CHILDREN'S HOSPITAL

The Cancer Program and the LaNasa-Greco Center for Cancer and Blood Disorders

annual report

2008 ANNUAL REPORT
2007 STATISTICS
WEB VERSION

About Children's Hospital

Children's Hospital began as a dream in the minds of a group of very special community leaders about a decade before the hospital became a reality. In the years following World War II, a poliomyelitis epidemic attacked thousands of children, leaving many handicapped. Concerns about these children led the late Elizabeth Miller Robin, a polio victim herself, to establish a rehabilitation hospital for children. The facility opened in 1955.

What makes the hospital unique is the combination of the latest developments in medical treatment and an atmosphere of love and concern for the whole child. Throughout its history, Children's Hospital has served as a teaching facility where faculty from the Louisiana State University Health Sciences Center forms a strong pediatric teaching program. In 1976, Children's Hospital was expanded to become a full-service general pediatric hospital. It has since expanded continually to meet the growing health care needs of our community.

Children's Hospital is a 218-bed, not-for-profit regional medical center offering the most advanced pediatric care. It cares for children from birth to 21 years in more than 40 specialties, including life-threatening illnesses, routine childhood sicknesses and preventive care.

For more information about Children's Hospital, call (504) 899-9511 or visit our Web site at www.chnola.org.

AFFILIATIONS AND ACCREDITATIONS

Children's Hospital, New Orleans is affiliated, accredited or supported by the following local and national organizations:

ACCREDITATION

American Academy of Pediatrics
American College of Surgeons (ACoS) Commission on Cancer
Joint Commission on Accreditation of Healthcare Organizations (JCAHO)
National Marrow Donor Program

MEMBERSHIP

Child Health Corporation of America
Children's Oncology Group (COG)
Louisiana Hospital Association
National Association of Children's Hospitals & Related Institutions, Inc. (NACHRI)
Metropolitan Hospital Council of New Orleans

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The Cancer Program and The LaNasa-Greco Center for Cancer and Blood Disorders

Table of Contents

Chairman's Report

Renée V. Gardner, MD

After a continuous process of self-assessment, we believe that we have a solid program offering excellent, state-of-the-art care to the children of Louisiana and the Gulf coast. We, during the year 2007 – 2008, have focused our attention on implementing improvements, not only in our response to natural disaster but also in the continuum of care, presenting to all the current standards of care. As a part of the Minority Community Clinical Oncology Program (CCOP), we with our colleagues in Medical Oncology, Surgery, and Radiation Oncology, offer an opportunity to the community to participate in the latest clinical trials and to take advantage of the newest, most innovative technical advances and scientific research extant in the world. We continued our interactions with the bench researchers in an effort to translate such advances to the bedside.

In our effort to bring about improvements in patient care, we worked assiduously with the Emergency Department to improve the timeliness of the response of our physicians to children having oncologic disorders and presenting with fever. As a result, physicians at Children's Hospital have an even more heightened awareness of fever as a medical emergency. We can now say that oncology patients with febrile illness are treated with an appropriate sense of urgency and even more rapidly than previously. We also worked with the Child Health Corporation of America (CHCA) Collaborative to ensure that every effort was being made to monitor and decrease the rate of central line infections in our oncology patients. We are pleased to report that our efforts were successful with our rate of nosocomial line infections being brought below the national average. These are just two of many projects initiated with an aim towards optimizing healthcare delivered at Children's Hospital.

We have continued to work closely with a number of organizations in alliances which permit us to find and offer to our families and patients resources that can ease the difficult road to cure. One such program which we delight in is the SMILE program of the American Cancer Society. In this program, first and second year medical students from Louisiana State University Health Sciences Center (LSUHSC) are encouraged to form close and durable relationships with children with cancer. Our children have loved their "buddies" and the relationships have endured for years after the child's completion of cancer therapy.

The collaborative relationships we have forged have allowed us to direct our

patients to lodgings (at Hope Lodge, accomodations provided by ACS; and the Ronald McDonald House), transportation and supplemental financial assistance.

As a result of our efforts, we have gained approval from the American College of Surgeons Commission on Cancer (ACoS, CoC), which came to survey our program in February 2007. The survey was successful and the cancer program is approved through the year 2010. We are one of a handful of pediatric programs in the country to have received such recognition, meeting standards approved by ACoS for the care of children with cancer. Our efforts at improving our program, especially our response to natural disaster were recognized when Dr. Gardner was asked to speak at an ACoS-sponsored Workshop in the summer of 2007 in Chicago. We have also made certain outreach efforts to the community. Our physicians have educated the community at large on a wide variety of topics, using television and radio. Educational fora have centered around local and national authorities such as Dr. David Jacobson, who spoke on graft-vs-host disease, and Dr. Patricia Braly, who presented a Rehab conference at Children's Hospital on breast cancer awareness and screening.

New members on the Cancer Committee included Dr. Maurice Sholas, a certified phsyiatrist who offered comprehensive Rehabilitation services to our patients, and Ms. Amy Lee, a Child Life specialist who has initiated some very innovative programs for our patients. One such program, greatly enjoyed by our children, is the Beads of Bravery program which gives all newly diagnosed patients a necklace, each bead allowing them to tell of their individual fight against cancer.

All we have done, all we do is with a single-minded purpose: giving our kids the very best.

Cancer Committee

The mission of the Cancer Committee of Children's Hospital is to monitor the care given to children with cancer and implement those ideas that will lead to improvement in that care. Since 1989, the Cancer Committee has acted under the aegis of the American College of Surgeons, Commission on Cancer (ACoS, CoC), using guidelines established by them for pediatric cancer centers in the United States. We remain an approved pediatric cancer referral center. We formally became the Center for Cancer and Blood Disorders in 2002 and have offered, in that capacity, up-to-date treatment protocols and clinical trials which provide patients with the opportunity to take advantage of the most advanced and current therapies. It also affords them the opportunity to learn of new advances as soon as they emerge.

The Cancer Committee is comprised of professionals who render care to children with cancer. Together, they embody the multidisciplinary concept of cancer treatment, i.e., taking a unified but comprehensive approach to care or "treating mind, body and soul." As pediatric hematologists/oncologists, pediatric neurosurgeons, urologic and orthopedic surgeons, radiation oncologists, pediatric radiologists and pathologists, these professionals combine their specific outlooks to view the patient as a whole and offer suggestions and plans to improve care. Child psychiatrists, psychologists, social workers, play therapists, non-denominational pastoral workers and rehabilitation specialists also bring to the table their unique outlooks on the support of these children.

This past year, we also worked closely with organizations such as the American Cancer Society and Leukemia/Lymphoma Society. Such connections have helped us to better reach out to the community at large and initiate programs for cancer prevention and education. They have also helped us better assist families in resettling into the post-Katrina environment with its attendant stresses and exigencies. Examples of joint efforts by the Hematology/Oncology Division and these organizations have included lodging of our patients at the American Cancer Society's Hope Lodge, the provision of a grant that provides transportation vouchers for needy parents and the Smile Program. The Smile Program is an endeavor which remains dear to our hearts; it was developed by the American Cancer Society, and is designed to enable the establishment of Big Brother/Sister-like relationships between our patients, especially those with cancer, and medical students at the Louisiana State University Health Sciences Center (LSUHSC). Such relationships have lasted, at times, beyond the tenure of the students at the medical schools; life-long bonds have been forged which sustain our children for years afterwards.

We also have been able to variably call upon the services of anesthesiology, pharmacy, cardiology, ophthalmology, nursing and laboratory services to ensure greater quality control. Nursing staff has provided special insight into the problems that sometimes develop on the unit. They have been instrumental in carrying out some key projects on patient satisfaction,

infection control and analgesic administration that have allowed us to come up with creative solutions to problems seen in patient care.

The Cancer Committee also oversees clinical research activities, both those associated with our hospital and those carried out through our affiliation with the Children's Oncology Group (COG), of which we have been a member institution since 1987. COG is a national, collaborative pediatric cancer research organization, sponsored by the National Cancer Institute at the National Institutes of Health (NCI, NIH). Over 90 percent of children who are diagnosed with cancer in the United States, Canada and other countries throughout the world are enrolled in protocols for therapeutic, cancer control, epidemiology or biology trials through COG. It is our stance that a high percentage of our patients should participate in such trials in order to advance our knowledge of childhood cancer and to provide the patients with the latest advances in treatment and knowledge about the process of their diseases. It is acknowledged that clinical trial participation has been associated with improved survival overall after diagnosis of cancer.

We regularly have residents, fellows and other allied health specialists in attendance at our meetings. This provides an opportunity to educate them regarding the interactions and intricacies involved in care of children with cancer and other blood disorders. Children's Hospital is closely affiliated with LSUHSC and is one of its major teaching hospitals, providing high-quality education to all these individuals. The environment provided by Children's Hospital has likely influenced the career choices of the LSUHSC medical students who, in high proportion, elect to pursue a pediatric or med/peds residency. Education, in general, remains an essential goal at Children's Hospital, with the Cancer Committee recently incorporating programs on cancer prevention trials such as the FreshStart program, a comprehensive approach to the cessation of smoking during pregnancy and after delivery. We are involved in providing information to the families of children in Louisiana through our Web site, addressing their concerns about environmental and toxic hazards that might be encountered upon their return to New Orleans and its environs.

We hope that this annual report of the Children's Hospital Cancer Committee will provide you with information about the oncology and hematology services available at Children's Hospital. Further information can be obtained by calling the Division of Hematology/Oncology at (504) 896-9740.

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Survey of Knowledge and Attitudes towards Human Papillomavirus Vaccine for Adolescents and Teens

Sarah Dendy, Caneita Creighton, Maria C. Velez, MD, and Renée V. Gardner, MD

INTRODUCTION

It is estimated that in the United States, there will be 11,070 cases of invasive cervical cancer with 3,870 deaths in the year 2008. Although multiple risk factors exist, such as smoking, compromised immunity and nutritional factors, the primary cause of cervical cancer is known to be infection with human papillomavirus (HPV) [1]. HPV is a sexually transmitted disease that is very common. In 2006, the US Food and Drug Administration approved Gardasil® (Merck and Co., Inc., Whitehouse Station, New Jersey, USA), a quadrivalent vaccine protecting against HPV types 6, 11, 16 and 18. Types 16 and 18 are two of the 15 oncogenic HPV types and account for 77 percent of cervical cancer cases in the United States. Types 6 and 11 are responsible for about 90 percent of anogenital wart cases [2].

The success of any vaccination program for specific pathogens, however, centers around the public's recognition of the risks or dangers of the infection and awareness and acceptance of the vaccine program. Four prior studies have examined attitudes that are prevalent in four different countries and the knowledge held by their populaces regarding HPV. In those studies, 15 to 75 percent of individuals had prior knowledge of HPV [3-6]. In one survey of university students, 60 percent had heard about HPV through media. Only 39 percent received information about the virus from a healthcare provider [4]. In another study performed in Canada, 89 percent of women questioned stated that they would recommend the vaccine to their daughters or nieces. The figure rose to 91 percent if the vaccine were to be offered free of charge; the number of women who would recommend the vaccine's use also rose if the vaccine were recommended by a physician [5]. Other factors influencing vaccine acceptance included concern about vaccine safety, side effects, earlier onset of sexual activity and a belief that vaccination against STDs would promote promiscuity. A Dutch study found that greater knowledge of HPV correlated with higher levels of education, but also found that vaccine acceptance was not related to knowledge of HPV, age, religion or education [6]. These findings were consistent with another study in which education and job status were found to have no significant impact on vaccine acceptance [7].

Although it appears to be a natural presumption that physicians would be the primary resource for dissemination of education regarding HPV and the vaccine, one survey of physicians in New Mexico found that physicians are generally not comfortable bringing up the subject of HPV and sexuality with their patient population [8]. The most commonly cited reasons for the failure of the physician to discuss the topic were: complexity of HPV counseling, discomfort due to lack of knowledge about HPV, and time constraints. Some physicians expressed hesitation because of the conservative nature of their communities and resistance from parents to the topic of STDs. It is clear from all these reports that knowledge of HPV and the vaccine needs to be improved.

FIGURE 1. KNOWLEDGE OF VACCINE

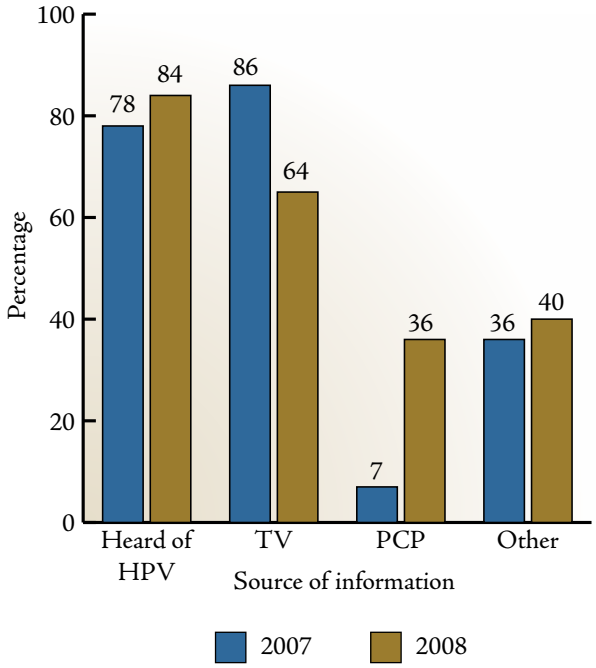


FIGURE 2. ACCEPTANCE OF VACCINE

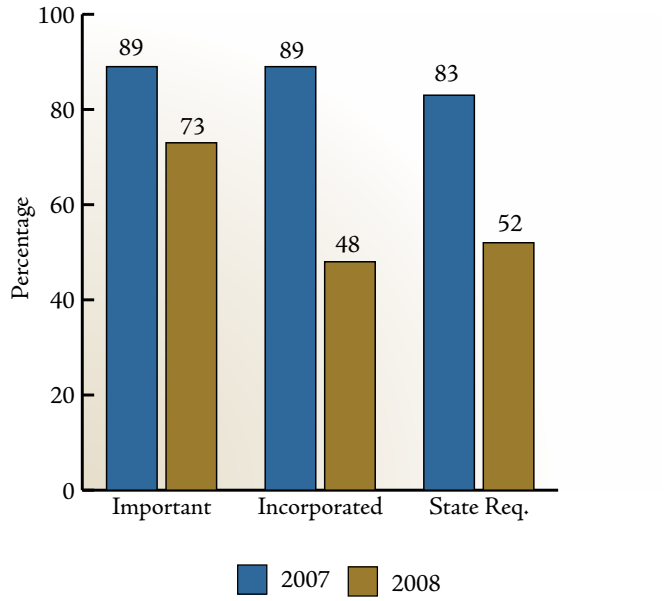
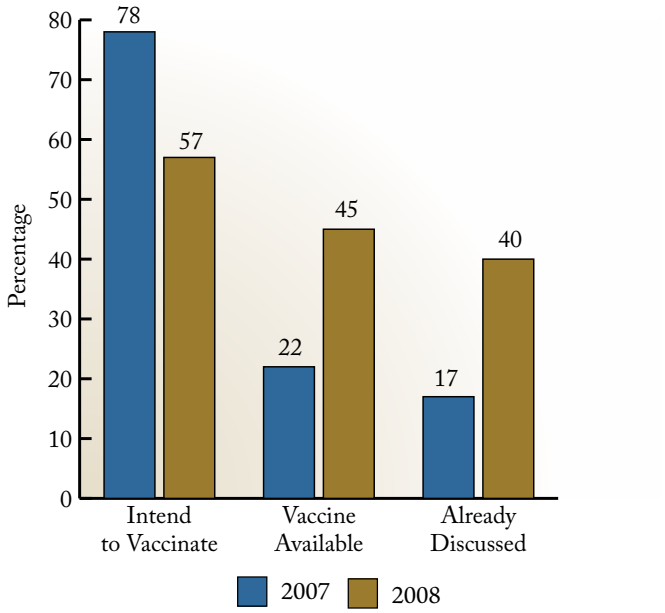


FIGURE 3. INTENT TO VACCINATE



The objectives of this project were to assess knowledge about HPV, to probe the source of knowledge, and to ascertain the acceptance of HPV vaccine for adolescent girls among our patient population followed at the Children's Hospital of New Orleans Hematology/Oncology clinic. We also wished to learn what measures might need to be taken to improve educational efforts by us and physicians in the general community. Our aim was to heighten awareness of HPV, and improve acceptance of the vaccination effort, not only for the patients and their parents but also for physicians in the community.

