tumor includes baseline laboratory work to assess renal function, liver function, coagulation and hematologic status. Ultrasound is often the initial imaging study and usually helps to identify the origin of the mass. Once a renal-based mass is identified in a child, ultrasound is utilized to evaluate the

vascular system for tumor thrombus. If present, the extent of tumor thrombus should be documented. If the thrombus extends above the level of the hepatic veins, surgical resection of the mass is delayed until after chemotherapy is given in an attempt to shrink the thrombus and lessen the risk of morbidity associated with the surgery. After ultrasound, a CT of the abdomen is obtained to further evaluate the origin and extent of tumor, as well as to assess the opposite kidney for disease. Chest radiographs are obtained to evaluate for pulmonary metastases. Chest CT is usually obtained as well. A small percentage of patients may have lung nodules present on CT of the chest but not visualized by plain films. The management of these patients is controversial, as many of these nodules that are identified only by CT are not metastatic disease.

Surgery

In a multidisciplinary approach to Wilms' tumor, the surgeon is responsible for resection of all viable tumor, if possible, and for providing accurate staging so that the appropriate adjuvant therapy can be utilized. With this in mind, in North America, most patients with a single isolated Wilms' tumor without complicating factors such as metastatic disease or renal tumor vein or inferior vena caval extension, undergo initial radical nephrectomy with nodal sampling and evaluation of the contra-lateral kidney both by palpation and visualization. However, if there is evidence of the above-mentioned complicating factors or if it felt by the surgeon that the tumor is of such a large size that tumor spillage would be likely,

then initial biopsy followed by adjuvant therapy is appropriate. In the case of known bilateral disease, the objective is to preserve as much renal parenchyma as possible. Therefore, the patient usually undergoes laparotomy with biopsy of each tumor as well as lymph node sampling to facilitate accurate staging. Adjuvant therapy is usually initiated following histologic evaluation of the biopsy material. Following appropriate adjuvant therapy, partial nephrectomy on each side is then performed, if possible. On occasion, it may be necessary to perform a unilateral nephrectomy on one side and a partial nephrectomy on the other side if one of the lesions is so large that a partial nephrectomy is not possible.

In those patients who are felt to be candidates for initial unilateral radical nephrectomy by the surgeon, a generous subcostal incision is made which usually extends into the contralateral subcostal region. Often, either the liver or spleen and the colon or small bowel are adherent to the tumor, but are not being invaded by the tumor, and are dissected free from the tumor capsule. Due to the large size of the tumor, it is usually not possible to ligate the renal artery or vein initially. Rather, the surgeon attempts to dissect the tumor away from adherent organs or structures and ligates and divides the artery and vein as one of the last steps. The ureter is usually ligated and divided as close to the pelvic rim as possible. Once the tumor is removed, lymph nodes are taken from the ipsilateral renal hilar area as well as the periaortic region and the contralateral kidney is assessed. Following closure of the incision, a portacath is often

placed under the same anesthesia for postoperative chemotherapy, but this procedure may be delayed for a later date in certain circumstances.

In those patients in whom a biopsy is initially performed, a small incision is made along the line of the planned larger incision for the second operation as this small incision and the dissection through the abdominal wall should be excised at the second operation to remove all residual tumor. An appropriate biopsy is then taken from the tumor in this fashion. This procedure is not as simple as it sounds as the tumors are quite vascular and bleeding can be a problem from the small tumor biopsy site.

Pathogenesis and Pathology

Wilms' tumor is a malignant neoplasm that recapitulates the histologic appearance of a human developing fetal kidney, albeit disorganized (Figure 1). Microscopically, Wilms' tumors express of an array of cell types and tissue components, including differentiating epithelial and stromal derivatives as well as undifferentiated blastema, which are normally not seen after 36 weeks of human fetal development. In a small proportion of people, these developing cells may persist within the kidney beyond 36 weeks of gestation and are called "nephrogenic rests." Most of these rests ultimately undergo spontaneous involution within the first year of life. It is believed that some of these rests, before they involute, serve as the seeds from which Wilms' tumors may germinate. Most often the rests are tiny in size and not detected without a microscope.

Rarely rests can be seen with the naked eye and may be multiple and cover much of the entire kidney, a condition referred to a "nephroblastomatosis." Whether microscopic in size or visible to the naked eye, nephrogenic rests are benign growths and are believed to represent the first "hit" in the two-hit hypothesis of malignant transformation. The second "hit" is believed to be some other genetic or chromosomal change that imparts a full malignant potential to these rests. Once malignant transformation has occurred, these tumors are often very aggressive, grow extremely rapidly to large palpable abdominal masses that may weigh in excess of three pounds and quickly metastasize to liver, lungs and lymph nodes.

Aggressive as they may be, even in the face of spread beyond the confines of the kidney of origin, 95% of all Wilms' tumors are very sensitive to chemotherapy with excellent overall prognosis. The other 5% are resistant to chemotherapy and have a much worse prognosis if they have escaped the confines of the kidney of origin and the potential to be completely removed surgically. This distinction in chemosensitivity can be reliably predicted based on several microscopic features of Wilms' tumors that collectively define the two histologic grades of the tumor, i.e. "non-anaplastic" or "favorable histology" (Figure 1) and "anaplastic" or "unfavorable histology" Wilms' tumor (Figure 2). There are three features that define the so-called "anaplastic" unfavorable tumor: 1. abnormally large nuclei; 2. nuclear hyperchromicity (unusually dense nuclear chromatin that reflects abnormally

increased amounts of DNA and chromosomal duplications); 3. Atypical mitoses that also reflect excessive genetic material within tumor cells and disorganized cell division.

The principle role of the pathologist is to evaluate the biopsy and nephrectomy specimens for the following: 1. establish that the renal tumor is a Wilms' tumor and not one of the other benign and malignant tumors that occur in children less frequently; 2. determine whether the primary tumor has been completely resected or not; and 3. establish whether the tumor has favorable or unfavorable histology. In addition, the pathologist may select portions of the tumor for ancillary genetic, research or other clinical studies.

