

# 2007 Annual Report

2 0 0 6 S T A T I S T I C S



CHILDREN'S  
HOSPITAL

**THE CANCER PROGRAM AND THE LANASA-GRECO CENTER  
FOR CANCER AND BLOOD DISORDERS**

# About Children's Hospital, New Orleans

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](http://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

## **About the Cover**

Pictured at Audubon Zoo are Lauren Wright, 3; Chellia Tyson, 2; and Makayla Dillion, 2.

## **Acknowledgements**

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# 2007 Annual Report

## THE CANCER PROGRAM AND THE LANASA-GRECO CENTER FOR CANCER AND BLOOD DISORDERS

### P A T I E N T P R O F I L E



**NICOLE DUPONT**  
*New Orleans, Louisiana*



**SHIVAS GILOTRA**  
*Kenner, Louisiana*



**DEVIN LEBOEUF**  
*Thibodaux, Louisiana*

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# Chairman's Report

**Renée V. Gardner, MD**

The previous year has been an incredibly busy one. After the events of the past two years, including the summer of 2005, we have focused our efforts on continued recovery and giving excellent comprehensive care to the children of Louisiana who have been diagnosed with cancer, sickle cell disease and other blood disorders. As a part of that effort, we remain a part of the Minority Community Clinical Oncology Program (CCOP) awarded to the Stanley S. Scott Cancer Center in New Orleans—one of a few centers in the United States that have been so honored. We also are a part of the Cancer Control Consortium and are the only Bone Marrow Transplantation Center in the Gulf Coast region that has been officially approved or certified by the Children's Oncology Group (COG) to perform transplantations.

In 2006 - 2007, we also received other welcome recognition of our efforts to maintain a high caliber of education and care:

1. We received commendation and approval for our program from the American College of Surgeons (ACoS), Commission on Cancer. We are one of a handful of pediatric centers in the country who received their ratification of a pediatric oncology program as meeting the standards or guidelines approved by them for providing for the needs of and rendering care for children with oncologic disorders.
2. Our fellowship program was again accredited by the Accreditation Council for Graduate Medical Education (ACGME) to the year 2011. Teaching remains an important focus for our program and the continuation of the program and its accreditation attests to the hard

work and effort made by the faculty of the Division of Pediatric Hematology/Oncology, spearheaded by Dr. Maria C. Velez, and associates who are dedicated to setting high standards and lofty goals of education and health care delivery.

The world remains interested in our experiences revolving around Hurricane Katrina, especially our responses to perceived shortcomings after the storm. Our efforts to improve after the hurricane included a rehaul or improvement of our Web site; plans to acquire electronic medical records; better dissemination of hurricane preparedness plans; provision to families and physicians of information about each child's illness, including the use of handouts and fliers informing parents and patients of our planned whereabouts in the event of evacu-

ation; and the use of memory sticks by children's health care providers to allow better continuity of information and care. Such was the interest of others in our experiences that our members were continually asked to relate them at national and international fora, including a Survey Savvy Workshop sponsored by the American College of Surgeons, where our preparations were taken as a lesson on disaster preparedness and reaction for other programs.

Our patients are still coming home and, as previously noted, we have entered into various partnerships with organizations such as the American Cancer Society to provide services for our families. Such services have included the presentation of travel vouchers to families in need, a service provided through a grant from the American Cancer Society; and also the use of Hope Lodge, a facility for those

with cancer who will need lodging during prolonged stays for therapy. The Social Services Department of Children's Hospital is also giving assistance to those in need of such help. Children's Hospital has received a grant of monies from the government of Qatar in the wake of Katrina, and I think that it can be truthfully said that no child requiring care has been or ever will be turned away from this institution. The Administration of this institution has been phenomenal in seeing to the continued provision of care to the children of Louisiana.

Unfortunately, this year has not been without sadness. Several of our members have left us, going on to other opportunities and workplaces. This number has included not only more recent acquaintances such as Dr. Jeffrey Hittson of the Pathology Department or Nurse Coordinator Kathleen Finigan, but

also long-time friends such as Mrs. Michele Hermann, director of Medical Records; Ms. Laurie Hebert, our cancer registrar, and Dr. Raj Warriar, co-founder of the Department of Hematology/Oncology. Dr. Warriar has gone on to become vice-chancellor of the University of Manipal, Manipal, India. While we laud Dr. Warriar for this well-deserved recognition and coveted position, we sincerely miss him as a friend, mentor and caregiver. However, we are ever more committed to the commission that we have all accepted in becoming physicians, nurses, support staff, technicians and the like—that of delivering excellence in healthcare, teaching, research, and the attainment of humane and compassionate service.