MATERIALS AND METHODS

All data was collected over a seven-week period in the Hematology/Oncology clinic at Children's Hospital in New Orleans. A 16- question survey was developed in order to assess knowledge, education and acceptance of HPV and the HPV vaccine. Girls ages eight to 22 years were targeted. Parents of younger girls and female patients who were ages 14 and older were asked to complete the survey. All surveys were conducted face to face. A second survey was developed to determine physicians' views on HPV and the vaccine. The nine question survey was e-mailed or mailed to over 1000 Louisiana pediatricians. Eighty-three physician surveys were returned.

RESULTS

Fifty subjects were surveyed over a 2-year period (2007-2008). The minimum age of patients was 8 years , the maximum was 22 years (mean 14.6 years, median 14 years). Fifty-eight percent of the patients were African-American, 28 percent were Caucasian, 6 percent Hispanic, and 8 percent other. Of those surveyed, 84 percent had heard of HPV. Their sources of "first" information were TV (54 percent), primary care physician (30 percent), and other (34 percent). "Other" included magazines, newspapers, family, friends, school and job. Of those who had heard of HPV, 45 percent felt they were well-educated about the virus and/or the vaccine. Their sources of education were TV (n=6), primary care physician (n=15), and other (n=11). The subjects were given a multiple choice questionnaire to determine their actual knowledge. When asked what HPV infection causes (e.g., genital warts, cervical cancer, STDs, or all of the above), however, only 35 percent answered correctly ("All of the above"). Over half of the respondents thought HPV was only linked to cervical cancer.

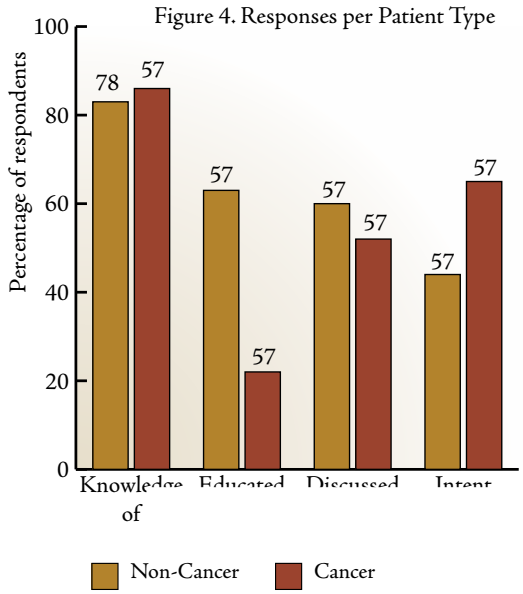
Of the subjects interviewed, 73 percent felt that the vaccine was important but only 48 percent thought it should be incorporated into the typical vaccine schedule. Another 41.6 percent responded that they were "Not sure" about whether the vaccine should be a part of the scheduled vaccinations. Common reasons for why it should not be incorporated included: insufficient information about the vaccine, concern over possible side effects, and resistance to the concept of compulsory vaccinations. Fifty-two percent of the respondents felt

that the state should require all girls to get vaccinated, while 41 percent were unsure of the appropriateness of universal immunization. Subjects were asked if the vaccine was available at their physicians' office. Only 22 percent responded "yes"; another 53 percent were not certain. Nineteen percent of those interviewed have discussed HPV and the vaccine with their physician.

We noted that over the two-year period, there were distinct changes in the patterns of information dissemination. From 2007 to 2008, the percentage of those who had been informed of HPV by their primary care physician quintupled (from 7 percent to 36 percent); correspondingly, the number of individuals for whom television was a primary source of information fell from 86 percent to 64 percent. However, more disturbing is a trend that became apparent with continued surveys: the number of those surveyed who felt that the vaccine was important, should be incorporated into a routine vaccination schedule, and should be mandated by the state health departments decreased. For instance, the percentage of those who felt that the vaccine should be made a requirement fell from 83 percent to 52 percent, over the year. More alarming was the decline in those who expressed an intention to either receive or have their child receive the vaccine. Within the year, that number had decreased from 78 percent to 57 percent. All of the reasons for this reluctance to proceed with vaccination are not clear but one concern expressed was the perception of the vaccine as being unsafe, after adverse publicity about the vaccine and potential side effects was noted. One statement often heard was that more time needed to elapse during which the vaccine's safety could be studied further.

Of the 80 physicians for whom surveys were available, 98 percent of the physicians had the vaccine available at their office. Ninety-five percent stated that they always or often educated their patients about HPV and the vaccine, with 5 percent performing education sometimes or rarely. The two reasons for the physicians' not educating the patients about this issue were time constraints and a desire for the patients to express interest in the subject first. The physicians were asked what percentage of their patients asked about HPV and vaccine. The majority responded that less than 50 percent of patients requested information about the virus or vaccination. On a scale of 1 - 10, 10 indicating the highest importance, the average rating for importance relegated to the vaccine was 8.08. Most (91 percent) of the physicians believed that the vaccine should be incorporated into the typical vaccine schedule. When queried at which age the vaccine should be administered, 47 percent said children ages 10 - 12 years should be vaccinated, while 24 percent said between ages 12 - 14 years, and 24 percent said "As Recommended".

FIGURE 4. RESPONSES PER PATIENT TYPE



DISCUSSION

In our survey, 84 percent had heard of HPV, a number that compares favorably with those cited in the literature of 15 percent to 75 percent [3, 6]. Television was the number one source of initial information about HPV; this is consistent with other published reports [4]. Over the study period, the number of patients reporting having received information from their primary care physician has risen. This is encouraging since while the awareness of the vaccine is relatively high, obvious misinformation or incomplete information was evident, since correct or even comprehensive knowledge of the virus' effects and the vaccine is not apparent from our multiple choice questionnaire.

Unfortunately, only slightly more than half of the participants intend to get the vaccine for either themselves or their child. There is a considerable amount of anxiety, uncertainty, or reluctance expressed about having the vaccine administered. This reluctance reflects a lack of information or publicity that is negative and concerns about possible adverse reactions. A significant number of individuals had not spoken with their physician at length about the vaccine or HPV. Yet, almost a significant proportion of physicians averred that they always educate

their patients. This discrepancy may result from the fact that our physician respondents are self-selected. That is, physicians who do not educate their patients or who do not have the vaccine available, for instance, may be less likely to return the survey. The small sample size then may not be representative of the medical community at large.

Our sample size is small and limited in area. Also, because the patients and parents were already in a hospital setting, they may have been more receptive to the idea of cancer prevention. We looked at those respondents carrying cancer diagnoses and compared their responses with those having benign diagnoses. Those individuals with cancer diagnoses were less likely to have received any education regarding HPV or vaccine (22 percent vs 63 percent for non-cancer diagnoses for education re. HPV). However, they were more likely (65 percent vs 44 percent non-cancer) to agree that states should require the vaccine. These differences suggest greater receptivity to cancer prevention techniques due to greater sensitization to the issue among this patient population. Clearly, better effort needs to be made to educate our patient population and there is a need for oncologists to be in the forefront of getting this information out.

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Medulloblastoma Variants: Spectrum and Survival at Children's Hospital

Dane Sandquist, MD. Joe Nadell, MD, Randall Craver, MD

INTRODUCTION

Medulloblastomas are primitive embryonal tumors arising in the cerebellum, most often in the midline and in the first two decades of life. With radiation and chemotherapy, five-year survival is in the range of 60 - 70 percent.[1,2] Children less than 3 years of age at diagnosis tend to do poorly, mainly because the devastating effects of radiation in this age group limits it use. Other high-risk features include metastases at the time of diagnosis, and those with demonstrable residual tumor after resection. Here the survival is in the range of 25 percent.[3]

In recent years, different histologic variants of medulloblastoma have been recognized by the World Health Organization (WHO). These include the classic (NOS)(~80 percent), desmoplastic (DES)(~15 percent), excessive nodularity (EN), anaplastic (ANA) and large cell (LC) (~4 percent).[1,2,3] The EN variants arise in younger children, often infants, and have a much more favorable course in general, especially in the light that survival in children diagnosed before three years is less than older children.[4] The survival of DES reportedly may be better than NOS; however this has not been consistently demonstrated in the literature.[1,2,5,6] The histologic definition of DES has changed over the years, and in the past may have included EN variants. LC and ANA frequently are grouped together, as both tend to behave more aggressively.[1,2,5,6]

We reviewed our 25 year experience with diagnosing and treating medulloblastomas at Children's Hospital, with the objective of determining the spectrum and frequency of variants encountered, determining the overall cumulative survival of all our medulloblastoma patients, compare the survival of different variants in our population and compare the survival in different age groups. We will also compare our overall cumulative survival to the literature.

MATERIAL AND METHODS.

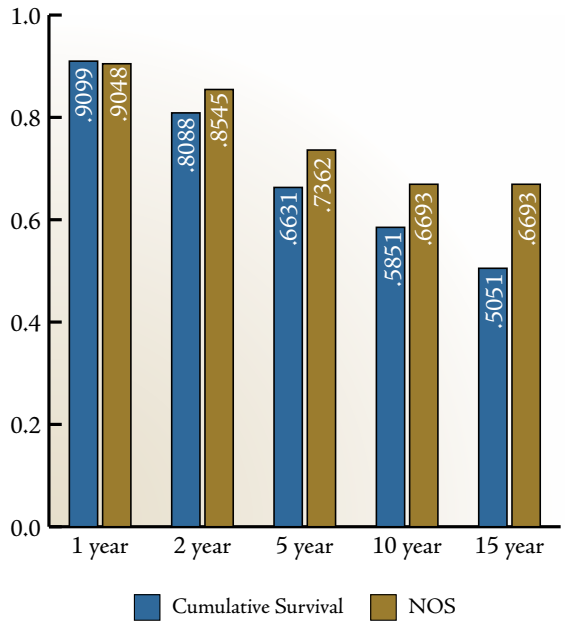
From the tumor registry at Children's Hospital, we obtained patients who were diagnosed, treated and followed at Children's Hospital. All slides were reviewed and classified as to variant based on the WHO criteria. The histology from the first resection, before treatment, was used for classification. Follow-up was provided by the tumor registry. Cumulative survival statistics were obtained using the Kaplan-Meier method.

RESULTS

Forty-three children were identified with medulloblastoma, slides were available for review in 35, follow-up was available in 34. The eight other individuals were either diagnosed elsewhere, and/or the slides were unavailable for review. The ages at diagnosis ranged from 13 months to 17 years, the average age was 6.2 years. Nineteen were male and 16 female. Table 1 is the cumulative survival of the entire group of 34, and is compared to the survival of the NOS variants. Table 2 is the cumulative survival data on the children under 3 and 3 or older at diagnosis.

All of the different variants were identified in our group of children. NOS was the most frequent variant with 22 (63 percent-average age 6.2 years), followed by ANA 5 (14 percent-average age 6.4), DES 4, (11%- average age 7.5), EN 3 (9 percent-average age 2), and LC 1 (3 percent-age 13).

TABLE 1. SURVIVAL



Eight children (4 NOS, 2 ANA, 2 EN) were under 3 at diagnosis. Four died within two years. The two with follow-up more than two years have survived 17 (NOS) and 19 (EN) years. Twenty-seven children were 3 or older at diagnosis. Variants included 18 NOS, three ANA, four DES, one EN (4 years at diagnosis), and one LC. One child

with ANA was lost to follow-up soon after diagnosis. Two deaths occurred between five and 10 years (NOS and DES, both at 8 years), and one recurred and died at 14 years (DES). All four with DES died, two with late recurrences (eight and 14 years). Two EN have survived 19 years (diagnosed at one) and 17 years (diagnosed at four). Two of five ANAs were under 3 at diagnosis. None of the four DES was less than 3 at diagnosis. The one LC is alive at 18. No second malignancies have occurred.

DISCUSSION

The cumulative five-year survival was .6631, which is comparable to the average stated in the literature of 60-70 percent. However, the 10- and 15-year cumulative survivals continue to decline from .5851 to .5051, and these deaths were due to late recurrences.

NOS variant was the most frequent variant, with a cumulative survival at five years of .7362, slightly better that the overall five-year cumulative survival.

None of our four patients with DES survived, with two of four deaths occurring after five years (eight and 14 years). The poorer outcome in this subset is discordant with what is cited in the literature, which is split between either an improved or similar prognosis. This may reflect the change in histologic criteria.

Our data supports that EN carries a good prognosis, with no deaths. Two were diagnosed at 1 (survival follow-up of one and 19 years), the other at four (survival follow-up of 17 years) This may represent a less biologically aggressive tumor combined with perhaps a more easily resectable tumor, as all were totally resected. Only the older child, 4 at diagnosis, received radiation.