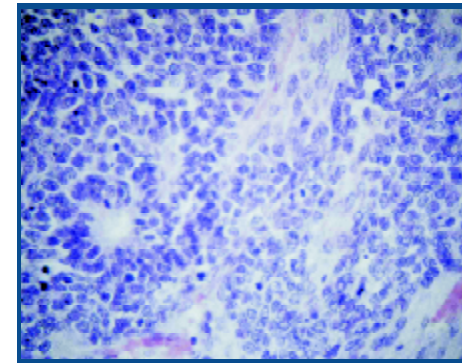


Figure 1: Non-anaplastic favorable Wilms' tumor

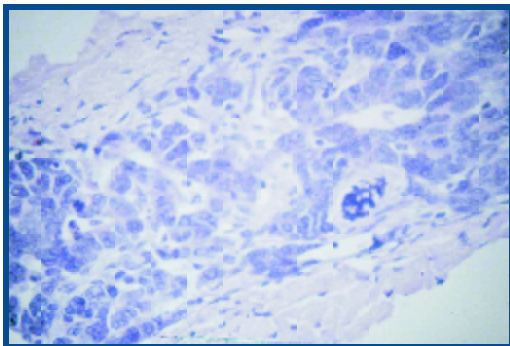


Figure 2: Anaplastic unfavorable Wilms' tumor

Staging

The well-established National Wilms' Tumor Study Group (NWTSG) Staging System is utilized for patients with Wilms' Tumor (Table I). Patients with unresectable tumors must be assumed to have at least Stage III disease and treated as such. Wilms' tumor may appear to be unresectable on CT because of possible invasion of the liver. However, direct visualization at surgery usually reveals a clear plane between tumor and the liver and resection will be possible. Because of the need for extensive sampling of the tumor to determine histology and prognosis, surgical resection is preferred over biopsy when at all possible desired to reduce the risk of late effects.

NATIONAL WILMS' TUMOR STUDY GROUP STAGING SYSTEM FOR RENAL TUMORS (TABLE I)

Stage	Description
I	Tumor confined to the kidney and completely resected. No penetration of the renal capsule or involvement of renal sinus vessels.
II	Tumor extends beyond the kidney but is completely resected (negative margins and lymph nodes). At least one of the following has occurred: (a) penetration of the renal capsule, (b) invasion of the renal sinus vessels, (c) biopsy of tumor before removal, (d) spillage of tumor locally during removal.
III	Gross or microscopic residual tumor remains postoperatively, including inoperable tumor, positive surgical margins, tumor spillage involving peritoneal surfaces, regional lymph node metastases, or transected tumor thrombus.
IV	Hematogenous metastases or lymph node metastases outside the abdomen (e.g., lung, liver, bone, brain).
V	Bilateral renal Wilms' tumors at onset.

Genetics & Molecular Biology

Several genes are known to predispose to Wilms' tumor (WT). WT1, located on the chromosome 11 short arm at band p13, is deleted in Wilms' tumors associated with the WAGR syndrome (Wilms' tumor, Aniridia, Genitourinary anomalies, mental Retardation). Individuals with the WAGR syndrome have a 30% risk of WT. Denys-Drash syndrome (DDS) is associated with point mutations of the WT1 gene. DDS is characterized by pseudohermaphroditism, early renal failure with diffuse mesangial sclerosis, and Wilms' tumor. Germline WT1 mutations are found in only ~5% of patients with sporadic WT.

A second WT gene, "WT2", located at 11p15, is linked to Beckwith-Wiedemann syndrome (BWS), an overgrowth syndrome with a 5-10% risk of WT. The WT2 locus has 10 imprinted genes, including insulin-like growth factor-2 (IGF2), H-19, and p57^{Kip2} (CDKN1C), which have been implicated in Wilms' tumorigenesis.

Approximately 1% of Wilms' tumors are familial with one or more family members with the disease. The mode of inheritance is thought to be autosomal dominant with variable penetrance and expressivity. Linkage analysis has shown two loci in addition to the WT1 and "WT2" loci to be linked to WT predisposition in families with WT; FWT1 on chromosome 17q and FWT2 on 19q. Still other families show no linkage to WT1, "WT2", FWT1, or FWT2 suggesting other WT susceptibility genes exist.

The WT1 gene, the most extensively studied gene, has 10 exons with a molecular weight of 45-49 kilodaltons. WT1 encodes a zinc-finger transcription factor and is critical to normal kidney and gonadal development. WT1 is a tumor suppressor gene. Function of the normal WT1 gene is regulation of transcription of other genes that influence cell growth, differentiation, and apoptosis.

Cytogenetic, comparative genomic hybridization (CGH), and loss of heterozygosity (LOH) studies of Wilms tumor tissue have found recurring genetic abnormalities. Loss of chromosome 16q loci (~10-20% of tumors) and deletions on chromosome 1p (~10% of tumors) are associated with an adverse prognosis independent of tumor stage and histopathology. Mutations of the p53 gene, located on chromosome 17p, are associated with anaplasia, a poor prognostic indicator.

Treatment

Since the NWTSG was formed in 1969, five clinical trials have been completed. CMH participated and evaluated patients on these clinical trials. The benefits of national collaboration are clear. Two-year survival rates have risen from 20% to greater than 90% for Wilms' tumor through the work of the NWTSG. Furthermore, therapy for certain subgroups has been reduced to minimize toxicity and cost of therapy, with continued excellent outcomes. The results of the NWTSG trials have allowed us to stratify treatment by stage and histology, so that the patient receives the least amount of therapy necessary. Treatment of the patient with

Wilms' tumor requires the expertise and collaboration of the surgeon, pathologist, pediatric oncologist and radiation oncologist to achieve such excellent outcomes. Careful resection, accurate staging, postoperative chemotherapy, and radiation therapy are all key components in the management of these patients. Pulse-intensive chemotherapy is given utilizing Vincristine and Dactinomycin for patients with Stage I & II Favorable Histology. Adriamycin and radiation is added for those patients with Stage III & IV FH disease.

Outcomes

From 1992-2001, 46 patients have been diagnosed with Wilms' tumor at Children's Mercy Hospital, with a mean of 5.5 new cases/year for the past six years. Favorable histology was found in 44 patients at CMH, 56% males and 44% females. Of those patients with favorable histology, overall survival is 91% with a median follow-up of 42.5 months (range 0-119 months).

Figure 3 compares the overall survival rates of CMH patients with Stage I-IV Wilms' tumor, favorable histology with the NWTSG survival rates. One patient was diagnosed with Stage V, favorable histology at CMH which is not reported in figure 3.

Future goals include the ability to prospectively identify those patients at risk for relapse using biologic markers. Once identified, treatment for these patients could be intensified. Further reductions in therapy for those patients that are at minimal risk of relapse are desired to reduce the risk of late effects.