# 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 Fresh-Start 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.

## 2006 – 2007 Cancer Committee

**Renée V. Gardner, MD**

Cancer Committee Chairman, Hematology/Oncology

**Evans Valerie, MD**

Physician Liaison, Pediatric Surgery

**Elany Balbuena-Rome**, Medical Records

**José Bermudez, MD**, Neurosurgery

**Simone Bienvenu, RN**, Quality Assessment & Improvement

**Rachel Bufkin, CTR**, Cancer Registrar

**Kay Casey, MSW**, Social Services Department

**Randall D. Craver, MD**, Pathology/Laboratory Department

**Camille Ennis, RN**, Clinical Trials Center

**Douglas S. Faust, PhD**, Psychology

**Cathleen Finigan, RN**, Hematology/Oncology

**Cherie Hadley, RN**, Hematology/Oncology

**Marie-Louise Haymon, MD**, Radiology

**Laurie Hebert, RHIA, CCS, CTR**, Cancer Registrar

**Stephen Heinrich, MS, MD**, Orthopedic Surgery

**Michelle P. Hermann, MS, RHIA**, Director of Medical Records

**Amy Lee**, Child Life Specialist

**Joseph Nadell, MD**, Neurosurgery

**Lisa Patterson, RN**, Hematology/Oncology

**Mary Perrin**, Vice-President, Hospital Operations

**Giddel Thom, MD**, Fellow, Hematology/Oncology

**Arnette Scavella, MD**, Fellow, Hematology/Oncology

**Maurice Sholas, MD**, Physical Medicine & Rehabilitation

**Tammuela C. Singleton, MD**, Hematology/Oncology

**Robert Swanton, MD**, Radiation/Oncology

**Maria C. Velez, MD**, Hematology/Oncology

**R.P. Warriar, MD**, Hematology/Oncology

**Lynn Winfield, RN, BSN**, Nurse Manager, 4 West

**Lolie C. Yu, MD**, Hematology/Oncology

**Ellen Zakris, MD**, Radiation/Oncology

**Robert Zanca**, Clinical Trials Center

# Analysis of Late Effects of Brain Tumors Diagnosed at Children’s Hospital, New Orleans, 1986 – 2000

**Elizabeth Conrad, BA; Randall Craver, MD; Maria C. Velez, MD and Renée V. Gardner, MD**

Brain tumors are the second most common malignancy in children and have an incidence of 3.3 cases per 100,000 children per year. The incidence peaks in the first decade of life and is characterized by a slight male predominance (M:F=1.1:1). Treatment of brain tumors is multidisciplinary, involving surgery, radiation therapy and chemotherapy. While deaths due to central nervous system (CNS) tumors are the highest among pediatric cancers, improved diagnostic techniques and superior treatment modalities or approaches have resulted in better overall survival for all CNS tumors of about 70 percent. Such improvement, however, has not come without a price, since morbidities, especially those involving the endocrinologic, neurologic, or psychosocial and intellectual arenas,

have become increasingly apparent with the evaluation of larger numbers of survivors.

Morbidities that have been described include linear growth defects in up to 30 – 35 percent of brain tumor survivors. This is especially a problem for those who receive craniospinal irradiation at doses exceeding 1800 cGy. Neurocognitive sequelae can be severe and limiting. The risk of this development increases with young age at time of treatment, higher radiation dose and female gender. Such complications usually become apparent one to two years after treatment and unfortunately are progressive over time.