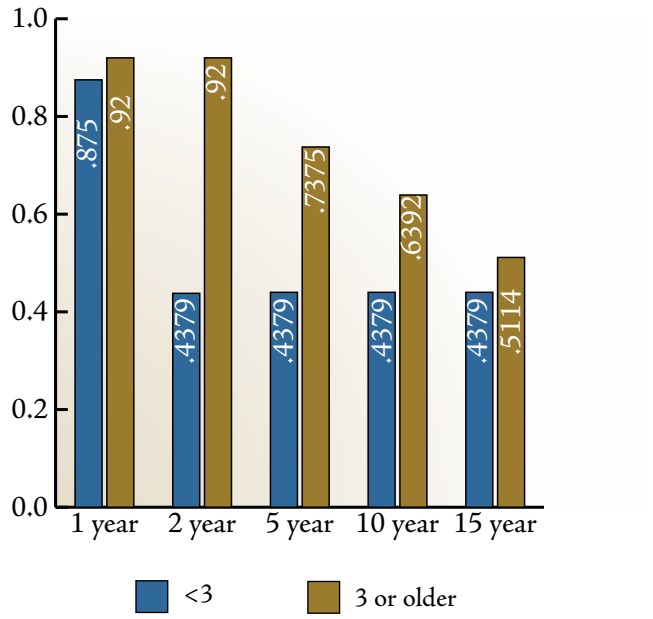
Of the four ANAs with follow-up, one died, but the others are recent without five years of follow-up. LC is often grouped with ANAs and may carry an unfavorable prognosis. Our one case is alive at 18.

Those less than 3 at diagnosis continue to do poorly, with most deaths within two years, unless the variant is EN. The only patient that is still alive without the EN variant in this group is a child with ANA, who is alive at 2.

So far, none of our survivors have developed a second malignancy. Radiation and chemotherapy may contribute to the development of secondary malignancies. Alternately, whatever genetic predisposition that led to the original medulloblastoma may also predispose to subsequent malignancies, or work in concert with the radiation and/or chemotherapy to contribute to the development of a secondary malignancy.

Our overall five-year survival is similar to that reported in the literature. The late recurrences (less than five) are responsible for the continued decline in survival statistics. Continued long term follow-up of these children, even into adulthood, is required to see what other problems (late recurrences, second malignancies) these survivors may face.

TABLE 2. SUMULATIVE SURVIVAL — AGE



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Medulloblastoma Variants

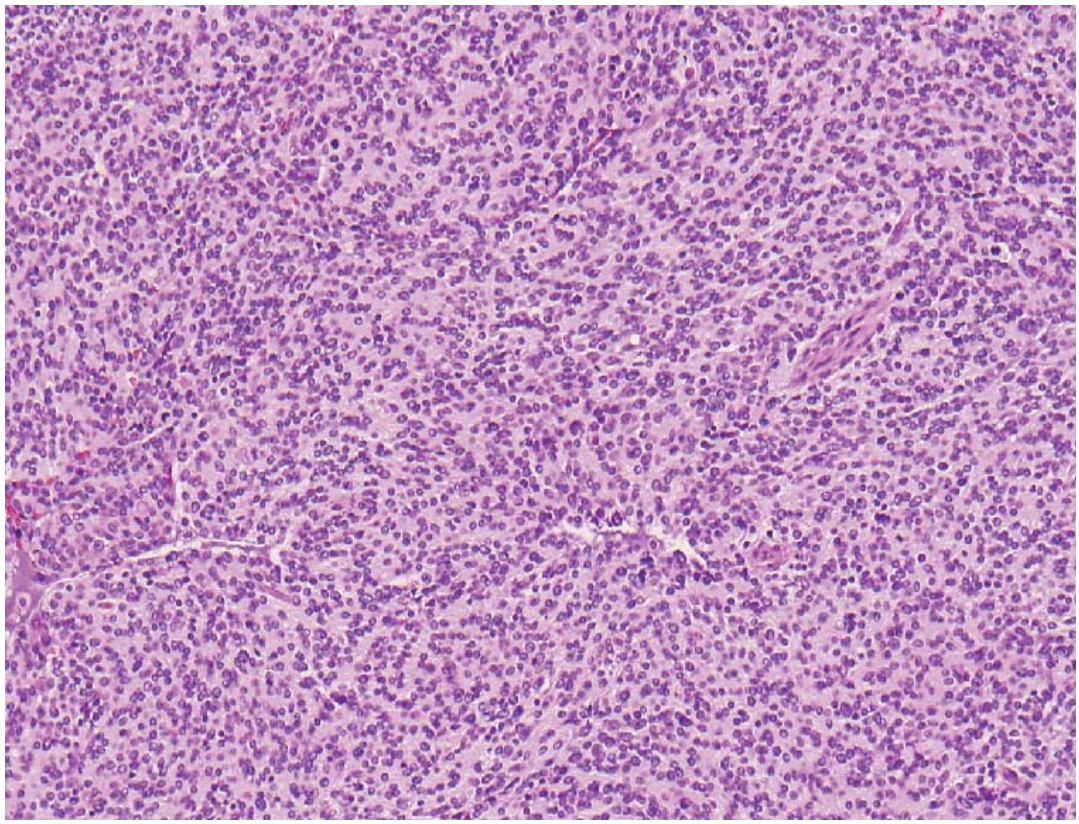
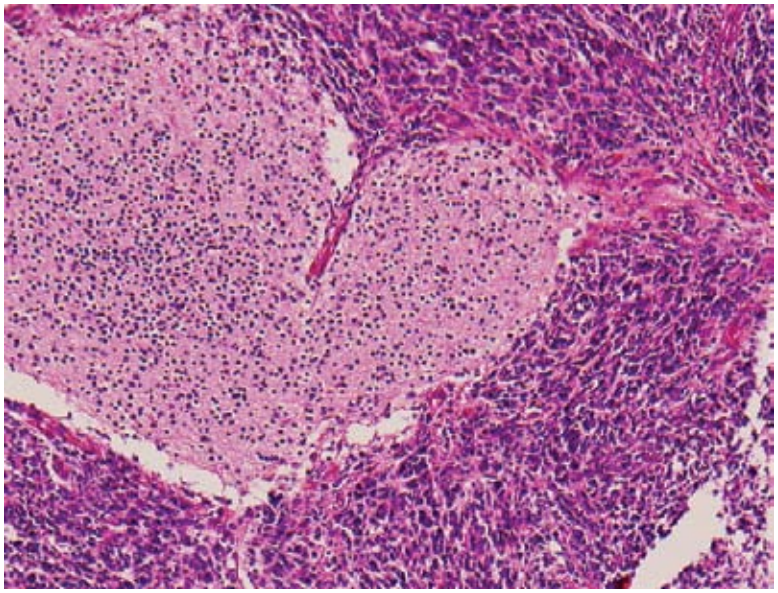


FIGURE 1
Classic medulloblastoma with sheets of small cells with minimal differentiation (Hematoxylin and eosin, 100X)



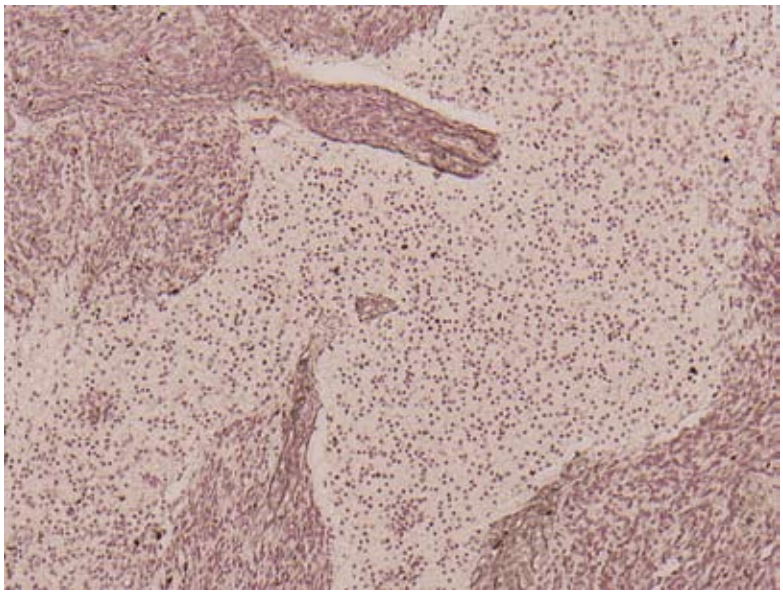


FIGURE 2 A & B
Desmoplastic medulloblastoma. a) distinct nodules containing neurophil surrounded by b). reticulum rich spindled cells (a. Hematoxylin and eosin, 100X b. reticulum, 100X).

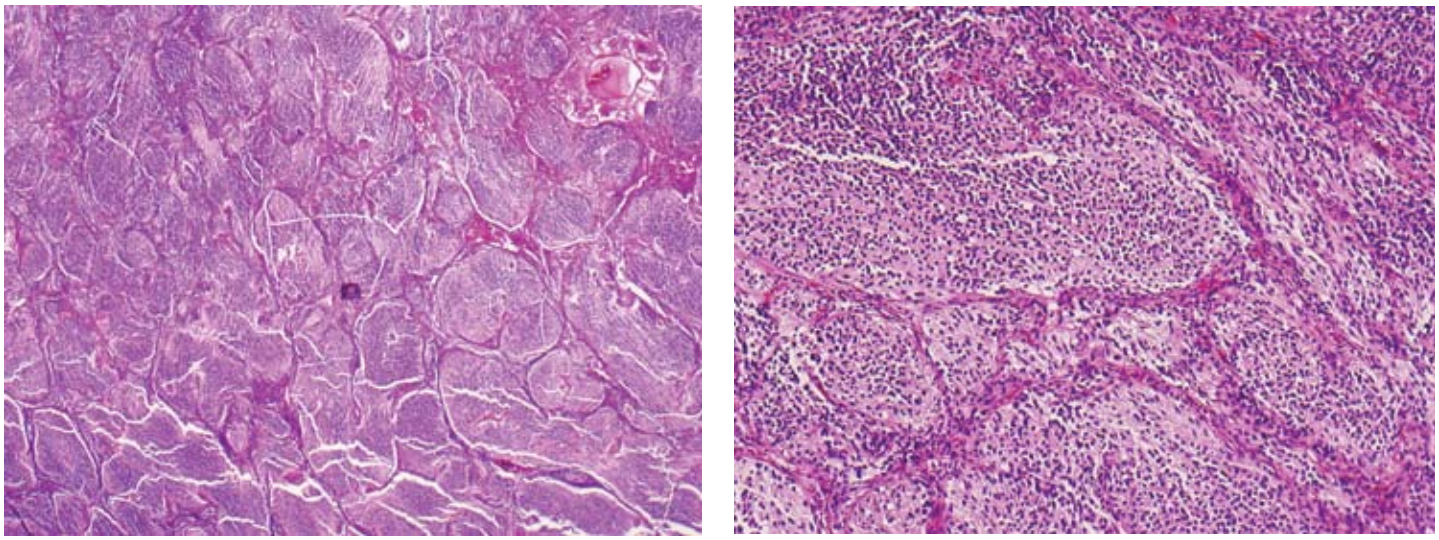


FIGURE 3A & B

Medulloblastoma with excessive nodularity. a) low and b) higher power views. The tumor is extensively nodular with a small amount of intervening spindled stroma separating nodules characterized by neuronal differentiation and neurophil (Hematoxylin and eosin, a-20X, b-100X).

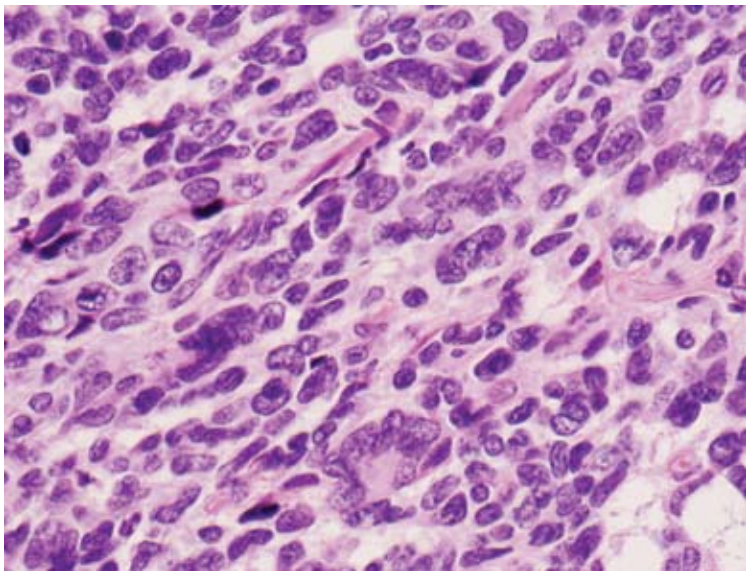


FIGURE 4

Anaplastic medulloblastoma. The nuclei are markedly pleomorphic and hyperchromatic (Hematoxylin and eosin, 100X).

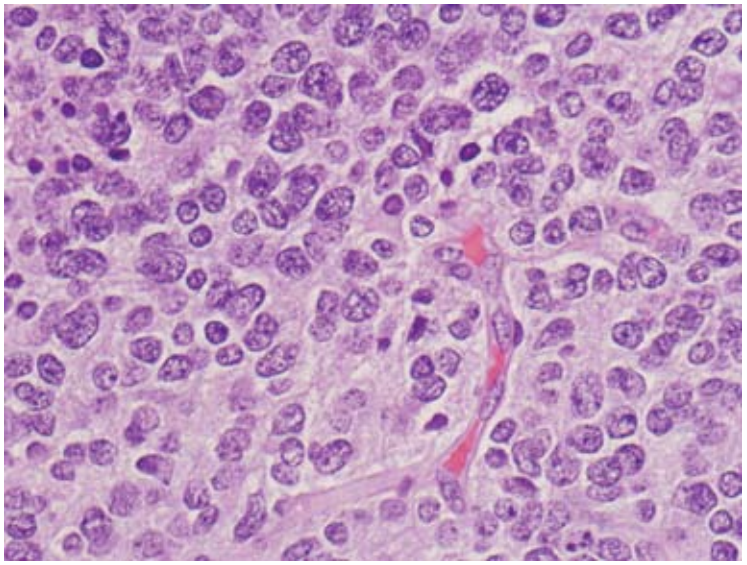


FIGURE 5

Large cell medulloblastoma. The cells are enlarged, yet they are uniform in size and shape (Hematoxylin and eosin, 100X).

Support Services

SOCIAL SERVICES

Despite the milestones that have been made in the treatment of pediatric cancer, it remains a devastating diagnosis that affects not only the patient but the entire family. Social workers at Children's Hospital are highly trained to assist families dealing with the diagnosis of cancer. They provide emotional support to the families; guide them through the maze of financial obligations, directing them to the most appropriate sources of monetary assistance for the child's medical care; indicate transportation services that might be used during treatment; and help them find temporary housing while here in New Orleans, when this is suitable. They are present during the initial parent-physician conference, offering emotional or psychological buttressing in a time of extreme anxiety. Through individual and group counseling, the social workers help patients and families identify their concerns, consider effective solutions, and better cope with the child's illness.

PSYCHOLOGY

The Psychology Department provides comprehensive evaluation and management of the emotional and behavioral disorders stemming from the diagnosis of cancer. The psychologists work closely with the hematology/oncology physicians and social workers to ensure the maintenance of the mental health and stability of these patients under stressful conditions.

Psychologists also provide baseline information about the neuropsychological function of the children, whether they have a hematological or oncologic problem, something that is crucial when treatments may have a deleterious impact on their neuropsychological status. Counseling is provided for patients and families that enables them to freely discuss their concerns regarding the diagnosis, treatment, treatment aftermath, school and other social concerns.