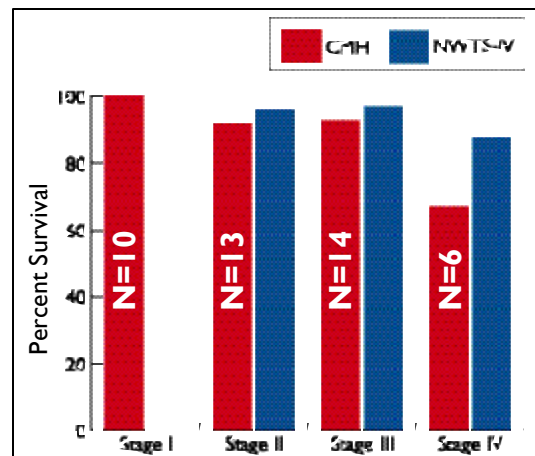


Figure 3: Overall survival (%) for Favorable Histology Wilms' Tumor patients treated at CMH compared to patients treated on NWTSG-IV study (Green, DM, et al. J Clin Oncol 16:3744-3751, 1998). The CMH results are skewed due to the small sample size (44) compared to 863 pts on NWTSG-IV with Stage II-IV. The CMH patients were treated on or followed the most current NWTSG clinical trials.

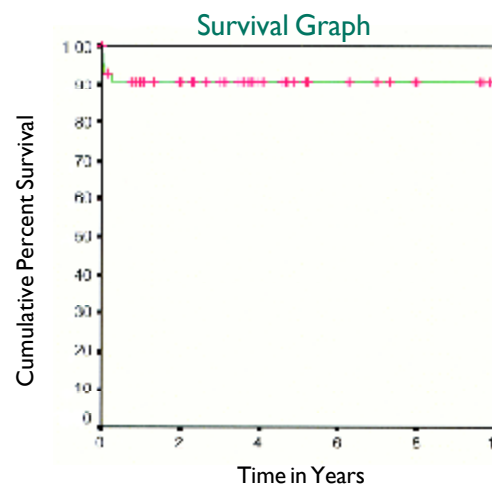


Figure 4: The overall survival rate for patients treated at CMH with favorable histology, Stage I-IV Wilms' tumor from 1992-2001.



Nicholas

Nicholas is a busy 3-year-old boy. He loves books and animals, particularly dinosaurs. He also enjoys swimming and playing with cars.

Nicholas has been a patient at Children's Mercy since April 2002 and finished up his treatment in September.

When Nicholas' parents noticed a hard mass on his side, they took him to the pediatrician and were sent directly to Children's Mercy.

After being diagnosed with Wilms' tumor, Nicholas went right into surgery to have his left kidney removed. After a week in the

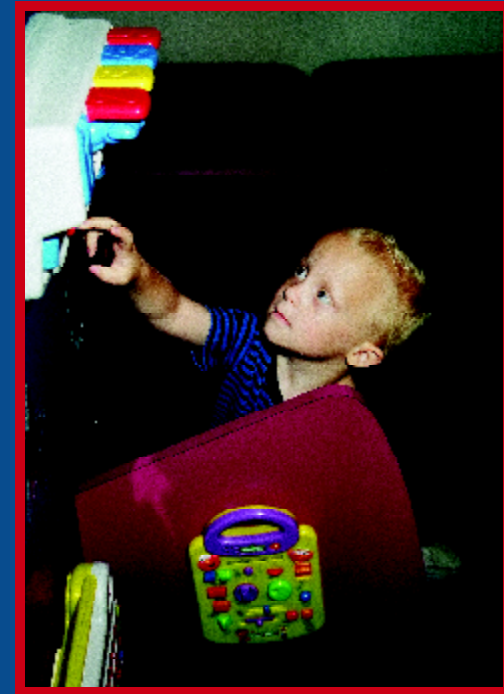
hospital, Nicholas went back home to his books and dinosaurs.

Nicholas' mother Amy said that support from family and from the hospital helped them get through the difficult time.

"There is all kinds of support at Children's Mercy," says Amy. "Not just from doctors and nurses. The whole thing is very impressive."

Amy thinks that Nicholas' young age helped him through his battle.

"You have no idea what to expect when you get into something like this," says Amy. "But he has been a real trooper."

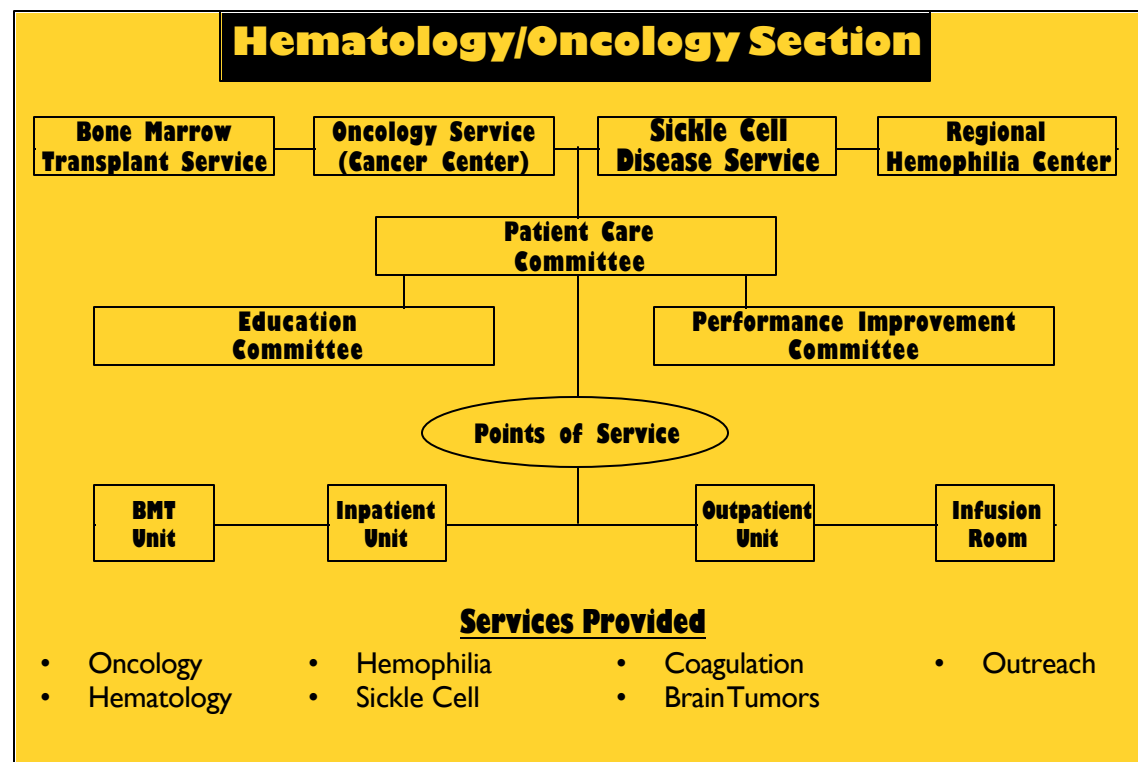


The Section of Hematology/Oncology

The Section of Hematology/Oncology at Children's Mercy Hospitals and Clinics has four distinct services that support the care of children with malignant or hematologic disorders. The Regional Hemophilia Center supports seven sites in a five-state region to provide comprehensive treatment for both adult and pediatric patients with bleeding disorders, as well as coagulation/thrombosis disorders. The Sickle Cell Disease Service offers specialized care to this unique population of patients in an effort to effectively treat acute and chronic pain, as well as long term sequelae related to sickle cell disease. The Bone Marrow Transplant Service provides hematopoietic stem cell rescue to patients receiving ablative therapy and requiring marrow rescue. This is done utilizing umbilical stem cells, matched-related donor cells, and matched-unrelated donor cells. This service participates in a national marrow search program and has cells available to them from all across the world. The Oncology Service is dedicated to the treatment of malignant disorders. Each service has a designated director of service and the section has a section chief and a section manager who oversee the medical, nursing, research, and operations. The section is comprised of approximately 145 faculty/staff.