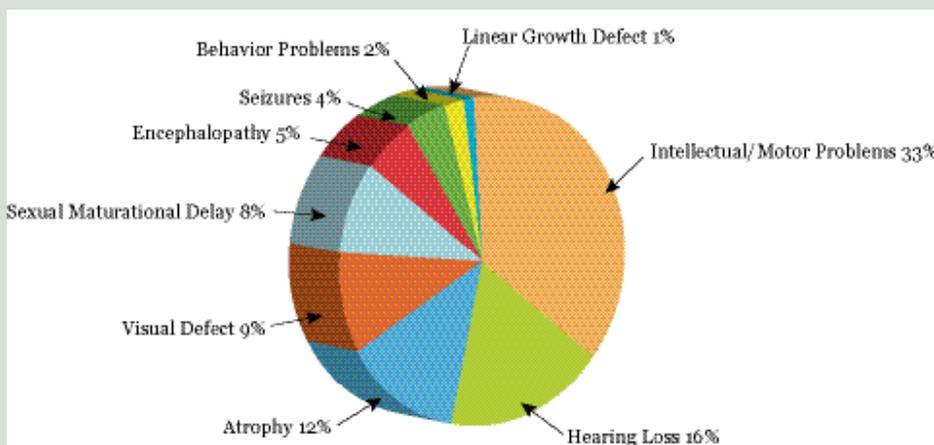
Other problems seen in survivors of central nervous system tumors

include: 1. auditory deficit, especially in those receiving concomitant platinum-derived agents and irradiation; while this deficit can be merely loss of high frequency hearing, not affecting hearing within speaking range, the loss can be profound or complete; 2. ocular dysfunction including cataracts, Sjogren’s syndrome (extreme dryness of the eyes); 3. behavioral problems which make school reentry and achievement very difficult; and 4. the occurrence of second malignancies.

Effects of irradiation on the brain can be either acute (occurring during therapy), subacute or early delayed (a few weeks to two months afterwards); or late (at times occurring years after administration of therapy). They may range from fatigability, short-term memory loss, or focal brain necrosis, white matter changes termed leukoencephalopathy, or significant drops in IQ.

It is therefore imperative that we recognize early on these long-term sequelae and devise strategies to deal with them. The aim then of this study was to analyze data on children diagnosed at Children’s Hospital with malignant CNS tumors from 1986 through 2000, and surviving at least five years from diagnosis, with an objective of: determining the rates of early and late sequelae in these children; correlating histologic diagnoses and the development of late sequelae; and evaluating the therapies received

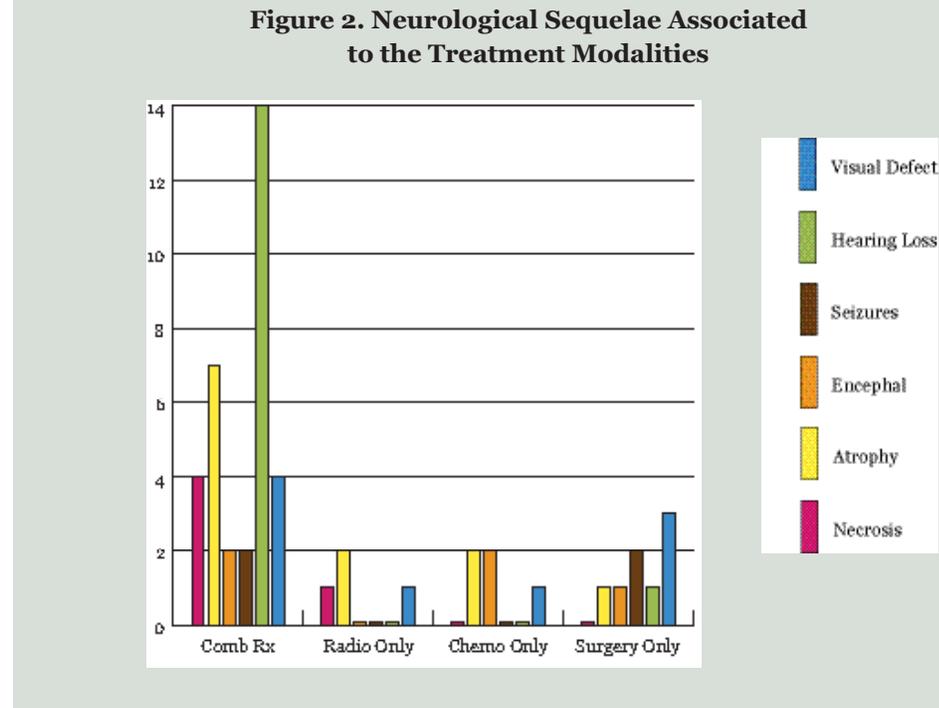
**Figure 1. Reported Late Effects**



by these children and their association with the identified morbidities.