PSYCHIATRY

The LSU Child Psychiatry Department has worked closely with the Hematology/Oncology Division, providing care and advisement for difficult emotional and behavioral problems. They, along with the hematology/oncology physicians and Social Services Department, have been instrumental in the organization and oversight of a pioneering multidisciplinary psychosocial conference which regularly meets to advise the hematology/oncology team on how to deal with the trauma and stress of the diagnosis of cancer, and to effectively interact with parents and patients under their care.

CHILD LIFE DEPARTMENT

Music therapists, therapeutic recreation specialists, and child life specialists are available to promote a positive working relationship with children on the unit, through the use of play activities. Such activities allow each child to attain and maintain his/her maximum functional level and self-expression.

An extremely attractive playroom, with a view of an athletic field, is located on the unit. It is equipped not only with toys, but with a computer using the STARBRIGHT program which permits access to children with cancer who are receiving care at other facilities throughout the country. The playroom philosophy is to encourage each child to make choices about their play; to foster age-appropriate developmental activities; and to help each child gain mastery, understanding and positive coping techniques regarding their particular illness through medical play. Activities may be structured or unstructured. In addition, activities available to all children within the hospital, such as Movie Night or Bingo Night, remain a star attraction for our patients with cancer. The Music, Recreation and Child Life Department is dedicated to improving the quality of life of children facing the many challenges of cancer treatment while they remain hospitalized.

OCCUPATIONAL THERAPY

Occupational Therapy's involvement may include assessment and treatment of the patient's upper extremity status (i.e., range of motion, strength, endurance); fine motor skills; visual perception; visual motor skills; and activities of daily living, such as eating, dressing, bathing, toileting and grooming.

Occupational Therapy actively promotes independence, feeling that by doing so, social and emotional needs, as well as the physical, can be effectively met.

PHYSICAL THERAPY

The Physical Therapy Department specializes in the assessment and treatment of gross motor function in the child with cancer. Physical Therapy is consulted on both an inpatient and outpatient basis for children who will undergo stem cell transplant, as well as for those children who might have motor deficits resulting from either primary disease or treatment effect.

REHABILITATION MEDICINE

The Rehabilitation Medicine team at Children's Hospital has worked closely with the hematology/oncology physicians to provide a comprehensive approach to the treatment of patients who may have experienced a loss or impairment of functional abilities as a result of their disorder or treatment of the disorder, whether temporary or permanent. Patients with stroke in sickle cell or with hemiparesis in brain tumor are just a few of those children who have benefited from the efforts of this service. Working with physical, occupational and speech therapy services; nursing, nutritional and other services, Rehabilitation Medicine, under the guidance of Drs. Ann Tilton and Joseph Nadell, has integrated these and other services in coordinated plans intended to improve and strengthen the patient's functional capabilities. The Rehabilitation team has organized and integrated individualized programs for each patient and has become an invaluable mainstay of treatment for the child with cancer and other hematologic disorders.

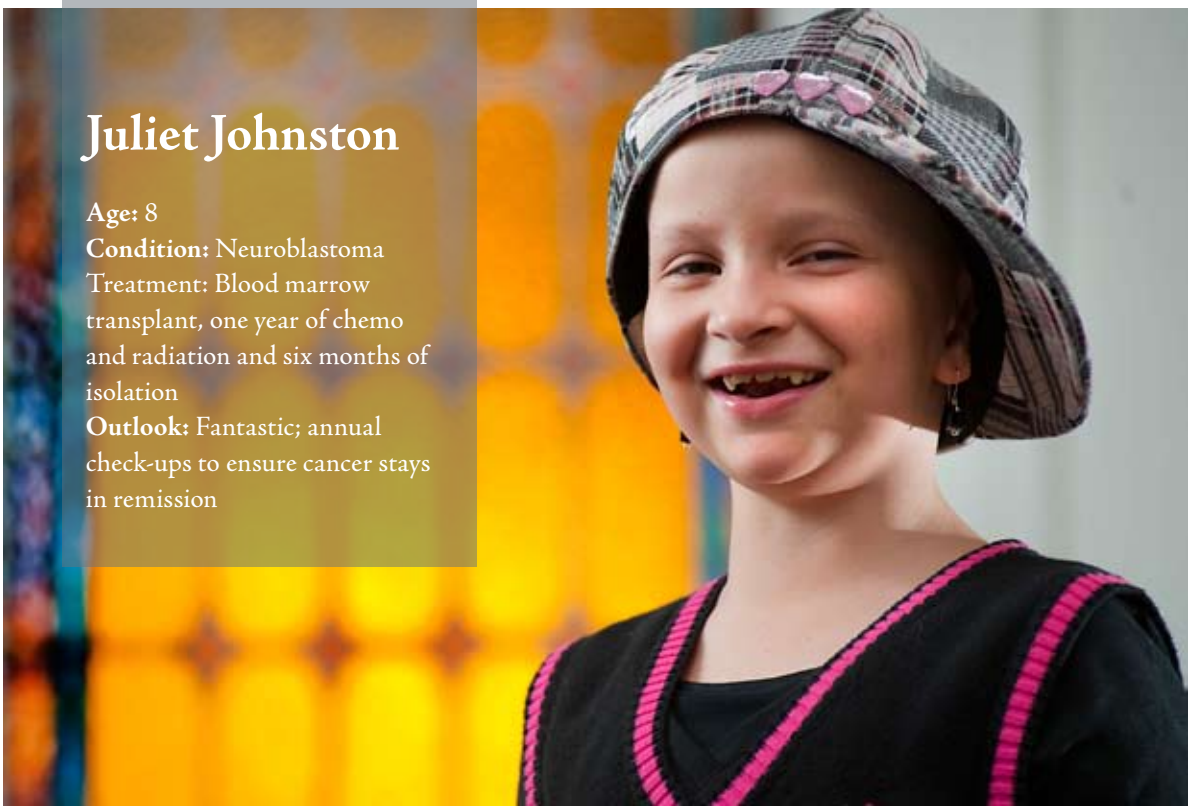
DIETARY AND NUTRITIONAL SERVICES

Children undergoing chemotherapy or bone marrow transplantation may suffer lack of appetite and failure to thrive. The Dietary and Nutritional Services Department at Children's Hospital provides a complete nutritional assessment, including anthropometric and calorie/protein requirements. They work closely with the physician team, making suggestions for enteral and parenteral supplementation. Each nutritional care plan is individualized to the patient's specific needs, with particular attention to the needs posed by a child with cancer. Parents are thoroughly counseled on diets meeting their child's needs, whether low bacterial, low tyrosine, etc. The nutritionist assists the hematology/oncology team with assessment of daily calorie counts and provision of special instructions, when necessary. Safe food handling is emphasized for the immunocompromised patient and the nutritionist meets with the family as much as necessary to promote compliance through trust and knowledge.

PHARMACY

The pharmacists work closely with the physicians, nurses and other healthcare team members to provide the best possible treatment for our patients. Not only do they prepare the therapeutic drug and advise on its administration and dosing, but they monitor patients who are on, at times, complex chemotherapeutic protocols, in order to prevent errors. They also assist the team with formulation of computer-generated orders, a practice which minimizes error. The Department of Pharmacy is actively involved in both patient and resident-fellow education, giving lectures and providing comprehensive drug information. Pharmacists work with the Quality Assurance/Improvement Department to design drug-use evaluation projects that will be administered by the Pharmacy and Therapeutics Committee.

patient profile



Juliet Johnston

Age: 8
Condition: Neuroblastoma
Treatment: Blood marrow transplant, one year of chemo and radiation and six months of isolation
Outlook: Fantastic; annual check-ups to ensure cancer stays in remission

When 3-year-old Juliett Johnston complained about persistent abdominal pain her parents, Jacklyn and Jeffrey, brought their daughter to Children's Hospital to be examined. X-rays and an ultrasound revealed she had a solitary kidney. Worse, a mass was growing atop it.

Juliett was diagnosed with neuroblastoma, a common childhood cancer that usually originates in nerves in the abdomen or chest, most commonly in the adrenal glands above each kidney. It spreads quickly, and she was given a 30 percent chance of survival.

"You don't prepare for it," Jeffrey said. "Dr. Gardner told us she had a mass, and we asked, 'What's a mass?' We had to hear tumor before it set in, and then the thought of her losing her only kidney presented another set of issues."

"All the other concerns flooded in right after," Jacklyn added. "Where is she going to be treated? How far will we have to travel? How much is it going to cost?

"Children's Hospital was the answer," she said. "We were able to come to one place to see all of the doctors and receive all the treatments she needed. It was so convenient, so reassuring."

Juliett began a year of inpatient treatment at Children's Hospital that included a bone marrow transplant, chemotherapy, radiation and six months of isolation to protect her weakened immune system, but she beat her cancer.

"She doesn't understand how lucky she is," Jacklyn said. "We're very fortunate, and couldn't be more grateful to Children's Hospital."

PASTORAL CARE

When a child is diagnosed with cancer, the child and his/her family experience a crisis which evokes intense and often overwhelming feelings of anxiety, helplessness, anger, guilt, fear, depression, shock and denial. Questions may be raised, such as: Why is this happening to me? Is God punishing me by causing my child to become ill? How can a loving God allow an innocent child to become so seriously ill? How am I going to get through this? Who is going to help us now?

Pastoral care services are provided to assist the child and family members as they ask these and other questions and express their feelings. The chaplain "walks with" each family, providing ministry according to the family's spiritual needs and denomination. He listens to the stories told by each family and child and provides support where needed. He prays with the child and family when prayer is requested, and also shares joyous moments, especially when the child's medical treatment is going well. A chaplain is on call at all times, in case of emergencies. Religious materials such as Bibles, daily meditation and Sunday services are available. The chaplain participates in weekly meetings with the staff and also participates in family conferences when asked to do so.

VOLUNTEER SERVICES

Volunteers work on the Hematology/Oncology unit, providing special services to the patients and their families. Volunteers usually request to work on this unit due to personal involvement with either a family member or friend who has gone through treatment at Children's Hospital or another institution. These volunteers bring with them insight, understanding and compassion which comes from their first-hand experience. They assist the Music, Recreation and Child Life staff with activities on the unit. They also spend time in the patient's room, playing games, reading, talking or just listening to the patient. They may also relieve the parents for a short time, providing respite for them. They remain important members of the treatment team.

STARBRIGHT WORLD

STARBRIGHT World is a computer system with programs that help seriously ill children confront the challenges they face every day. One component of STARBRIGHT World is a private online network that connects children and teens in hospitals throughout the country. It enables young patients to share experiences, fears, frustrations and humor through Internet technologies such as Web sites, chat rooms, bulletin boards and video conferencing. Patients meet online and talk face-to-face with peers who understand the realities of living with a serious or chronic illness.

CAMP CHALLENGE

Children's Hospital, along with the Cancer Association of Greater New Orleans and the Childhood Cancer Families Network, sponsors Camp Challenge, a unique, week-long camping experience geared to children with cancer and other blood disorders and their siblings. The camp is held annually in Louisiana and is planned and staffed by physicians, nurses, social workers and volunteers. It provides recreation and the camaraderie of associating with other children who have undergone similar experiences with cancer and chronic or serious illnesses. The children look forward to the opportunity to swim, ride horseback, engage in competitive sports, and generally have a ball while forgetting the all-too-present concerns of sickness and hospital.

RONALD MCDONALD HOUSE

The Ronald McDonald House provides temporary residence for the families of children receiving treatment for cancer and other serious illnesses in New Orleans area hospitals. Non-resident families are given the opportunity to stay at the house, located in Mid City, New Orleans. It is a place where families can get away from the hospital, yet remain in touch with the support of hospital and medical staff within a moment's notice. It is a home away from home for these families.

CANDLELIGHTERS

Candlelighters is a national nonprofit organization that provides hope, support, education, counseling and encouragement to those children and families touched by cancer. Candlelighters organizes activities and programs for families, provides psychosocial support, offers financial relief to patients' families, and works to raise awareness of childhood cancer and related issues. The organization also produces a quarterly newspaper available at no charge for parents of children with cancer.

MAKE-A-WISH

Through its wish-granting work, the Make-A-Wish Foundation of the Texas Gulf Coast and Louisiana has enriched the lives of countless children who have life-threatening illnesses. It provides children throughout Louisiana with an opportunity to participate in activities that they might never otherwise have been able to enjoy a trip to Walt Disney World, a shopping spree, a remodeling of their room.

A CHILD'S WISH

A Child's Wish is a Louisiana-based nonprofit organization that fulfills the dreams of children who are terminally ill or have life-threatening illnesses. Staffed by volunteers, this organization uses donations to enable children to achieve their wishes.

OPERATION SMILE

Children's Hospital participates in this program with the American Cancer Society. First- and second-year medical students are partnered with cancer patients and their siblings. The purpose of the program is to allow children to have their own "buddy" who will provide emotional and psychological support, as well as friendship, and to participate with them in non-medical activities.

CAPS FOR KIDS

Caps for Kids is an international non-profit organization dedicated to providing headwear autographed by athletes, entertainers and other notable personalities to children, adolescents and young adults with cancer who lose their hair as a result of their treatment. Caps for Kids was founded in 1993 by Dr. Stephen Heinrich, a pediatric orthopaedic surgeon at Children's Hospital. The program now exists at more than 70 hospitals in the United States, four in Canada, and one in Frankfurt, Germany.

Cancer Registry

An essential component of the Children's Hospital cancer program is the database maintained by the cancer registry. The cancer registry database, also known as the cancer data management system, is supported by IMPAC Medical Systems software program, called METRIQ. It is a system designed for the collection, management and analysis of the data on cancer patients. The information that is provided by the cancer registry is utilized in research, education and patient care evaluation. It has also proven to be of financial importance in administrative planning of allocation of hospital resources.

January 1, 1986 was established as our reference date, and as of December 31, 2007, the cancer registry has accessioned 1,523 cases. A comparison of Children's Hospital data from 2005, 2006 and 2007 is presented in the Cancer Statistics section of this report. The following discussion will focus primarily on Children's Hospital analytic case data from 2007. In 2007, a total of 110 cases were accessioned:

- 68 percent (n=75) being analytic and 32 percent (n=35) being non-analytic.
- 63 percent (n=47) were male and 37 percent (n=28) were female.
- 12 percent (n=9) of our patients resided in Orleans parish.
- The median age at diagnosis of our patients was 9.
- 39 percent (n=29) were white males with the highest incidence of cancer.
- 20 percent (n=15) were white females with the second highest incidence of cancer.
- 23 percent (n=17) were ALL patients which was our most common histology in 2007

In order to evaluate cancer care outcomes, the cancer registry maintains long-term follow-up on eligible patients included in the registry. To successfully achieve survival rates the American College of Surgeons (ACoS) requires an 80 percent follow-up rate on eligible patients, and a 90 percent follow-up rate for eligible patients diagnosed within the last five years. The cancer registry has been able to successfully maintain the required follow-up rate.