Hospital/Interdepartmental Collaboration

- Children's Mercy Cancer Care Committee – meets quarterly
- Tumor Boards – meets weekly for a minimum of 48 meetings annually



- Bone Marrow Transplantation Meeting – weekly
- Hematology/Oncology Multidisciplinary Team – meets weekly
- Hematology/Oncology Inpatient Rounds – meets on 4HT daily
- Patient Care Conferences – done as needed and can be requested by any team member
- FACT Committee (Psychosocial team, child psychologist, social worker, pastoral care, child life, music therapist, nursing) – meets weekly
- Hematology/Oncology Section Meeting – monthly
- Senior MD Staff Meeting – 2-3 times monthly
- Physician Assistant/Advanced Practice Nurse Meeting – 3 times per month
- MD/Physician Assistant/Advanced Practice Nurse Meeting – monthly
- Patient Care Services Leadership Council (hospital-wide committee) – meets weekly
- Nursing Practice Council (hospital-wide committee) – meets monthly
- MEDS Committee (hospital-wide committee) – meets twice monthly
- Transfusion Committee – meets every other month
- Hematology/Oncology Core Charge Nurse Meeting – monthly
- Hematology/Oncology Updates – meets quarterly
- COO/VP of Patient Care Services Meeting – monthly
- CEO Assembly – meets monthly
- Hematology/Oncology Patient Care Committee – meets monthly

- Hematology/Oncology Education Committee – meets monthly
- Hematology/Oncology Performance Improvement Committee – meets quarterly and on an “as needed” basis
- Hematology/Oncology Research Meeting – monthly
- Hematology/Oncology Journal Club – meets monthly
- Children’s Mercy Cancer Center (auxiliary) – Board of Directors meets every other month.

Hematology/Oncology Structure Description Patient Care Committee

- Works in collaboration with all four services.
- Efficient utilization of resources to include labor, supplies, and physical space. This would include the development, implementation, and ongoing evaluation of a staffing/patient ratio and skill mix.
- Promotion of the standard delivery of patient care to include order templates, preprinted orders, treatment guidelines, and/or clinical pathways.
- Promotion of a well defined, timely discharge process.
- Provide a “seamless care” environment to include 4HT, H/O Clinic, and CMH Home Care.
- Promotion of interdepartmental collaboration to eliminate impediments to patient care. The collaboration includes pharmacy, surgery, laboratory, radiology, and home care.
- Foster an environment that provides peer/ staff recognition.

- Foster professional development through specialty certification, committee activity, nation/local association involvement (APON, C.O.G., National Hemophilia Association, National Sickle Cell Foundation, National Bone Marrow Consortium).

Education Committee

- Works in collaboration with all four services.
- Foster creative/innovative approaches to providing staff education which include, but are not limited to: poster presentations, “bathroom ed,” self-learning modules, individualized orientation plans, and formal/informal inservices.
- Support the reduction/elimination of medication/treatment related errors in collaboration with the patient care committee through the education of staff.
- Provide up-to-date educational material to patients/families to include: parent notebooks, Care Cards, Medication Cards, and other educational tools; i.e. S.C.O.R.E. cards.
- Provide a hospital-based chemotherapy competency validation process for staff that includes knowledge assessment (written test) and safe handling/administration (demonstration/application) which allows for routine revisions/updates, as appropriate.
- Develop parent classes to provide a “classroom-like” setting for parents/caregivers to be educated about the impact of a child diagnosed with cancer to include clinical, psychosocial, financial, and

orientation to hospital/community resources.

- Develop a “back-to-school”/school re-entry education program for patients and siblings experiencing childhood cancer/hematological disorders.

Performance Improvement Committee

- Works in collaboration with all four services, but “enhancements for Oncology Service” are under the oversight/direction of the Cancer Care Committee.
- Foster an environment of continuous evaluation and improvement of patient care outcomes.
- Incorporate all staff in process improvement to include medical, nursing, psychosocial team, nutrition team, etc.
- Provide ongoing education/information to staff regarding PI activity and outcomes (i.e. PI bulletin board).
- Foster interdepartmental process improvement (i.e. Emergency Medicine, PICU, laboratory, etc).
- Support the TEAM model for process improvement.
- Provide a system for “quick assessment and change” to include task forces.

Pediatric Hematology/Oncology Fellowship Program

The fellowship program at Children’s Mercy Hospital trains the future pediatric hematology/oncology specialists to conduct patient care and research. Pediatric hematology/oncology fellows at Children’s Mercy are fully trained pediatricians who dedicate a minimum of three years of training in

hematology/oncology medicine and research. The first year is dedicated primarily to clinical care and becoming familiar with procedures. The subsequent two years are dedicated heavily to clinical and laboratory research. Children's Mercy Hospital currently supports three fellowship positions for the Hematology/Oncology Section.

The Children's Mercy Hospital Cancer Care Committee

The Children's Mercy Hospital Cancer Care Committee is a standing medical staff committee that is charged with overseeing the Oncology services within the hospital. It is chaired by the Director of Oncology and has both physician and non-physician members (see member listing). Numerous associated specialties that also participate in the care of oncology patients are represented on the committee. It meets quarterly and reviews the patient acuity, programmatic efforts and needs, and quality assurance efforts that are related to Oncology services. This committee oversees the study and enhancement activities of the cancer program as required by the American College of Surgeons' accreditation.