We conducted a retrospective analysis of charts, collecting data on all patients diagnosed with CNS tumors through the inclusive period, using Tumor Registry data. Although 296 patients were identified, patients with spinal cord tumors, germinomas, and CNS lymphomas, as well as various miscellaneous malignant tumors were excluded. Patients included for study carried diagnoses of medulloblastoma, astrocytoma or ependymoma and, as noted, had survived at least five years from diagnosis. IRB approval was obtained prior to conduct of the study.

Of 296 patients originally identified as having a CNS tumor, 225 were found to have a malignant tumor. After eliminating patients who did not fit the inclusion criteria that had been set, 69 patients were eligible for study. However, 17 charts were either not available for review or were incomplete. Ultimately, 42 charts remained for consideration. Of those tumors reviewed, 50 percent or 21 were astrocytomas, 38 percent or 16 were medulloblastomas, and 12 percent or 5 were ependymomas. There were 27 females and 15 males for a male:female ratio of 1:1.7. Thirty (71 percent) patients were white, 15 (24 percent) were black, 1 (2 percent) was Hispanic, and 1 (2 percent) was



Asian. The average age at diagnosis was 5 years. When histologic tumor types were compared for age at presentation or diagnosis, patients with astrocytoma and medulloblastoma presented at comparable ages (4 years [range, 0.25 – 9 years, astrocytoma] vs. 4.5 years [range, 1 – 14 years, medulloblastoma] while those with ependymoma had a median age at presentation of 8 years [range, 1.3 – 12 years]. The average time to diagnosis was 3 months and there was no significant deviation in this data based on histology.

A number of late effects were noted among our survivors. These are shown in Figure 1. Intellectual or

motor problems (33 percent), hearing loss (16 percent), and cortical atrophy (12 percent) were reported most often. Neurologic sequelae were variable and included: radiation necrosis and cortical atrophy, as well as seizures, visual defects, hearing loss and encephalopathy. As might be expected, the greatest number of complications was noted in those individuals who had received combined modalities of radiation and chemotherapy, after surgery (Figure 2). The same was true for neuroendocrinologic deficits which again were more likely to occur in those receiving combination therapy. Interestingly, our patients who received only radiation therapy had no recorded neuroendocrinologic difficulties, but those getting only chemotherapy had a minimal number of recorded deficits of this type. The deficits reported in affected individuals included growth hormone deficiency, hypothyroidism and delayed sexual maturation. While cognitive and behavioral problems were seen after all treatment types, again combination therapy was more likely to be associated with this morbidity.

**Table 1. Types of Morbidity**

Type of Morbidity	Lit.-Based (%)	Children's Hospital	Citation
Decreased growth	30 – 35	17	3
Loss of IQ	42 <sup>*</sup>	31	4
Hearing loss	10 – 15	40	5
Second malignancy	14 – 20	0	6
Hypothyroidism	30 – 90 <sup>†</sup>	19	7

*Comparison of Our Experience with Literature-Based Data*

<sup>\*</sup>Data is taken from paper considering outcome for treatment of medulloblastoma

<sup>†</sup>Represents actuarial risk

## Summary

The greatest number of late effects was then seen with combined chemotherapy-radiation regimens and accordingly in those diagnosed with medulloblastoma. Patients receiving such therapy had a higher percentage of problems with sexual maturational delay or precocious puberty, growth hormone deficiency, linear growth defects, learning impairment, brain atrophy and necrosis. At least 1/3 of patients experienced intellectual impairment after such treatment. Seizure disorders were seen more commonly in those undergoing surgical resection only.

There are several studies that have examined late sequelae of brain tumor and the therapies rendered. A comparison of these studies with our own may be hampered by incom-