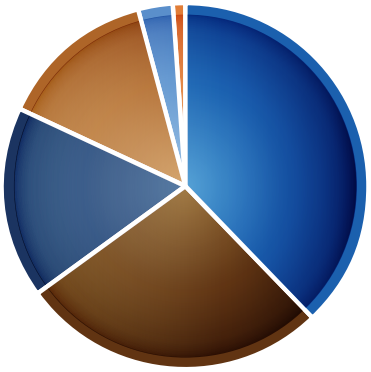
TOP FIVE CANCER SITES

Site	Number of Cases	Percentage of Cases
Bone Marrow	23	31.0%
Brain & CNS	19	25.0%
Lymph Node	9	12.0%
Adrenal	5	7.0%
Soft tissue	5	7.0%

Data is submitted to the National Cancer Data Base (NCDB) and the Louisiana Tumor Registry (LTR). In return, the NCDB provides local, state and national statistics to cancer programs that enables them to benchmark patient care and quality improvement efforts. The LTR also provides local and state statistics as a benchmarking tool for cancer programs.

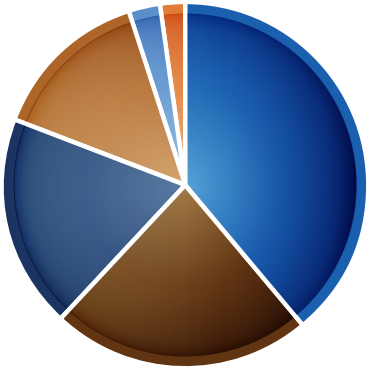
Knowledgeable personnel, including at least one CTR (Certified Tumor Registrar) staff the cancer registry. The cancer registry is located in the Medical Records Department. All inquiries may be directed to Rachel Bufkin, CTR, at (504) 894-5255.

DISTRIBUTION BY SEX AND RACE
(ANALYTIC CASES ONLY)



2005 – 2006

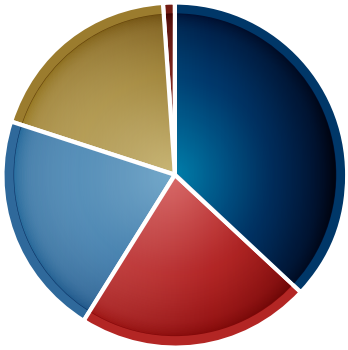
White male	38.0%
White female	27.0%
Black male	17.0%
Black female	14.0%
Other female	3.0%
Other male	1.0%



2007

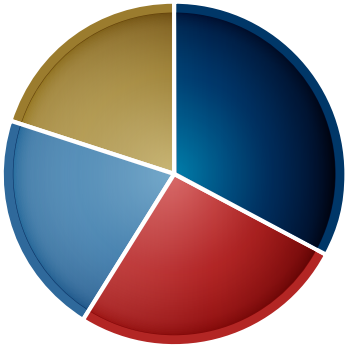
White male	39.0%
White female	23.0%
Black male	19.0%
Black female	14.0%
Other female	2.9%
Other male	2.1%

AGE AT DIAGNOSIS
(ANALYTIC CASES ONLY)



2005 – 2006

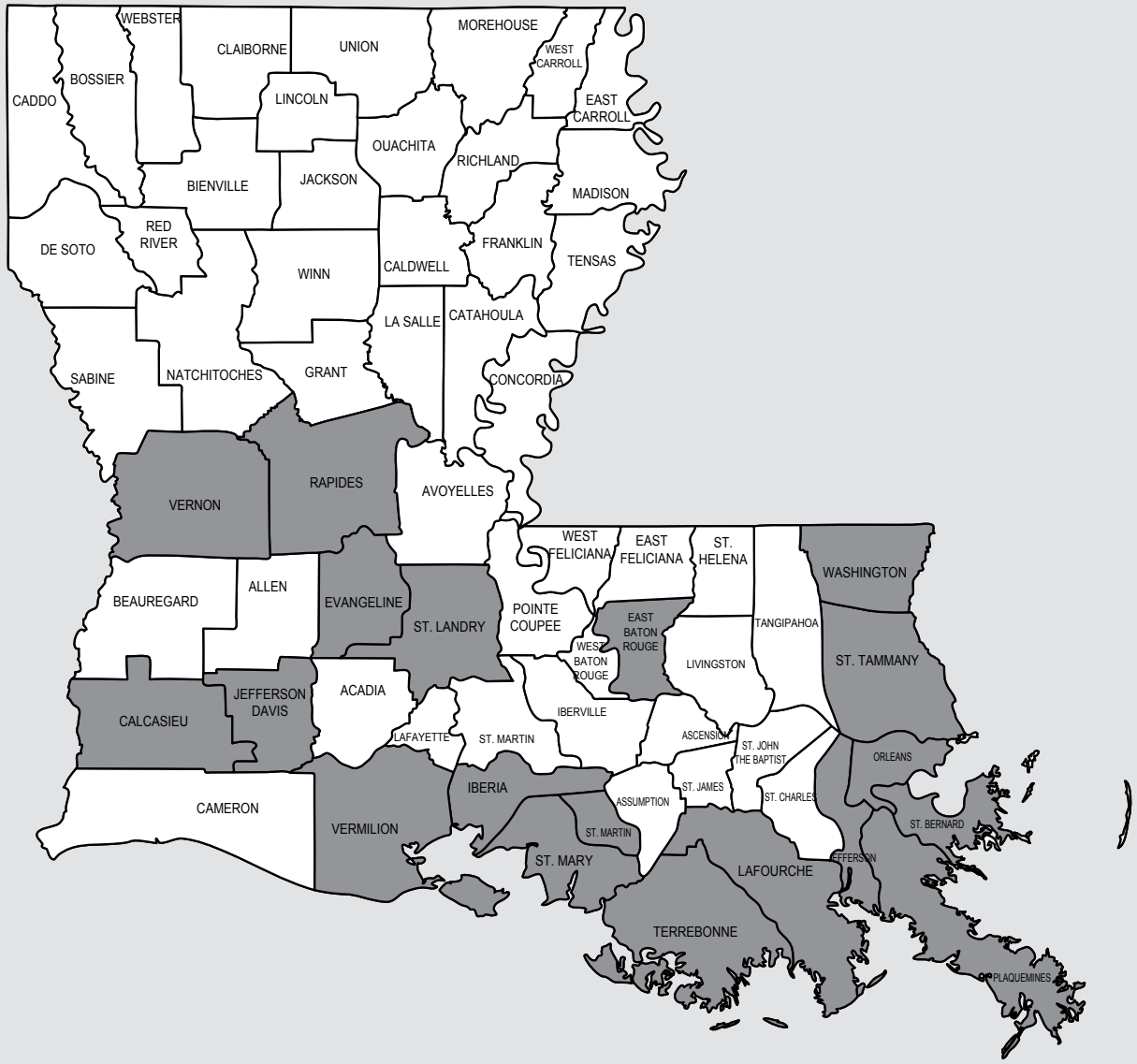
0 – 4 years	37.0%
5 – 9 years	22.0%
10 – 14 years	21.0%
15 – 19 years	19.0%
Over 19 years	1.0%



2007

0 – 4 years	33.0%
5 – 9 years	20.0%
10 – 14 years	26.0%
15 – 19 years	21.0%
Over 19 years	0.0%

Newly Diagnosed Patients



Parish	2005	2006	2007	Parish	2005	2006	2007
Acadia	1	0	0	Rapides	0	0	1
Ascension	0	1	0	St. Bernard	2	0	1
Assumption	0	1	0	St. Charles	1	0	2
Beauregard	1	1	0	St. James	1	1	0
Bossier	1	0	0	St. John th Baptisit	1	2	2
Calcasieu	3	6	2	St. Landry	0	0	1
East Baton Rouge	1	1	4	St. Martin	1	0	1
Evangeline	0	1	1	St. Mary	1	1	3
Iberia	0	1	3	St. Tammany	8	4	10
Jefferson	6	10	18	Tangipahoa	3	4	0
Jefferson Davis	4	1	1	Terrebone	4	2	1
Lafayette	0	2	4	Vermilion	0	0	1
Lafourche	2	3	1	Vernon	0	0	1
Livingston	2	0	0	Washington	0	3	1
Orleans	7	4	10	Out-of-State	5	4	5
Ouachita	2	0	0	Out-of-Country	1	0	0
Plaquemines	0	1	1	Total	58	55	75
Pointe Coupee	0	1	0				

Types of Cancer by Histology

	2005		2006		2007	
	# Patients	% Patients	# Patients	% Patients	# Patients	% Patients
Adenocarcinoid Tumor	1	1.7%	0	0.0%	0	0.0%
Astroblastoma	1	1.7%	0	0.0%	0	0.0%
Astrocytoma	2	3.5%	3	5.6%	5	8.0%
Atypical Teratoid Rhabdoid Tumor	1	1.7%	1	1.8%	2	3.0%
Blastoma, Pleuropulmonary	0	0.0%	1	1.8%	0	0.0%
Carcinoma, NOS	1	1.7%	1	1.8%	0	0.0%
Craniopharyngioma	1	1.7%	1	1.8%	0	0.0%
Desmoplastic Small Round Cell Tumor	1	1.7%	0	0.0%	0	0.0%
Desmoplastic Neuroepithelial Tumor	1	1.7%	1	1.8%	0	0.0%
Embryonal Carcinoma	0	0.0%	1	1.8%	1	1.0%
Ependymoma	1	1.7%	2	3.6%	3	4.0%
Ewing's Sarcoma	0	0.0%	1	1.8%	3	4.0%
Fibrosarcoma	1	1.7%	0	0.0%	0	0.0%
Ganglioglioma, NOS	1	1.7%	0	0.0%	1	1.0%
Ganglioneuroblastoma	0	0.0%	1	1.8%	1	1.0%
Germ Cell Tumor	0	0.0%	0	0.0%	1	1.0%
Glioblastoma	1	1.7%	0	0.0%	0	0.0%
Glioma, NOS	3	5.2%	2	3.6%	2	3.0%
Hemangiosarcoma	0	0.0%	0	0.0%	1	1.0%
Hepatoblastoma	3	5.2%	1	1.8%	0	0.0%
Hepatocellular Carcinoma	0	0.0%	0	0.0%	2	3.0%
ALL(Acute Lymphocytic Leukemia)	12	20.7%	9	16.3%	17	23.0%
AML (Acute myelocytic Leukemia)	2	3.5%	2	3.6%	4	6.0%
JMML (Juvenile Myelomonocytic Leukemia)	0	0.0%	0	0.0%	1	1.0%
Hodgkin's Lymphoma	5	8.7%	3	5.6%	8	11.0%
Non-Hodgkin's Lymphoma	4	6.9%	5	9.2%	1	1.0%
Langerhans Cell Histiocytosis	1	1.7%	3	5.6%	3	4.0%
Medulloblastoma	2	3.5%	0	0.0%	3	4.0%
Meingothelial meningioma	0	0.0%	1	1.8%	1	1.0%
Myelodysplastic Syndrome	0	0.0%	2	3.6%	1	1.0%
Neoplasm, Uncertain Behavior	1	1.7%	0	0.0%	0	0.0%
Neuroblastoma	1	1.7%	4	7.3%	8	11.0%
Neuroectodermal Tumor, Primitive	0	0.0%	0	0.0%	1	1.0%
Oligodendroglioma	0	0.0%	1	1.8%	1	1.0%
Osteosarcoma, NOS	2	3.5%	1	1.8%	0	0.0%
Peripheral nerve sheath tumor, Malignant	1	1.7%	1	1.8%	0	0.0%
Pigmented dermatofibrosarcoma protuberans	1	1.7%	0	0.0%	0	0.0%
Retinoblastoma	0	0.0%	1	1.8%	1	1.0%
Rhabdoid Tumor, Malignant	1	1.7%	0	0.0%	0	0.0%
Rhabdomyosarcoma	2	3.5%	2	3.6%	2	3.0%
Sarcoma	0	0.0%	1	1.8%	0	0.0%
Schwannoma, NOS	0	0.0%	1	1.8%	0	0.0%
Wilms Tumor	4	6.9%	2	3.6%	1	1.0%
Total	**58**	**100.0%**	**55**	**100.0%**	**75**	**100.0%**

About the Center

THE LANASA-GRECO CENTER FOR CANCER AND BLOOD DISORDERS

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Pediatric Nurse Coordinator

SOCIAL WORKERS
Kay Casey, LCSW
Peggy Williams, LCSW
Camille Cancienne, GSW

RESEARCHERS
James Hempe, MD
Augusto Ochoa, MD
Arnold Zea, PhD
Eduardo Davila, MD
Yan Cui, PhD

The LaNasa-Greco Center for Cancer and Blood Disorders at Children's Hospital offers comprehensive and current therapies for the treatment of all types of malignancies and blood disorders including, but not limited to, leukemia, thalassemia, sickle cell anemia and hemophilia, among many others.

In 1989, Children's Hospital was approved as a Pediatric Hospital Cancer Program by the American College of Surgeons. Our program is affiliated with Louisiana State University's Minority Community Clinical Oncology Program (MCCOP), which is accredited by the National Cancer Institute. Children's Hospital is also a member of the Children's Oncology Group (COG), a national study group of premier research institutes in the United States and Canada. Our hospital has the only approved COG bone marrow transplant program in Louisiana.

Though patient care is our primary focus, Children's Hospital is an active participant in clinical and basic research of childhood cancers and blood disorders.

Our physicians have access to the most modern therapies for treatment of malignancies and blood disorders in children.

The Center for Cancer and Blood Disorders is also a teaching facility for medical students, nursing students and those completing graduate and postgraduate training. The hospital plays a major role in the training of pediatric hematology/oncology fellows. Our program is part of the LSU Health Sciences Center (LSUHSC) Department of Pediatrics and the Stanley S. Scott Cancer Center of LSUHSC.

In 2007, Children's Hospital recorded **146,100 patient visits,** with children coming from all 64 parishes in Louisiana, 43 states, and 15 foreign countries. The hospital provided care to 50,887 unique patients. The LaNasa-Greco Center for Cancer and Blood Disorders itself had 5,723 clinic visits, 3,488 of which were for the treatment of children with cancer, and 953 for the care of sickle cell patients.

TRANSPLANTS BY DISEASE 1989-2008

Acute Lymphocytic Leukemia	41
Acute Myelogenous Leukemia	34
Chronic Myelogenous Leukemia	7
Acute undifferentiated Leukemia	3
Biphenotypic Leukemia	1
Juvenile Myelomonocytic Leukemia	2
Aplastic Anemia	11
Brain/CNS Tumors	8
Histiocytosis	2
Immunodeficiency	17
Lymphoma	15
Malignant Histiocytosis	2
Myelodysplastic Syndrome	18
Fanconi's Anemia	4
Neuroblastoma	38
Thalassemia Major	1
Sarcoma or Other Solid Tumor	10
Sickle Cell	7
Wilms Tumor	3
Metabolic Disorder	5
Total	**225**

OUR STAFF

The Center for Cancer and Blood Disorders at Children's Hospital comprises the largest group in the Gulf South of hematology and oncology physicians and nurses dedicated exclusively to pediatrics. They are specially trained to care for the unique needs of children and work side by side with a medical staff of more than 250 pediatric specialists, including pathologists, radiologists, oncology surgeons and neurosurgeons.