The Children's Mercy Cancer Center Tumor Board Meetings

The Children's Mercy Tumor Boards represent discussions about newly diagnosed, recurrent, and unusual oncology patients. All patients diagnosed at Children's Mercy Hospital are discussed in this conference. The conference consists of a review of the patient's history, physical findings at diagnosis, laboratory values, radiological exams, surgical

interventions, and pathology findings. This is followed by a review of the patient's therapeutic options, current therapy, response to therapy, and anticipated prognosis. This is attended by physicians including specialists from oncology, surgery, radiology, pathology, orthopedic surgery, otolaryngology, neurosurgery, ophthalmology, neurology, neuropsychology, rehabilitation medicine, endocrinology, and radiation therapy. Additionally, advanced practice nurses, staff nurses, nursing management, dieticians, pharmacists, social workers, child life therapists, chaplaincy, and other members of the patient's multidisciplinary team are in attendance. This provides a forum for general review, education, and invited input and enhances the multidisciplinary team approach for children with cancer utilized at Children's Mercy Hospital. These tumor boards are conducted in compliance with the American College of Surgeons' accreditation requirements.

Parent-To-Parent Program

A program designed to connect parents who have been through the cancer experience with parents of newly diagnosed children. The support one parent can give another is immeasurable. The program focuses on the initial phase of the cancer experience; however, many of these parents develop strong, long-lasting relationships as they journey through the cancer experience together. These volunteer parents provide a mission statement "To offer comfort and compassion to all oncology families, from the comfort and compassion that we ourselves received." This program has a social worker who dedicates 16 hours per

week to designing psychosocial support activities, both at CMH and outside to promote the emotional well-being of the parents. The parents are the focal point of this program and they lead the initiatives.

Social Work and Community Services

There are four full-time and two part-time social workers dedicated to the Hematology/Oncology Section. The primary focus of this team is to assist the patient and family in understanding the impact the diagnosis of cancer will have on their family dynamics and life style. Social workers are skilled in counseling patients, parents, and siblings with issues of grief, anger, and overall well-being. They have a fundamental knowledge of pediatric hematology/oncology which provides them with the framework to support the family in comprehending the diagnosis and treatment plans, and, as important, the non-medical ramifications associated with the treatment of childhood cancer. The social workers, as well as other health care team members, assist the families in recognizing their role as partners in the care of their child and in recognizing the community support available to them. The utilization of this community support is crucial to the success of any treatment plan.

Child Life Therapist/Music Therapist

One of the greatest challenges of working with children is the ability to reach them at their developmental and cognitive level. The impact of play and music has been demonstrated to have a positive effect in the

treatment of childhood cancer. The Section of Hematology/Oncology is provided with two full-time child life therapists and a part-time music therapist. This talented group works with patients, parents, and siblings to aid in the adjustment and ongoing support associated with the diagnosis and treatment of childhood cancer and hematological disorders. Each of these therapists is master's prepared and assists family members and health care team members on effective strategies/interventions that allow patients to make choices and allow them a sense of self-expression. Medical play utilizing art, story telling, and music are important elements in effectively educating and preparing the pediatric patient for invasive and traumatic procedures utilizing age-appropriate measures. Sibling support is an important part of the day-to-day activities of these therapists, as well. The sibling can be instrumental in assisting the pediatric patient through the coping process. Both Child Life and Music therapists are available in the outpatient and inpatient areas and they are capable of continuing an intervention beyond the hospital admission. Our music therapist is currently participating in a NIH-funded research initiative to better define the impact of music therapy as an intervention in the bone marrow transplant patient.

Chaplaincy

One full-time chaplain is assigned to the Hematology/Oncology section to support the spiritual needs of the patients and their families and there is a chaplain available 24 hours a day to all patients. The diagnosis of Wilms' tumor can present significant religious/spiritual

questions for the patient and family which can lead to a crisis of faith as families try to sort out the questions and emotions that accompany a diagnosis of cancer. Personal faith and the faith of the community can be a tremendous source of hope and strength during this challenging time. In addition to supporting the patient and family, the chaplain is an integral part of the support system for the staff who, too, can struggle with spiritual/religious and ethical issues. Children's Mercy Hospital strives to support all religious affiliations.

Psychology

Children's Mercy Hospitals and Clinics believes that the physical and emotional aspects of a child's care are tightly connected, particularly when diagnosed with childhood cancer. A full-time psychologist supports the Hematology/Oncology section in providing support to the patient, parents, and siblings. This support ranges from strategies for coping with a new diagnosis to interventions to improve medication palatability/intake, which is extremely challenging in the pediatric patient population. This psychologist is a member of the Hematology/Oncology team and the section of Developmental and Behavioral Sciences at CMH. The Children's Mercy Cancer Center provides funding to support this position. The majority of psychological services are provided on an outpatient basis. The Developmental and Behavioral Sciences section supports the mentoring/education of psychology students, as well. Outpatient appointments are available by calling (816) 234-3674.

Nutrition Services

Nutrition and patient outcomes related to pediatric oncology have been linked closely over the years. Nutrition is an important component to aid in the prevention and correction of nutritional deficiencies, thus improving the overall well-being of the child undergoing the treatment of cancer. There is one full-time and one part-time registered dietician and a nutrition technician who support the section of Hematology/Oncology. This includes nutritional assessments, interventions, as well as participation in nutrition focused research/data collection. The nutrition service provides support in all service areas to include inpatient, outpatient, and home care.

Pharmacy

The decentralization of pharmacy to the patient care area demonstrates a strong multidisciplinary approach to patient care. The section of Hematology/Oncology is supported by two clinical pharmacists, one satellite pharmacist, and one pharmacy technician. Each of these staff is trained in the safe and proper handling of chemotherapy in accordance with current safety regulations. The pharmacy conducted a satisfaction survey with nursing staff which demonstrated improved satisfaction among nursing staff. In addition, medication error percentage rates continue to be below the national benchmark. This integration is closely linked to improved medication delivery/administration outcomes. This satellite is located on 4 Henson Tower and supports both the inpatient and outpatient service sites.



Nidia

Nidia is a carefree 12-year-old girl who loves to play basketball and go rollerblading. She also enjoys reading books.

Nidia has been a patient at Children's Mercy for almost a year while she received treatment for Wilms' tumor.

Nidia's mother noticed a bump on her daughter's stomach and took her right to a doctor to have it checked out. After being sent to Children's Mercy, Nidia went straight into surgery to have

the mass removed. She is now finished with her treatment.

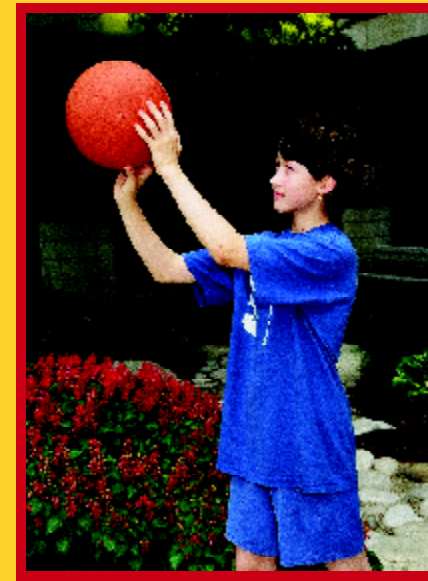
Nidia is very grateful that she was able to beat the disease.