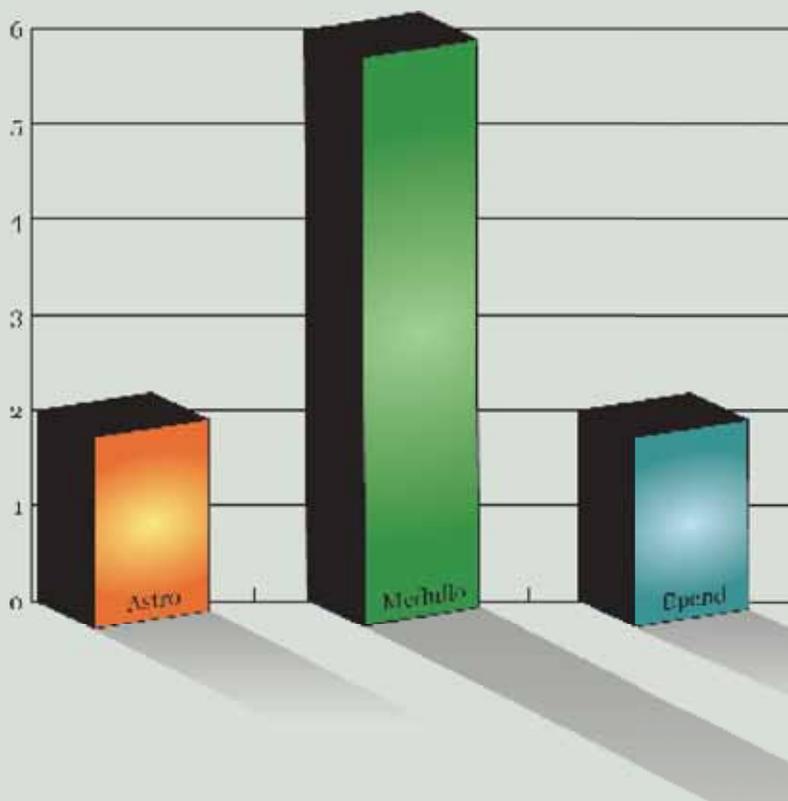
parability of techniques and treatment approaches over the years with current management strategies. Our patient population differed somewhat from the published data. For instance, we had a M:F ratio of 1.7:1 (national M:F=1.1:1). Also, patients diagnosed at Children's Hospital with astrocytoma were diagnosed at an earlier age than in published series (median age, 9 – 10 years, national), while our patients diagnosed with ependymoma tended to be older (median age, 5 years, national).

Outcomes varied as well. In our study, for instance, 36 percent of patients experienced moderate to severe hearing loss; this can be contrasted with 10 – 15 percent hearing loss reported in the literature. However, the higher frequency of hearing loss in our population may be the result of more recent incorpo-

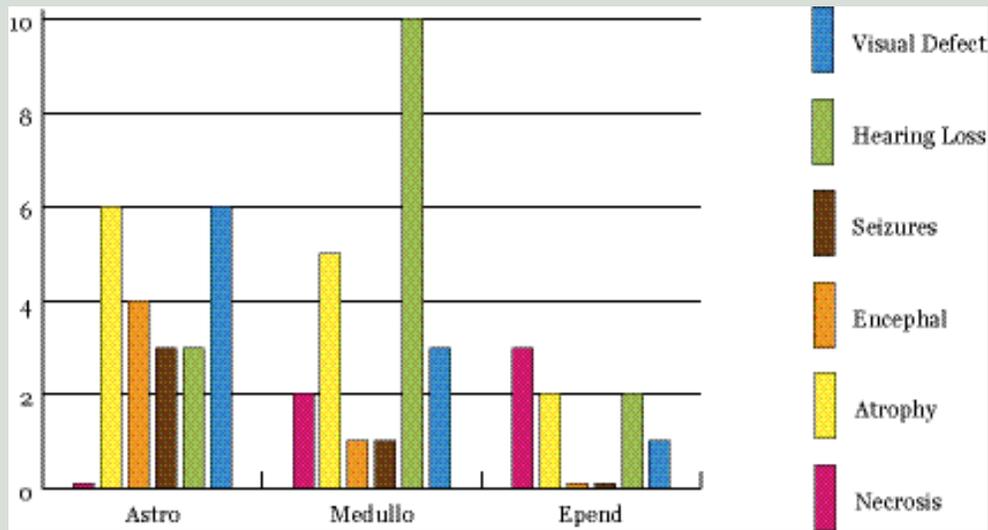
ration of platinum-based medicines into treatment regimens which include radiation. It is notable too that only 19 percent of our population developed hypothyroidism. This can be compared to a much higher rate reported by others. With regards to IQ or other parameters of intellectual functioning, we observed loss of intellectual functioning in 31 percent of patients (published, >40 percent). Significantly we did not see any second malignancies (see Table). Whether these differences are due to variances in the therapeutic regimen or better surveillance or supportive measures is unclear.