Our pediatric experts realize that caring for children with malignancies and blood disorders commands a delicate balance of medical care and emotional support. Support for patients and their families is provided by child psychiatrists, psychologists and social workers. Other members of the multidisciplinary team include bone marrow transplant coordinators, pharmacists, dieticians, laboratory technologists, and physical, occupational, speech and hearing, music and recreation and child life therapists.

ONCOLOGY SERVICES

LEUKEMIA/LYMPHOMAS

A full range of treatment options is available for children with acute or chronic lymphocytic and myelogenous leukemia, including chemotherapy, stem cell transplantation and radiation therapy. Oncology physicians and nurses offer and implement the treatment plan adequate for each child based on the type of leukemia, its stage and certain prognostic factors. Children with Hodgkin's disease and non-Hodgkin's lymphoma (NHL) are thoroughly evaluated and promptly treated according to the specific

subtype and stage of the disease. They are supported by a team of psychologists, social workers and other specialized professionals who provide compassionate "total care" for the child and family.

SOFT TISSUE AND SOLID TUMORS

At Children's Hospital, pediatric experts treat a variety of tumors including neuroblastoma, tumors of the central nervous system (brain and spine), soft tissue sarcoma, bone sarcoma, retinoblastoma and Wilms' tumor. The Center for Cancer and Blood Disorders is represented by the following medical and surgical disciplines: pediatric oncologic surgery, pediatric neurosurgery, pediatric neuro-oncology, genitourinary oncologic surgery, orthopaedic oncologic surgery, pediatric ocular surgery, radiation oncology and pediatric pathology. Members of our medical team are highly skilled individuals dedicated to providing the latest innovative treatments to our young patients.

BONE MARROW/HEMATOPOIETIC STEM CELL TRANSPLANT PROGRAM

Hematopoietic stem cell transplantation (HSCT) has become an alternative treatment of malignant diseases for many patients. The list of diseases for which hematopoietic stem cell transplantation has been considered grows continually. The sources of stem cells are varied: bone marrow, peripheral blood stem cells mobilized by growth factors or chemotherapy, and cord blood.

The Children's Hospital's Hematopoietic Stem Cell Transplant Program began in January 1989. From January 1989 to December 2006, 212 transplants were performed. Of those transplants performed, 143 were allogeneic and 69 were autologous. By far, the most common conditions for which HSCT has been carried out are hematologic malignancies, e.g., acute leukemia.

Diseases such as leukemia are treated at Children's Hospital with the same protocols as those that the 240 COG institutions (i.e., St. Jude, MD Anderson, Johns Hopkins) have adopted throughout the nation. COG has recognized Children's Hospital as the only approved bone marrow transplant site in Louisiana for COG protocol studies.

A multidisciplinary team of physicians, nurses, social workers, nutritionists, pharmacists, physical therapists, psychologists and blood bank personnel is available, with experience and commitment to the clinical practice and basic science of hematopoietic stem cell transplantation. In July 2000, Children's Hospital, led by Dr. Lolie Yu, became accredited by the National marrow Donor Program (NMDP) as a transplant center. Through the NMDP, Children's Hospital has access to the largest worldwide registry of hematopoietic stem cell donors. This affiliation provides patients with the best chance of finding a suitable donor for transplantation.

In keeping with our willingness to innovate in order to provide patients the benefit of advanced knowledge and technology, we were the first transplant center to implement the use of mesenchymal stem cells in transplantation. This procedure was performed to treat graft vs. host disease more effectively. We also were the first program in Louisiana to perform dual cord blood transplantation and have entered into a study with Celgene to perform transplants utilizing human placenta-derived stem cells in combination with cord blood stem cells.

For more information regarding the hematopoietic stem cell transplant program at Children's Hospital, please contact Dr. Lolie Yu at the Hematology/Oncology Department at (504) 896-9740.

CHILDREN'S ONCOLOGY GROUP

COG is a National Cancer Institute (NCI)-sponsored cooperative group of individuals and institutions dedicated to treating cancer among children and adolescents. COG's purpose is to: 1. improve the diagnosis and management of children and adolescents with cancer, with the aim of curing every newly diagnosed patient; 2. investigate the etiology, pathology and pathophysiology of childhood cancer; 3. assure that every child with cancer achieves the highest quality of life during and following treatment; 4. expeditiously disseminate knowledge of these objectives in all appropriate media.

Children's Hospital and LSUHSC/Stanley S. Scott Cancer Center have been members of COG for almost 20 years. This allows the Children's Hospital/LSUHSC Minority Community Clinical Oncology Program (MCCOP) to offer innovative and up-to-date clinical trials as part of the NCI-sponsored COG.

HEMATOLOGY SERVICES

The hematology/oncology service treats a wide variety of hematologic disorders including sickle cell disease and other anemias, neutropenias, platelet and bleeding disorders.

More children with blood disorders come to Children's Hospital for treatment than to any other hospital in the state. They receive the highest level of care from a medical staff experienced in the latest treatments for a full spectrum of disorders.

HEMOPHILIA AND OTHER BLOOD DISORDERS

Patients with hemophilia, von Willebrand's disease, and other bleeding disorders are evaluated and treated with the most current therapies. Appropriate support for patients

and parents is offered as needed. Nurse coordinators educate and coordinate the patient's care in clinic as well as at home. We have partnered with manufacturers of Factor to secure for our patients mobile devices that permit electronic data and therapeutic management. This has allowed parents of patients with bleeding disorders to record bleeding episodes and infusion details that enable the physician to better manage the acute and chronic complications of the disorder. We also were participants in the Hemophilia and Thrombosis Research Society registry. The Registry provided insight into the differing management strategies employed by hemophiliacs, into the natural history of patients with inhibitors, and assessment of alternative therapies for acute bleeding episodes (NovoNordisk).

OUTPATIENT CLINICS

Treatments that once required that a child be admitted to the hospital are now often given on an outpatient basis. Patients visiting the Hematology/Oncology outpatient clinic at Children's Hospital will find themselves in a newly renovated space that provides an environment in which the comfort and care of the child and family are placed first. Located in the hospital's Ambulatory Care Center, a separate patient suite with private entrance and waiting area has been dedicated for patients with cancer or blood disorders. The location is convenient for families and provides the safest conditions for immunocompromised patients.

Patients visiting our outpatient clinic are closely monitored by their pediatric hematology/oncologist and nurses trained in chemotherapy administration and receive a variety of treatments, including blood transfusions, platelet transfusions and gammaglobulin infusions.

In addition to nine private rooms, there is a large treatment room (which also includes a private treatment room where stem cell or red cell exchanges can take place or patients can recover from anesthesia). In this room, patients may watch TV, play video games, or relax while watching tropical fish aimlessly wander in tanks set within the walls of the room—all this to induce a much friendlier and non-threatening environment while the child receives transfusion and other therapies.

The clinic sees on average 20 patients per day and is open Monday through Friday, 8 a.m. to 4:30 p.m.

If the need arises during a clinic visit, patients can be promptly admitted to the hospital's acute care unit, designated specifically for Hematology/Oncology patients.

SICKLE CELL ANEMIA

Comprehensive management of sickle cell disease, including transfusion therapy, skilled pain management, and chelation therapy is made available at Children's Hospital. We currently care for between 250 and 300 patients with sickle cell disease at Children's Hospital in New Orleans. Satellite clinics are located in Baton Rouge and Lake Charles. From the time the patients are first identified as having a hemoglobinopathy, they are offered the most progressive treatment available for stroke prevention, oral chelation, retinopathy screening, and monitoring for long-term complications of sickle cell disease. We have been involved in clinical trials sponsored by Novartis, Celgene, and other pharmaceutical companies; this has been done to avail our patients of the newest advances in science related to this disorder, resulting in our being able to offer our patients the newest advances in the field of hemoglobinopathies as soon as they are proven safe and efficacious. In addition to sickle cell disease, we also treat individuals who are diagnosed with other hemoglobinopathies, e.g., CC Disease or thalassemia. We have explored therapeutic innovations such as non-myeloablative transplantation which offers our patients with sickle cell disease an opportunity to undergo the transplant without prohibitive risks. Our involvement in the National Marrow Donor Program and the National Cord Blood Registry permits us to offer this treatment modality to greater numbers of patients who might otherwise have had to forego this treatment option for want of an eligible donor. We are currently in an agreement with Viacord (Celgene) that will enable patients to bank cord blood—a service often beyond the financial means of many of our families.

RESEARCH

The members of the Hematology/Oncology section of the Department of Pediatrics (LSU and Children's) have maintained a lively interest in research, in the effort to improve care and expand knowledge regarding the various disease processes that are encountered by them. One main venue for research has been the Children's Oncology group, in which all members of the Division participate. Collaboration with other LSUHSC faculty and with Research Staff in The Children's Clinical Research Center has brought about exciting and fruitful results. The investigative efforts have included translational (bench to bedside) research:

1. Study of the role of the amino acid, arginine, on the cellular response of immune cells to cancer cells (Drs. Augusto Ochoa and Arnold Zea);

2. Development of an assay to determine the level of responsiveness to glucocorticoids (e.g. prednisone) in patients diagnosed with acute lymphoblastic leukemia (this testing would determine if an individual was resistant or responsive to a commonly used class of drugs used for the treatment of

a spectrum of leukemia subtypes (Dr. Wayne Vedeckis);

3. Study of dendritic cells as a means of enhancing engraftment of peripheral blood stem cells and of diminishing the probability of graft-vs-host disease in transplantation recipients; and

4. Study of xenotransplantation (transplantation across species).

We have just concluded our participation in a study of the oral chelator, Exjade, which has been utilized to treat individuals with transfusional iron overload (Novartis) and continue to participate in a number of pharmaceutical company-sponsored trials, as well. They include:

1. A study of the pharmacokinetics and safety of an antifungal medication, voriconazole, in those who are immune-compromised and at high risk for the development of fungal infection (Pfizer);

2. A trial to assess the safety and efficacy of a new intravenous immunoglobulin to treat patients with immune-mediated thrombocytopenia (Grifols);

3. A trial of transplantation with umbilical cord blood from multiple donors to treat those individuals with malignant and non-malignant hematologic disorders (Celgene); and

4. The study of donepezil in children who have attention impairment after cancer therapy (Eisai).

In addition to these research efforts, the Division of Hematology/Oncology continues its clinical research efforts as a means of interesting young people, whether high school students, medical students or residents, in pursuing a career in Hematology/Oncology, both basic and clinical. Drs. Gardner and Velez have been active as mentors for the Summer Cancer and/or Genetics Research Programs offered at LSUHSC and, as such, have studied subjects such as problems had by children in school re-entry, knowledge of and acceptance of HPV vaccine, brain tumors and late effects, etc. Studies aimed at insuring quality control improvement in the hospital setting have been very important to us, with the overreaching goal of improving patient care. As an example, we have interacted with our emergency room and residency staff, emphasizing the exigency of fever in neutropenic patients and the measures which need to be taken. Through improved cooperation, enhanced educational efforts, and the use of standardized, pre-printed orders, we have greatly shortened the time that it now takes to institute care in the emergency room for patients presenting with fever and low white blood cell counts. Similarly, central line infections on the Hematology/Oncology ward now have a prevalence that is lower than the national average. Another study led to the introduction of sample labeling practices in the operating or recovery room during procedures that promise to reduce error rates. All of these studies have resulted in the institution of new interventions and ultimately, we hope, will be responsible for the improvement of patient care.

LANASA-GRECO CENTER FOR CANCER AND BLOOD DISORDERS INPATIENT UNIT

The LaNasa-Greco Center for Cancer and Blood Disorders opened in November 2003 on the fourth floor of Children's Hospital. The inpatient unit boasts 18 private rooms in a state-of-the-art and comfortable environment for patients and families. Each room, as well as the entire unit, is equipped with high efficiency particle air (HEPA) filtration. The highly advanced air handling system allows bone marrow transplants to be performed in any room and is essential to reducing the risk of infection. Located away from other inpatient areas and accessed through a positive pressure vestibule, the unit allows for the highest level of protection for patients.

The unit, overlooking Audubon Park, also includes a playroom stocked with games, toys, art supplies and computers, and an activity center, where music and recreation therapists can interact with small groups of children for organized play. A parents' lounge is available for those needing peace or respite.

When admission is indicated, an individual treatment plan for each patient is devised by pediatric oncologists, oncology nurses and other members of the multidisciplinary team. Patients and their families develop a special bond with the staff on the fourth floor and the staff is committed to helping them cope both emotionally and physically with the side effects and complications associated with disease and treatment.

Cancer Conference

At Children's Hospital, the Cancer Conference remains the major educational element of the cancer program. These conferences are held weekly to improve the quality of care of pediatric cancer patients through educational discussions. Children's Hospital recognizes the importance of these multidisciplinary conferences and has been sponsoring them since 1980.

All aspects of pediatric cancer management are embraced at these conferences. Each presentation includes an outline of the medical history, physical findings, clinical and surgical course, radiological studies and pathological interpretations of each one of the cases to be discussed. An open discussion and review of pertinent medical literature follow each case presentation offering a comprehensive and multidisciplinary approach but, at the same time, tailored to the patient's individual needs.

During 2007, a total of 44 conferences were held. On average, approximately 21 physicians, residents, students and other cancer-related supporting staff personnel attended the weekly conferences. A total of 127 cases were presented in 2007. These cases consisted of prospective, retrospective and follow-up cases. It should be noted that 99 percent of the cases presented were prospective and were representative of the major sites of cancer at Children's Hospital.

All members of the medical staff are encouraged to attend and present their oncology cases at these conferences. Physicians can schedule case presentations by contacting the Hematology/Oncology Office at (504) 896-9740.

Hematology/Oncology Program

The Pediatric Hematology/Oncology section of LSUHSC Department of Pediatrics was formally accredited by the Accreditation Council for Graduate Medical Education (ACGME) in early 1989. It remains the only accredited fellowship program between Florida and Texas. We are proud to report that, this year, despite the upheavals of the post-Katrina milieu, we again received approval from the ACGME for the fellowship. The program now directed by Dr. Maria Velez and comprised of faculty members Drs. Gardner, Singleton and Yu, continues to draw individuals from around the country and throughout the world. Graduates of the program have gone on to distinguish themselves in many fields assuming, at times, roles of leadership wherever they have gone. The program utilizes the clinical resources and faculty expertise available at the Medical Center of Louisiana.