"I feel very lucky that I could get better," says Nidia.

Nidia knows that she could not have made it through the ordeal without the help from her family and staff at Children's Mercy.

"I want to thank everybody," says Nidia. "Every doctor and nurse because without them, I would still be very sick."



Enhancements to Patient Care

Hand-washing Observations

Rationale

Following the movement to a new unit with private rooms the observations of staff was that health care providers were not as diligent about washing hands before and after direct patient contact. It appeared the clean/new unit added to less focus on hand-washing than the previous old unit. In addition, there were increased concerns addressed by parents regarding the inconsistency with hand-washing by health care workers.

Intervention

- Implemented a staff observation process to identify if there were certain health care providers that didn't wash their hands. The conclusion was there was a concern regarding all health care providers with regards to washing hands.
- Brightly colored signs were displayed throughout the unit to remind health care providers to wash their hands.
- "Cal-Stat" was initiated as an option for washing hands when soap/water method was not an the best option; i.e. timeliness. The ultimate goal was to ensure hands were cleansed in accordance with Infection Control guidelines.
- Incorporated parents/patients as the observers of hand-washing. There was limited involvement; i.e. parents didn't follow through. It did generate a sense that patients/parents were included in the process.

Outcome

- Monitor continued throughout the year with a consistent compliance rate of 95% or greater the last two quarters.
- Staff became more sensitive to washing their hands and observing others.
- Parent/Patient complaints/concerns decreased; i.e. none noted in the last six months.
- Will continue to monitor randomly in 2002 as this is a high risk area for our unit.

Fever and Neutropenia

Rationale

Fever and Neutropenia present a high risk to immunocompromised patients with high mortality/morbidity rates if delay in treatment. Clinical Practice Guidelines developed several years ago and "best practice" delivery of antibiotics identified the first 60 minutes as the critical time. "Best Practice" is based on literature and on-site experts. In addition, many of our patients receive their care in outside Emergency Rooms when they live > 1 hour away which presents challenges with inconsistency.

Intervention

- Fever and Neutropenia kit had been developed several years ago, but the inconsistency of the patients having this available and the outlying sites utilizing it was a concern. Thus, a revised kit was developed with clearer instructions on the recommended steps to take for a patient

with F&N and the use of the kit. Some sites feel uncomfortable using the kits and some use the "practice guidelines," but will not utilize the antibiotics. Most utilize the kit and antibiotics.

- A central line instruction video was created to assist in the education of patients/families and health care providers. It details the proper way to draw blood/cultures from a central line. A disclaimer was added to note that this video does not validate competence, but merely assists the care provider in the proper technique in working with a central line.
- Physician Liaison contacted to follow up with all incidents where an Emergency Room did not provide "best practice" care; i.e. antibiotics within 60 minutes or any delay in treatment.. A report was given back to the H/O Education Committee/section manager by liaison for each incident.
- Nurse manager or designee on 4HT calls the local ER, when applicable to prepare them for the potential needs of this patient in their area. The parents provided verbal consent before this was done and this is documented in the medical record "Progress Note."
- Periodic chart reviews conducted to see if practice matched closely the clinical practice guidelines.

Outcome

- Increased compliance with patients/families having F&N kits with them at home.

Enhancements to Patient Care

- Proactive approach with outlying Emergency Rooms with notification prior to discharge, thus improving the communication between CMH and these outlying hospitals.
- Michelle McMillan, Physician Liaison, followed up on all incidents where care fell below “best practice” standard as defined by section of Hematology/Oncology at CMH and supported in the literature.
- Discharge coordinator and staff communication increased regarding the criteria for patients having a F&N Kit. Just living > 1 hour away was not sufficient. Discharge coordinator would identify the availability of adequate medical services and the patient’s/family’s comprehension level, as well as other criteria applicable to that family to determine whether patient would come directly to CMH or go to local ER. This alleviated those patients that would not meet the criteria and improved compliance with coming directly to CMH. There are times where a patient would receive antibiotics much faster by driving two hours and avoiding the local ER. This is determined each time by the APN/MD on call and providing instructions to the parents; i.e. determining the clinical stability of the patient and selecting the optimal mode of transport and provision of care.
- Central Line video is given to new patients/families as a part of their “Family Notebook.”

Patient/Family Education

Rationale

This monitor was a continuation from 2000 with increased concern regarding the newly diagnosed oncology patient and the ability of any caregiver to comprehend the extent/complexity of information required. A “mock teaching session” was conducted by the APN group to demonstrate this complexity. There was also a recognition that the parents learn in a variety of ways and that we need to address this diversity. In addition, there continued to be a delay or lack of adequate documentation regarding the teaching that had occurred and that this teaching is a continuum that should flow from service sites.

Intervention

- Multidisciplinary Teaching Record put “on-line” to allow accessibility by multiple care sites; i.e. inpatient, outpatient, Home Care. Initial record included only MD/Nursing and other disciplines were added over time.
- “Know To Go” developed and implemented.
- “Essentials” developed and implemented.
- “Family Education Hour” developed and implemented.
- Periodic Chart Reviews to track compliance with “best practice” standard of teaching being initiated within 24 hours of new diagnosis or newly placed central line.
- Additional Care Cards/Medication Cards were developed.

- Central Line instructional video created.

Outcome

- Decreased incidents of patients/families not complying with guidelines; i.e. suspected knowledge deficit/emphasis regarding the “emergent” items.
- Increased participation in “Family Education Hour” over time with variety of topics from clinical items to Managed Care to “Coping with Stress.” Evaluations have demonstrated parent satisfaction with the program.
- Chart Reviews have begun to show a shift from the APN/Nurse Clinician being exclusively the ones to initiate teaching to the staff nurse being the initiator.
- In addition, increased documentation from other disciplines noted.
- “Essentials” given to each new oncology patient/family.
- “Know To Go” knowledge assessment being given by the staff nurse has improved; however, we continue to see some patients who do not have this noted in the documentation.
- Focus on patient/family education in each H/O Update.
- Will continue to conduct chart reviews quarterly throughout 2002 as this is a high risk area.

Enhancements to Patient Care

Conscious Sedation

Rationale

Sedation is a high risk procedure requiring advanced skills by the medical/nursing staff. In addition, the individuality of each child for the sedation needs requires that this aspect of our care be monitored closely for safe practice. CMH Policy and Procedure is intact and compliance with staff regarding that policy is imperative. Also important is the recognition that procedure activity has increased significantly in the H/O Clinic.