However, it may be that more morbid consequences of therapy will be the price we must pay for improved and prolonged survival. If so, we must devise means of enabling these patients to better cope with

**Figure 3. Average Late-Effect Events Per Patient by Histology**



**Figure 4. Neurological Sequelae by Histology**



the debilities imposed upon them by the newer treatment strategies. Certainly, better supportive assistance is indeed called for, along with efforts at remediation. We in Hematology/Oncology are currently working together in multidisciplinary teams comprised of rehabilitation specialists, occupational and

physical therapists, nurses, audiometrists and others to insure that our patients, having survived brain tumors can go on to have meaningful and productive futures.

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# Assessment of Obstacles to School Re-entry Among Children with Cancer

**Harold E. Jimenez, BA; Maria C. Velez, MD; Lolie C. Yu, MD; Diane Franz, PhD and Renée V. Gardner, MD**

In 2004, 9,200 children were diagnosed with cancer in the United States. Between 1996 and 2003, the five-year survival rate was 81 percent. Survival unfortunately often means late sequelae, including learning and behavioral problems. In one study of childhood cancer survivors, 54 percent had mild (grade I – II) late effects but 39 percent developed moderate to severe (grade 3 – 4) morbidities; >2 late effects were observed in 70 percent of survivors.

The treatment of a child who has been diagnosed with cancer is of variable duration and intensity, depending on the type of cancer the child may have. The treatment period is rife with stress or anxiety and more often than not is associated with disruption of the child's educational experience. However, it is widely

accepted that an individual's later success in life depends greatly upon their performance in school. By missing an excessive number of days while attending clinic or during hospitalization, the child may be penalized later by failure in his current grade. He/she may find it more difficult to learn new material or maintain grade level competency after missing numerous days of instruction. Social readjustment to the school environment can be more difficult because of the extended absence from his peers, as well as the isolation and divergent experience that stem from having a life-threatening disease. Such social maladjustment may impede the learning process. Poor physical health may interfere with success also, but chemotherapy, surgery with resulting permanent physical defects, and radiation may all lead to neuropsycholog-

ic problems among survivors of childhood cancer and create difficulties for the child by damaging self-image or self-confidence. Neurocognitive defects, memory loss and attention deficits all can contribute to difficulties experienced by this special group of young people. In short, one cannot have normal intellectual development or educational attainment, development of social skills or establishment of normal peer relationships without the skills learned usually in schools earlier in life.

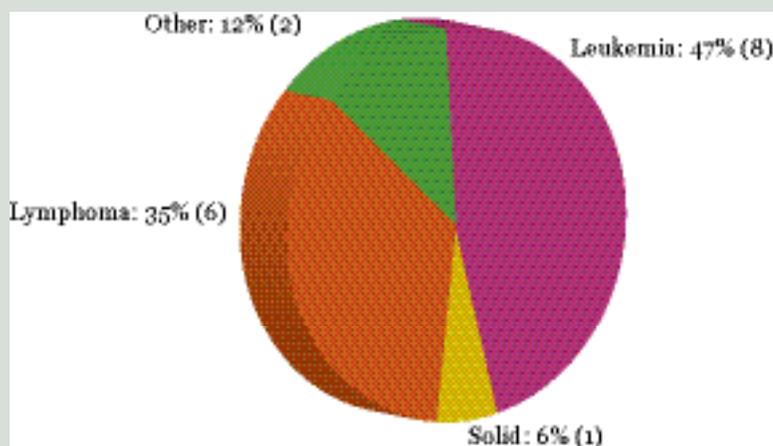
## Methods:

We wished to evaluate the effect(s) of various cancer therapies on the school performance and ease of school reentry of children diagnosed with cancer. The children had been treated with a variety of regimens at Children's Hospital. Parents of patients followed at Children's Hospital were queried about their child's school performance pre- and post-diagnosis, the presence of memory loss, documented loss of IQ, difficulties with behavior and learning problems, e.g. difficulties with comprehension or assimilation of new data. Surveys were conducted in compliance with HIPAA guidelines.