The program maintains an active partnership with the LSUHSC Stanley S. Scott Cancer Center. Teaching and patient care take place at Children's Hospital. Research activities are conducted through the establishment of partnerships with experienced and capable investigators such as Drs. Augusto Ochoa, Arnold Zea, James Hempe and Lily Leiva. Electives for the fellowship are offered in Blood Banking, Hemophilia Care, Radiation Oncology and Hematopathology. Fellows play an integral role in the planning and organization of conferences and lectures. Teaching activities include the Cancer Conference, journal club, protocol reviews, psychosocial conferences, core lectures, and professors' rounds. Invited speakers from many excellent institutions involved in cancer care, both local and national, help round out the fellowship's educational opportunities.

Community Outreach Program

Among the goals for our Community Outreach Program are the continuing efforts to educate and inform the public and health care community on the signs and symptoms as well as the incidence of cancer in children. We promote cancer prevention through presentations and discussions, encouraging adequate nutrition, sun exposure reduction (skin cancer prevention), and smoking cessation (tobacco use and cancer).

Informational sessions on cancer prevention are offered to school-aged children during their visit to Children's Hospital. Lectures are held in the local community for schools and businesses to address the significance of cancer prevention and encourage routine medical examination for early cancer detection including breast self-exam for females and genitourinary exam for males. Brochures are available for distribution at schools, health fairs and employee fairs through the Hematology/Oncology Department. These brochures are located throughout the hospital and in satellite clinics. Information about cancer prevention and interesting links can be found on the Children's Hospital Web site at www.chnola.org.

Treatment Protocols

PHARMACEUTICAL TRIALS

NOVARTIS PHARMACEUTICALS

A randomized, open-label, multi-center, phase II study to evaluate the safety and efficacy of oral ICL670 (deferasirox) 20mg/day relative to subcutaneous deferoxamine in sickle cell disease patients with iron overload from repeated blood transfusions

A one year open label, non-comparative extension to a randomized, multicenter, phase II study to evaluate the safety, tolerability, pharmacokinetics and the effects on liver iron concentration of repeated doses of 5-30 mg/kg/day of ICL670 relative to deferoxamine in sickle cell disease patients with transfusional hemosiderosis

PFIZER PHARMACEUTICALS (A1501081)

An open-label, intravenous to oral switch, multiple dose study to evaluate the pharmacokinetics, safety and tolerability of voriconazole in immunocompromised adolescents aged 12 to <17 years who are at high risk for systemic fungal infection.*

Epidemiology and Treatment of Circulating Anticoagulants in Patients with Hemophilia and von Willebrand's Disease – The HTRS Registry

ANTHERA PHARMACEUTICALS

Dose Escalation study: varespladib infusion (A-001) for the prevention of acute chest syndrome in at-risk patients with sickle cell disease and vaso-occlusive crisis

GRIFOLS PHARMACEUTICALS

A Multi-Center, Prospective, Open-Label, Clinical Trial to Assess the Safety and the Efficacy of a New Intravenous Immune Globulin (IGIV3I Grifols 10 percent) in Patients with Idiopathic (Immune) Thrombocytopenic Purpura*

CELGENE CELLULAR THERAPEUTICS

Investigation of HLA-matched Related, Human Umbilical Cord Blood Transplantation for the Treatment of Symptomatic Sickle Cell Disease or Beta-Thalassemia Major in Children

A Single-Arm Study to Assess the Safety of Transplantation with umbilical cord blood augmented with human placental-derived stem cells from partially matched related donors in subjects with certain malignant hematologic diseases and non-malignant disorders

EUSA/OPI SA

Usage of Erwinia Asparaginase (Erwinase Master Treatment Protocol) COG Studies

BRAIN/CNS

ACNS02B1 Pre-Clinical Pharmacology in Surgical Brain Tumor Specimens

ACNS02B3 A Children's Oncology Group Protocol for Collecting and Banking Pediatric Brain Tumor Research Specimens

ACNS0331 A Study Evaluating Limited Target Volume Boost Irradiation and Reduced Dose Craniospinal Radiotherapy (18.00 Gy) and Chemotherapy in Children with Newly Diagnosed Standard Risk Medulloblastoma: A Phase III Randomized Trial

A9952 Chemotherapy for Progressive Low Grade Astrocytoma in Children Less Than Ten Years Old

A9961 A Phase III Prospective Randomized Study of Craniospinal Radiotherapy Followed by One of Two Adjuvant Chemotherapy Regimens (CCNU, CDDP, VCR or CPM, CDDP, VCR) in Children with Newly-Diagnosed Average-Risk Medulloblastoma

P9934 Systemic Chemotherapy, Second Look Surgery and Conformal Radiation Therapy Limited to the Posterior Fossa and Primary Site for Children => 8 Months and <= 36 Months with Non-Metastatic (MO) Medulloblastoma: A Children's Oncology Group Phase III Study

CANCER CONTROL

AALL0331 Standard Risk B-Precursor Acute Lymphoblastic Leukemia, Phase III Group-Wide Study (QOL component)

AALL03N1 Understanding the Role of Adherence in the Ethnic Differences in Survival after Childhood

ALL

ACCL05C1* A Group-Wide, Prospective Study of Ototoxicity Assessment in Children Receiving Cisplatin Chemotherapy

ACNS0331 A Study Evaluating Limited Target Volume

Boost Irradiation and Reduced Dose Craniospinal Radiotherapy (18.00 Gy) and Chemotherapy in Children with Newly Diagnosed Standard Risk Medulloblastoma: A Phase III Randomized Trial (QOL component)
ALTE03N1 Key Adverse Events After Childhood Cancer
ACCL0331 A Randomized Double Blind Placebo Controlled Clinical Trial to Assess the Efficacy of Traumeel (IND #66649) for the Prevention and Treatment of Mucositis in Children Undergoing Hematopoietic Stem Cell Transplantation

ALL, AML

AALL0232 High Risk B-precursor Acute Lymphoblastic Leukemia- A Phase III Group-Wide Study
AALL0331 Standard Risk B-Precursor Acute Lymphoblastic Leukemia, Phase III Group-Wide Study
AALL03B1 Classification of Acute Lymphoblastic Leukemia
AALL03N1 Understanding the Role of Adherence in the Ethnic Differences in Survival after Childhood

ALL

AALL0434 Intensified Methotrexate, Nelarabine (Compound 506U78; IND#52611) and Augmented BFM Therapy for Children and Young Adults with Newly Diagnosed T-cell Acute Lymphoblastic Leukemia (ALL)
AAML0531 A Phase III Randomized Trial of Gemtuzumab Ozogamicin (Mylotarg®) Combined with Conventional Chemotherapy for De Novo Acute Myeloid Leukemia (AML) in Children, Adolescents, and Young Adults
ADVL04P2* A Feasibility Pilot and Phase 2 Study of Chemoimmunotherapy with Epratuzumab for Children with Relapsed CD22-Positive Acute Lymphoblastic Leukemia
9404 Intensive Treatment for T-Cell Acute Lymphoblastic Leukemia and Advanced Stage Lymphoblastic Non-Hodgkin's Lymphoma (T-Cell #4 Protocol)
9407 Induction Intensification in Infant Acute Lymphoblastic Leukemia
AAML03P1 Treatment of Newly Diagnosed Childhood Acute Myeloid Leukemia (AML) Using Intensive MRC-Based Therapy and Gemtuzumab Ozogamicin (GMTZ)
9904 AlinC17 Treatment of Patients with Newly Diagnosed Low Risk Acute Lymphoblastic Leukemia
9905 ALinC 17: Protocol for Patients with Newly Diagnosed Standard Risk Acute Lymphoblastic Leukemia (ALL): A Phase III Study

LIVER

AEPI04C1 Low Birth Weight & Other Risk Factors for Hepatoblastoma
P9645 Phase II Protocol for the Treatment of Children with Hepatoblastoma

LYMPHOMA

AHOD0031 A Phase III Groupwide Study of Dose-Intensive Response-Based Chemotherapy and Radiation Therapy for Children and Adolescents with Newly Diagnosed Intermediate Risk Hodgkin Disease
AHOD0431 Phase III Study for the Treatment of Children and Adolescents with Newly Diagnosed Low-Risk Hodgkin Disease
9425 Advanced Stage Hodgkins Disease - A Pediatric Oncology Group Phase III Study
9426 Response Dependent Treatment of Stages IA, IIA and IIIA Hodgkin's Disease with DBVE and Low Dose Involved Field Irradiation with or without Zinecard
A5971 Randomized Phase III Study for the Treatment of Newly Diagnosed Disseminated Lymphoblastic Lymphoma or Localized Lymphoblastic Lymphoma

NEUROBLASTOMA

ANBL0032 Phase II Randomized Study of Chimeric Antibody 14.18 (Ch14.18) in High Risk Neuroblastoma Following Myeloablative Therapy and Autologous Stem Cell Rescue
ANBL00B1 Neuroblastoma Biology Studies
ANBL00P2 Perinatal Neuroblastoma: Expectant Observation
ANBL0421 A Phase II Study of Irinotecan + Temozolomide in Children with Recurrent Neuroblastoma
A3973 A Randomized Study of Purged versus Unpurged Peripheral Blood Stem Cell Transplant Following Dose Intensive Induction Therapy for High-Risk Neuroblastoma
P9641 Primary Surgical Therapy for Biologically Defined Low-Risk Neuroblastoma

RENAL

9442 National Wilms Tumor Late Effects Study
AREN03B2 Children's Oncology Group Renal Tumors Classification, Biology and Banking Study
9440 National Wilms Tumor Study – 5: Therapeutic Trial and Biology Study

SARCOMA

AEWS02B1 A Groupwide Biology and Banking Study for Ewing Sarcoma
AEWS0331 European Ewing Tumor Working Initiative of National Groups Ewing Tumour Studies 1999 (EURO-E.W.I.N.G. 99)

AOST0331 A Randomized Trial of the European and American Osteosarcoma Study Group to Optimize Treatment for Resectable Osteosarcoma Based on Histological Response to Pre-Operative Chemotherapy
ARST0431 Intensive Multi-Agent Therapy, Including Dose-Compressed Cycles of Ifosfamide/Etoposide (IE) and Vincristine/Doxorubicin/Cyclophosphamide (VDC) for Patients with High-Risk Rhabdomyosarcoma
D9902 A COG Soft Tissue Sarcoma Biology and Banking Protocol
P9851 Osteosarcoma Biology Protocol: Companion to Group-Wide Therapeutic Studies
9354 A Randomized Phase III Evaluation of Intensified Vincristine, Doxorubicin, Cyclophosphamide, Ifosfamide, and Etoposide in the Treatment of Newly-Diagnosed Ewing's Sarcoma or Primitive Neuroectodermal Tumor of Bone or Soft Tissue. A POG/CCG Phase III Intergroup Study
D9602 Actinomycin D and Vincristine with or without Cyclophosphamide and Radiation Therapy, for Newly Diagnosed Patients with Low-Risk Embryonal/Botryoid Rhabdomyosarcoma: IRS-V/STS Protocol
D9803 Randomized Study of Vincristine, Actinomycin-D, and Cyclophosphamide (VAC) versus VAC Alternating with Vincristine, Topotecan and Cyclophosphamide for Patients with Intermediate-Risk Rhabdomyosarcoma

COG TRANSPLANT

(studies are listed above)

AAML0531 A Phase III Randomized Trial of Gemtuzumab Ozogamicin (Mylotarg®) Combined with Conventional Chemotherapy for De Novo Acute Myeloid Leukemia (AML) in Children, Adolescents, and Young Adults
AEWS0331 European Ewing Tumor Working Initiative of National Groups Ewing Tumor Studies 1999 (EURO-E.W.I.N.G. 99)
ANBL0032 Phase II Randomized Study of Chimeric Antibody 14.18 (Ch14.18) in High Risk Neuroblastoma Following Myeloablative Therapy and Autologous Stem Cell Rescue
ASCT0521 Soluble Tumor Necrosis Factor Receptor: Enbrel (Etanercept) for the Treatment of Acute Non-Infectious Pulmonary Dysfunction (Idiopathic Pneumonia Syndrome) Following Allogeneic Stem Cell Transplantation

MISCELLANEOUS BIOLOGY/RARE TUMORS

ABTR01B1 A Children's Oncology Group Protocol for Collecting and Banking Pediatric Research Specimens Including Rare Pediatric Tumors

NON-COG TRANSPLANT: OPEN TO ACCRUAL

National Marrow Donor Program (NMDP)/Center for International Blood and Marrow Transplant Research (CIBMTR) Research Database for Allogeneic Unrelated Hematopoietic Stem Cell Transplantation

A Phase I Study of Hematopoietic Stem Cell Transplantation (HSCT) in Non-malignant Disease Using a Non-myeloablative Preparatory Regimen with Campath-1H, Fludarabine and Melphalan

A Multicenter Investigation of Sibling Donor Cord Blood Transplantation for Treatment of Symptomatic Sickle Cell Disease or Beta-Thalassemia Major

High-Dose Cyclophosphamide, Carmustine and Etoposide with Autologous Bone Marrow Transplantation for Relapsed Hodgkin's Disease

Use of High-Dose Cytosine Arabinoside (ARA-C), Cyclophosphamide, Total Body Irradiation and Marrow Transplantation as Treatment for Patients with Acute Lymphoblastic Leukemia

A Pilot Study of Unrelated Umbilical Cord Blood Transplantation in Adults and Children with Bone Marrow Failure Syndromes or Inherited Metabolic or Hematologic Diseases

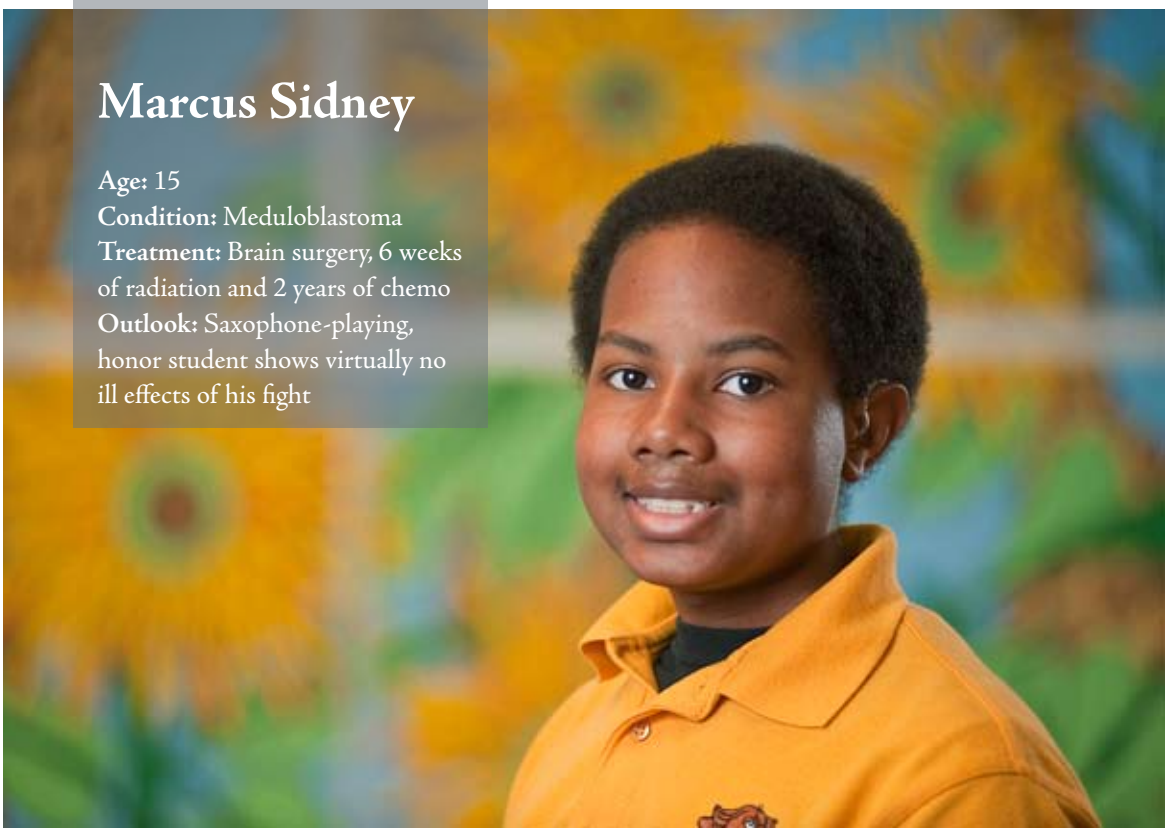
Selection of CD 34+ Cells for Stem Cell Transplantation of Hematologic Malignancies

Cyclophosphamide Conditioning Regimen for Marrow Transplantation from HLA Identical family Members for Severe Aplastic Anemia
NMDP/CIBMTR Research Sample Repository

Acclerating Immune Recovery Post-SCT via co-transfer of Dendritic Cell Precursors

* Protocol is currently under review by the Louisiana State University Health Sciences Center Institutional Review Board

"Studies closed to accrual" indicates that enrollment through the Children's Oncology Group can no longer take place, but patients can continue to receive therapy according to the protocol's guidelines, since these studies often represent the most current treatment approach available at the present time.