Intervention

- Conducted chart reviews on >95 % of all patients who had received conscious sedation in 2001.
- Provided education each month to staff regarding the areas of improvement noted from chart reviews.
- Collaboration with H/O nursing staff and Sedation Team nursing staff regarding the safe preparation/delivery of the sedation drugs; i.e. dilution versus Y connector with no dilution.
- Chart reviews reflected wide variation in MD practice for dosing.
- Quarterly reports from Sedation Service to H/O Section provided with follow up/ response, when applicable.

Outcome

- H/O Clinic: inconsistent compliance with documentation of pain assessment and discharge teaching noted throughout the year. 4HT inconsistent with documentation

regarding all areas of documentation. Observations/analysis did demonstrate that documentation does occur most of the time, but it does not get documented on Sedation Assessment Form. This is the goal! Poster presentation developed/ implemented collaboratively with H/O inpatient/outpatient nurses and Sedation Team nurses.

- Review of CMH Sedation Policy.
- MD "Peer Review" in 2002 regarding MD practices with conscious sedation.
- Endorsement of a revised policy on 4 HT regarding the preparation/administration of sedation drugs; i.e. Y connector with no dilution of medications. The observations/ analysis of this group was that the dilution was an added step which can lead to errors, thus the elimination of this step would allow for a more accurate delivery.
- "One dose per syringe" medication preparation implemented. This is defined as no more than a single dose can be drawn up in any syringe; i.e. multiple doses will NOT be drawn up in single syringe for titration.
- Pain Assessment chart reviews initiated in December which indicate 100% of chart reviews (n=30) had assessment completed upon admission to clinic.
- Continue to monitor closely in 2002.

Medication Safety

Rationale

The need to deliver/administer medications safely is a primary focus of all health care settings. In an environment where chemotherapy and narcotics are given routinely this becomes a stronger focus as these medications are high risk, high volume for a pediatric hematology/oncology inpatient/ outpatient setting.

Intervention

- Nurse manager/core charge nurses/section manager review medication events/trending each month at leadership meeting.
- Nurse manager/section manager participate in hospital-wide MEDS Committee to identify strategies for safe delivery/ administration.
- Implemented the "front sheet" MAR for new medications written within the previous 24 hours.
- Chemotherapy Task Force continues to review chemotherapy related medication events and develop guidelines to improve medication safety.
- Implemented "chemotherapy writing guidelines" for physicians, advanced practice nurses, and physician's assistants.

Outcome

- 0.088% medication error rate
- Decrease in chemotherapy related errors

Cancer Outreach/Education School Re-entry Program

Participants: Nurse, Social Worker, Child Life Therapist/Music Therapist

Goals/Objectives:

- Build connections between hospital, parents/child, and school.
- Identifies hospital personnel as a liaison to the school.
- Give school staff important information/allow them to ask questions to give them a better level of comfort in supporting/interfacing with the child.
- Peers “school mates” are given accurate information and are able to ask questions;

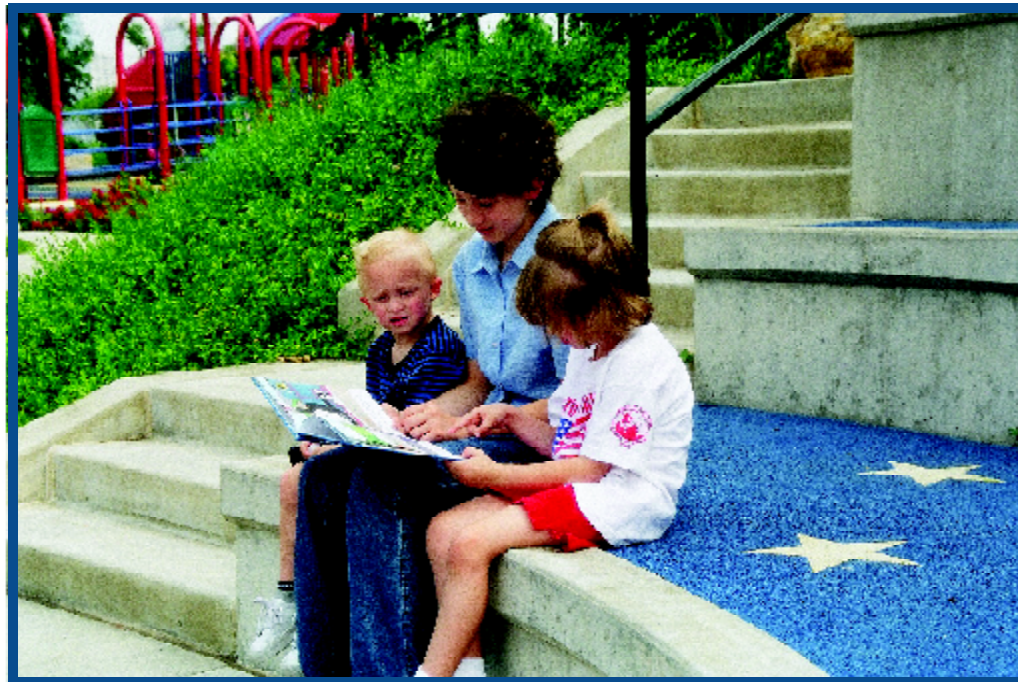
goal is to alleviate anxieties regarding cancer.

- Build a support system for the patient through peers which will decrease/alleviate teasing or other comments; diagnosis is out in the open.
- Provide an opportunity, if appropriate to that age group, for preventive education on smoking and sun exposure; i.e. adolescents.

Program Outline:

Common Fears

- Afraid to let go of child



- Child in the care of the school and trusting the school staff
- Afraid child may get teased, asked a lot of questions, and/or is unable to answer questions.

Child's Work

- School is your child's job
- Learn social skills
- Peer interactions, as well as, interaction with teachers/staff
- Learn success and failure, develop problem solving skills
- Academic environment
- Child can be a child and not a patient; school can be “normal” and a safe place

Evaluation

- Improved school attendance
- Effective communication between the school and the health care team.