## Results:

Seventeen patients were randomly selected for study. Their parents were appropriately consented and interviews were then conducted in the clinic. Patients were 6 – 21 years old at the time of study and had attended school prior to the initiation of treatment. They must have returned to school by the time of the interview. Among these chil-

**Figure 1. Diagnosis Type**



dren, 11 (65 percent) were male and 6 (35 percent) female. Twelve (70 percent) were white, 3 (18 percent) were black, and 2 (12 percent) were Hispanic. Grades attended ranged from pre-K classes to 12th grade. Three (18 percent) were 6 – 10 years of age, 5 (29 percent) were 11 – 15 years, while 9 (53 percent) were 16 – 21 years. Disease types are shown in the accompanying graph (Figure 1). Children with brain tumors were excluded from the study since they represent a group of patients in whom therapy- and disease-related morbidities, especially those of a neurocognitive nature can be severe and quite limiting. Treatments rendered included chemotherapy only (64 percent), combination of chemotherapy and surgery only (18 percent), and combination of chemotherapy with radiation and/or surgery (12 percent).

As expected, time lost during the school year because of treatment in hospital was at times inordinately

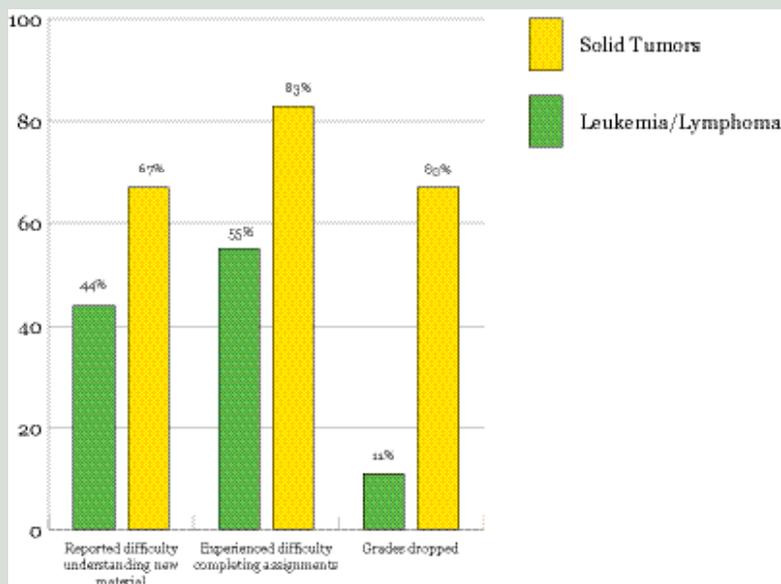
great. Seventy-six percent of respondents reported that their child was absent from school for more than 12 weeks. Even after returning to school, patients lost school time while attending clinics. These visits could be for therapy but also just for follow-up. Forty-six percent of children missed more than 10 days of school for attendance of clinic alone.

Just under half of the patients experienced no change in their grades, but 29 percent saw a decline in their grades after treatment, and 12 percent had improvement in their grades. Over half (53 percent) of parents felt their child had difficulty comprehending new material in their classes and 65 percent stated that the child had more difficulty completing academic assignments. Memory, at times, appeared to be affected and children were often inattentive in class. These reported changes in academic performance are demonstrated in Figures 2 and 3 and it can be seen that children with solid tumors had

significantly more academic difficulties than did those children diagnosed with leukemia or lymphoma.

A cancer diagnosis often signals behavioral problems, as well. After the child had received treatment, 59 percent of parents reported non-specified changes in the child's behavior. Of note, commonly children were described as more easily fatigued and more quiet or reserved. Thirty-five percent of children appeared to have difficulty maintaining or forming friendships and accordingly had fewer friends. Forty percent reported not enjoying going to school as much as they had beforehand. An increased incidence of behavior reports, e.g. demerits, detentions, or suspensions were observed in 29 percent of the studied children. Professional counseling was sought for 41 percent of the children. Here, however, such behavioral changes did not vary significantly according to disease type. The percentage of those receiving "special education" services was not identified.