Marcus Sidney

Age: 15
Condition: Meduloblastoma
Treatment: Brain surgery, 6 weeks of radiation and 2 years of chemo
Outlook: Saxophone-playing, honor student shows virtually no ill effects of his fight

When 7-year-old Marcus Sidney couldn't turn his head because of neck pain, his mother scheduled an appointment with an orthopaedic specialist at Children's Hospital. His doctor thought he had a muscle ailment. But when Marcus complained about losing his vision and hearing, his doctor ordered an MRI exam which reveled Marcus had a brain tumor. He was diagnosed with meduloblastoma, a highly malignant cancer that originates in the cerebellum. The Sidneys met with physicians in Children's Hospital's Hematology/Oncology and Neurosurgery departments who would care for their son. He would require immediate brain surgery, followed by weeks of radiation and months of chemotherapy.

"I was nervous, but his doctors put us at ease," said Marcus' mom, Wanda. "They're veterans, and we put our faith in their care."

Marcus' surgeon was able to remove 95 percent of the tumor from his brain, but he had to endure six weeks of radiation and two years of chemotherapy to beat the disease. Today, the 15-year-old, saxophone-playing, honor student shows virtually no ill effects of his fight; however, he has to wear hearing aids and has had minor eye trouble.

"When people ask, I tell them I had cancer when I was seven," Marcus said. "It used to be aggravating. But now I know I'm a survivor, and I don't mind telling people I beat cancer."

Wanda says she and her family feel blessed for the treatment they received at Children's Hospital. "We were told he could have had severe brain damage, but he's on the honor roll," she said. "We've had a wonderful experience with Children's Hospital and recommend it to everyone," she said. "The treatment we received here was awesome. They do such good work here. We love this hospital."

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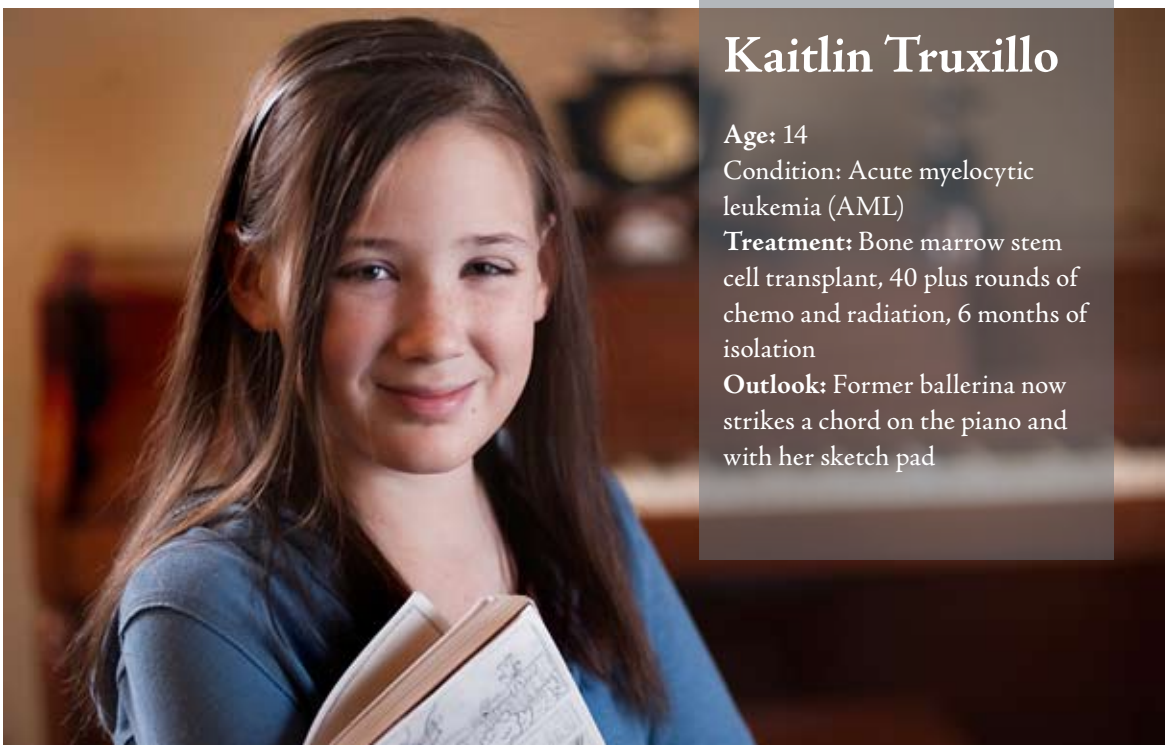

Kaitlin Truxillo

Age: 14
Condition: Acute myelocytic leukemia (AML)
Treatment: Bone marrow stem cell transplant, 40 plus rounds of chemo and radiation, 6 months of isolation
Outlook: Former ballerina now strikes a chord on the piano and with her sketch pad

patient profile

Every night that Kaitlin Truxillo was in Children's Hospital battling acute myelocytic leukemia (AML) her family members sang Disney's "A Dream is a Wish Your Heart Makes" as she fell asleep. Their wish – simply that 7-year-old Kaitlin would survive. The family was rocked when Kaitlin's mom, Helen, discovered two odd bruises on her daughter's back. After a blood test, their pediatrician sent them to Children's Hospital for a consultation, where Dr. Lolie Yu told the Truxillos their daughter had AML, a cancer of the bone marrow that is extremely dangerous because it enters the bloodstream and is quickly transported all over the body where it continues to grow and divide.

Cancer has been prevalent in the Truxillo family, so the family made a decision not to tell Kaitlin the full story. "She was dying. But I'm a firm believer in mind over matter, and we didn't want her to be afraid that she wasn't going to make it," Helen said. "So, we didn't use the C-word. We told her she had leukemia, but never really explained what it is."
With a 30 percent chance of survival, Kaitlin began treatment that included a bone marrow stem cell transplant, two different rounds of chemotherapy, 40 radiation treatments, six months of isolation because her immune system was compromised and a feeding tube for more than two years.

Her treatment left Kaitlin's bones brittle, forcing her to trade in physical activities, like ballet recitals, for sedentary activities, like drawing and piano recitals. At a performance just after Dr. Yu declared her cured, Kaitlin surprised her audience when she altered the program. Instead of playing the song she practiced for months, she flawlessly played "A Dream Is a Wish Your Heart Makes."

"I was shaking when I heard the first few notes," Helen said, "and then the tears came. It was one of the happiest moments in my life. She's been given her life back. Five years ago, she wasn't expected to be here. Five years later, she's cancer free, alive and doing great.

"I'm amazed by Children's Hospital," she said. "We looked at St. Jude and M.D. Anderson, but Children's Hospital had the best record of every hospital in the country for treating her cancer. I don't know if Kaitlin would have made it anywhere else."

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Glossary

Accession:
To list in order of acquisition. An accession number is assigned to each new patient who is eligible for inclusion in the Cancer Registry database.

Allogenic:
Having cell types that are antigenically distinct. In transplantation biology, denoting individuals (or tissues) that are the same species but antigenically distinct.

American Joint Committee on Cancer (AJCC):
A committee designated to coordinate efforts of sponsoring organizations to develop staging systems for various cancers within the TNM system in the United States.

American College of Surgeons (ACoS):
A fellowship of surgeons, organized in 1913 "to elevate the standard of surgery, to establish the standard of competency and character for practitioners of surgery," and, in general, to assure that surgeons are properly qualified.

Analytic Cases:
Cases that are first diagnosed and/or receive all or part of their first course of treatment at Children's Hospital. In accordance with the American College of Surgeons guidelines for approved cancer programs, these cases must be accessioned, included in the patient index file, abstracted and followed for the lifetime of the patient by the Cancer Registry.

Autologous:
Autogenous, related to self; originating within an organism itself.

Class of Case:
A classification of treatment status determined by a reporting hospital. This classification is determined at the patient's first admission. Whether a case is included in the hospital's treatment and/or survival statistics depends upon the patient's classification.

Initial Therapy:
Initial definitive treatment, or series of treatments, that normally modifies, controls, removes or destroys proliferating tumor tissue. This is usually initiated within the first four months (two months for leukemia) of diagnosis. Types of initial therapy include the list below:

Surgery:
The partial or total removal of the tumor, excluding biopsy.

Radiation:
Cancer-related direct beam and non-beam therapy. Non-beam includes radium, cesium and radioactive isotopes.

Chemotherapy:
Includes antimetabolites, alkylating agents, vinca alkaloids and antibiotics, among other agents.

Hormone:
Includes administration of hormones/ steroids, and in some cases, endocrine surgery.

Combination Therapy:
Includes possible combinations of surgery, radiation, chemotherapy and hormone therapy.

Immunotherapy:
Passive immunization of an individual by administration of pre-formed antibodies actively produced in an individual.

No Treatment:
A treatment option that includes cases in which no information was available or no treatment was received.

Non-Analytic Cases:
Cases that were not seen at Children's Hospital within the first four months following diagnosis (two months for leukemia) or who were first diagnosed at autopsy. This class of case is usually not included in a report of hospital's treatment and survival statistics. In accordance with the American College of Surgeons guidelines for approved cancer programs, these cases must be accessioned and a patient index record prepared. Although abstracting and lifetime follow-up are encouraged, these are matters of local decision by the hospital cancer committee.

Stage: The extent to which a primary tumor has spread from its original site. The extent of disease is determined at the time of diagnosis and/or initial therapy.

Surveillance, Epidemiology and End Results Program (SEER):
A registry conducted by the National Cancer Institute for the collection and analysis of data on the incidence and treatment of cancer and survival of cancer patients in the United States. A staging system was developed in 1977 by SEER and is approved for use in cancer registries by the American College of Surgeons Commission of Cancer.

Survival:
All survival statistics were calculated using the actuarial or life-table method for observed survival rate. This method takes into account both patients with observations for varying lengths and patients lost to follow-up.

TNM:
A staging system developed by the American Joint Committee on Cancer, in which T stands for the size of the tumor, N for lymph node involvement and M for metastasis.

Telephone Directory & Referral List

Children's Hospital Main Number	(504) 899-9511
Oncology Department	(504) 896-9740
Oncology Department Fax	(504) 896-9758
Oncology Unit – inpatient	(504) 896-9442
Oncology – outpatient clinic	(504) 896-9848
Neurosurgery Department	(504) 896-9568
Social Services Department	(504) 896-9367
Surgery Department	(504) 896-9478
Orthopaedics Department	(504) 896-9569
Medical Records/Tumor Registry	(504) 896-9585
Administration	(504) 896-9450
Diagnostic Radiology	(504) 896-9565
Pathology Department	(504) 896-9873
Bone Marrow Transplant Program Lolie C. Yu, MD	(504) 896-9740
Cancer Committee Chairman Renée V. Gardner, MD	(504) 896-9741
Cancer Program Liaison Evans Valerie, MD	(504) 896-3977

CANCER INFORMATION/RESOURCES

American Cancer Society	(800) ACS-2345
American Cancer Society, New Orleans Chapter	(504) 465-8405
National Cancer Institute	1-800-4CANCER

CANCER INFORMATION WEB SITES

American Cancer Society	www.cancer.org
National Cancer Institute	www.cancer.gov
Children's Hospital, New Orleans	www.chnola.org

FINANCIAL

Medicaid – Enroller	(504) 896-9152
Office of Family Security	(504) 599-1700
Social Security	(800) 772-1213
Children's Hospital Assistance Program (CHAP)	(504) 894-5166
American Cancer Society	(504) 469-0021
Leukemia/Lymphoma Society	(504) 887-0945
Optimist Leukemia Foundation	(225) 925-8926
Easter Seals (wheelchair loans)	(504) 455-5622
National Children's Cancer Society	(314) 241-1600
Cancer Recovery Fund	(717) 564-4100
First Hand Foundation	(816) 201-1569
Cancer Association of Greater New Orleans	(504) 733-5539
Total Community Action	(504) 821-2000

HOUSING

Ronald McDonald House	(504) 468-6668
American Cancer Society Patrick F. Taylor Hope Lodge	(504) 219-2202
Hotels – medical rates list available in Social Services Department	

WISHES

A Child's Wish	(504) 367-9474
Make-A-Wish	(504) 314-9474
Starlight	(323) 634-0080
A Special Wish	(614) 575-9474
Troop "B" State Police	(504) 450-7143

SUPPORT

Candlelighters	(301) 657-8401
Sperm Bank Reproductive Services	(504) 454-7973
Camp Challenge	(504) 347-2267
Sunshine Kids	(713) 524-1264
Hip Hop Hats	(813) 229-2377
Locks of Love	(888) 896-1588

MENTAL HEALTH

Rehabilitation Program	(504) 483-0415
Hospital Administration Review Process	(504) 568-5939
Angel's Place (Respite Care)	(504) 455-2620
COPELINE	(504) 523-2673
Caps for Kids	(504) 891-4277

DEATH

Compassionate Friends	(504) 887-4599
Seasons – The Center for Caring	(504) 834-1453
Hospice Care of Louisiana	(504) 484-6161

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