Other Outreach/Educational Programs

- Children's Mercy Cancer Center Website, **www.childrens-mercy.org**
- “Family Education Hour”
- Caregiver Handbook
- New Diagnosis Information Packet
- The “Bear Program” for re-integration back into the school system
- The Parent-to-Parent Referral Program for new parents

SPONSOR/ STUDY NO.	STUDY NAME/ PROTOCOL
I991	ALL Treatment for Standard Risk
2961	Phase III Untreated AML or MDS
A2971	Study for patients with Downs syndrome and AML, MDS or TMD
AAML0122	Phase II using FTI, Cis-RA, Ara-C and Fludarabine plus HSCT for JMML
A3961	Neuroblastoma Intermediate Risk patients
A3973	Purged vs Unpurged PBSC for patients with HR NBL
P9641	Treatment for Low-Risk NBL patients
ANBL0032	Phase III study using ch14.18 antibody in high risk NBL following myeloablative tx & autologous SCR
ANBL00P2	Perinatal study: Observation study of NBL
4941L	NWTS Late Effects Study open for all patients 5 years or more s/p treatment
A5971	Treatment for Disseminated Lymphoblastic Lymphoma or Localized Lymphoblastic Lymphoma
AHOD00P1	Relapsed HD protocol
P9645	Hepatoblastoma Tx Protocol
AOST0121	Metastatic Osteo w Herceptin Tx
AEVS0031	Tx for Ewing's/PNET/Askin's of bone/soft tissue using chemo intensification thru interval compression
99701	High-risk CNS embryonal tumors
99703	Brain tumor protocol with PBSC rescue
A9952	Tx for progressive LGG in less than 10 y.o.
P9934	Brain tumor protocol for non-mets medulloblastoma
O923	Phase I Carboxypeptidase for Tx of MTX overdose
ADVL0011	Temazolamide & CCNU for non-brainstem HGG
ADVL0017	Phase I using Flavopiridol
ADVL0018	Ch 14.18 and IL-2 for NBL
ADVL0022	Gemcitabine for ALL

P9761	Phase 2 Irinotecan for Solid Tumors
P9962	IT Topotecan for Meningeal Malignancies
ADVL0022	Phase 2 using Gleevec for Relapsed Solid Tumors — open/active
AORST0121	Phase 2 using Irinotecan w/ VCR & Tirapazime for Relapsed or Progressive Rhabdo — open/active
PCT Lab	Cryopreservation of Autologous or Allogeneic PBSC
COBLT	Cord Blood Transplantation Study: Unrelated Donor Umbilical Cord Blood as an Alternative Source of Stem Cells for Transplantation
COBLT - EXPACC	Cord Blood Transplantation Study: Expanded Access Protocol
Minnesota MT 9501	Treatment of Lysosomal and Peroxisomal Inborn Errors of Metabolism by Unrelated Umbilical Cord Blood Transplantation Schering-Plough
P02095	Open-Label, Limited Access Protocol of Posaconazole for Invasive Fungal Infections (only open for one patient)
NMDP	Data Collection for Matched Unrelated Donor Peripheral Blood Stem cell Transplants for Children where donors were treated with Growth Factors and Harvested by NMDP Transplant Centers
MSK 01-055	A Pilot Trial of Hematopoietic Stem Cell Transplantation for the Treatment of Patients with Fanconi Anemia Lacking a Genotypically Identical Donor Using TBI, Cyclophosphamide and Fludarabine
CMH Protocol	Stem Cell Transplant Data Registries & Specimen Submissions (IBMTR, PBMTTC, NMDP, CRIR)
PBMTTC GVH0112	Cytokine Gene Polymorphisms in Pediatric Patients Receiving Tacrolimus or Cyclosporin for GVHD Prophylaxis
COG ASCT0031	COG Phase III Hydroxychloroquine for tx of GVHD
CMH Protocol	Use of Umbilical Cord Blood as a Source of Progenitor Cells for Myeloablative Therapy Rescue
PBMTTC #014	Cytokine Mobilized Allogeneic Peripheral Stem Cell Transplantation in Children – A Pediatric Blood and Marrow Transplant Consortium Study
Clinimac	Ex Vivo T-Cell Depletion (IDE 8598) for Graft vs Host Disease Prophylaxis in Related Haplo-Identical Allogeneic Stem Cell Transplant Recipients
Clinimac	Single Patient Exemption for Ex Vivo T-Cell Depletion for Graft vs Host Disease Prophylaxis in Related Haplo-Identical Allogeneic Stem Cell Transplant Recipients
•	Immune Tolerance Induction Study
•	Fibrogammin P for patients with Factor VIII deficiency
•	Hemophilia Growth and Development Study – 3

- Safety & Efficacy of Recombinant Factor VIII during Long-Term Prophylaxis/on demand treatment in Previously Untreated Patients (PUP's) with Hemophilia A
- Factor VIII testing Program in PUP's with Hemophilia A
- Severe Chronic Neutropenia Registry
- Universal Data and Serum Specimen Collection System for Hemophilia
- Franco American Registry
- STOP II
- Chlamydia infection as a Risk Factor for Cerebrovascular Disease in Sickle Cell Anemia
- Morbidity & Risk Factor for Subsequent Strokes in Children with SS Anemia
- Retro Chart Review of ACS in Patients with SCA
- Genetic Risk Factors for CVA in Children with HbSS
- Effects of Codeine Meta Enzyme Activity CYP2D6 in Sickle Cell Patients and Implications for Pain Management
- MOGIS
- SS transition of Adolescents to Young Adults
- Cathflo Activase(CAPS) Genentech
- PROCRIT Ortho Biotech
- Voriconazole Pfizer
- Urate Oxidase Sanofi Pharmacueticals
- Fentanyl Janssen Pharmacuetica
- Quality of Life among Childhood Leukemia Patients KBR
- Quality of Life with Sickle Disease Patients on Chronic Transfusion KBR
- Surviving Childhood Cancer: Implications for Career Development KBR

PENDING IRB APPROVALS

P9407 Infant ALL Treatment Study

ALTE02CI Late QOL & Effects of NBL Survivors (CCG-388I & 389I)

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CANCER CARE BOARD MEMBERS

Andrews, Walter, MD, Chief	Transplant Surgery
Barker, Gerry, RDH	Dentistry
Bartholomew, Joy, RN, CPON	Hematology/Oncology
Cain, Jill, LAASW, MSW	Hematology/Oncology
Cooley, Linda, MD, Director	Cytogenetics Laboratory
Corse, Cindy, CTR	Medical Records
Covitz Hardy, Lynne, PhD, Clinical Psychologist	Developmental & Behavioral Sciences
Cox, Karen, RN, PhD, Senior Vice President, Patient Care Services	Nursing Administration
Devorin, Barb, RN, MSN, PNP	Neurosurgery
Emami, Abbas, MD	Hematology/Oncology
Fournier, Julie, RN, Charge Nurse II	Hematology/Oncology-Clinic
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Contributors: Linda Cooley, MD ~ George W. Holcomb, III, MD ~ Karen Lewing, MD ~ David Zwick, MD

Editors: Telisa Hassen, co-editor and designer ~ C.J. Hutto, RN, co-editor ~ Erin McLarney, Patient Biographies

Photos: Merrilee of The Cherished Child

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