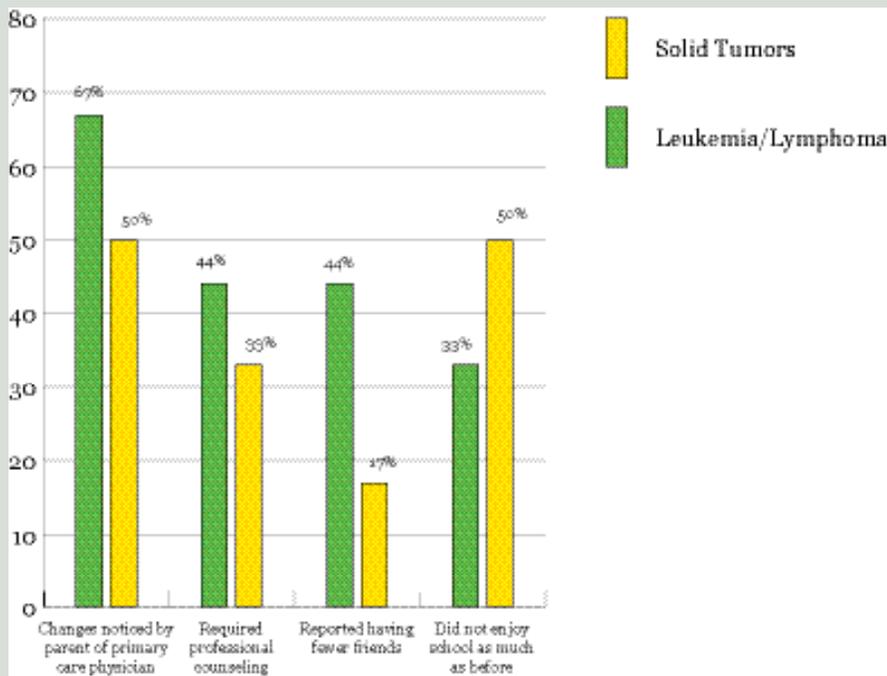
**Figure 2. Comparison of Academic Change Leukemia/Lymphoma (n=9) vs. Solid Tumors (n=6)**



**Discussion:**

Although the majority of our patients did not receive radiation, a treatment modality most frequently resulting in neurocognitive deficiency, a significant number of them were felt by their parents to have demonstrable difficulties with school performance, even when their grades did not suffer. Difficulty in completing academic assignments or difficulty comprehending new material, memory defects, and attention deficits were all variably reported. The child's behavior was also affected and at least a third experienced difficulty in making friends. It is notable that parents of children diagnosed with solid tumors were more likely to report these problems. This could be the result of more intensive regimens used in the treatment of solid tumors, that necessitated inpatient rather than outpatient therapies or were associ-

**Figure 3. Comparison of Behavioral Changes  
Leukemia/Lymphoma (n=9) vs. Solid Tumors (n=6)**



ated with more complications for which the child required hospitalization; accordingly, patients would have more absences from school, a factor that could impede their social and educational progress.

While the study raises many interesting questions and presents us with valuable data, the study group was small and conclusions are therefore limited. The study will continue on so that numbers can be expanded. Control groups are also needed to ensure that the observed effects are indeed related to treatment and not randomly occurring events. Treatment types have not been separated out yet, since statistical consideration of the differential effects of various treatment regimens will need larger numbers.

There is surprisingly scant data on the issue of school reentry in cancer patients. In one study, 27 patients, ages 16 – 26 years, were studied. A significant proportion of these

patients developed physical health problems which conceivably could have impeded their later academic performance. However, many of these individuals also had significant memory deficits and lower verbal and performance IQs. One in five was diagnosed with reading or writing problems that interfered with their academic success, and these children were much less likely to go on to and complete high school. Interestingly, in another study, 80 percent of leukemia survivors experienced learning problems after CNS prophylaxis with cranial irradiation. Those not receiving this modality of therapy had no more problems with academic performance than did healthy controls.

We acknowledge a need to look more closely at the children's pre-diagnosis academic function, since in children with other debilitating illnesses, such as severe burns, only those having problems before the injury went on to have problems afterwards. As

noted, a breakdown of treatment type is needed. Systematic evaluation of patients' pre- and post-therapeutic psychometric function is also a must. Nevertheless, despite the small study numbers and shortcomings of the current work, the need to devise an organized program to assist patients with school reentry is evident. With children having burn injury, it was noted that successful reentry was more likely if preparation started as soon as possible after diagnosis and onset of treatment.

Programs were individualized to meet a particular student's needs. Patients returned relatively quickly after discharge from the hospital, and team professionals remained available for consultation with teachers and counselors.

Efforts involving all members of the team, whether managing physician, nurses, social workers, counselors or physical and occupational therapists are essential. Recognizing the difficulties often experienced by our patients on taking the first step, i.e., returning to school, to regain normalcy is crucial. We have begun to lecture school professionals on the difficulties children experience during and after treatment for cancer. We have listed for these school officials problems, both acute and late, that can be seen in this population of children. We have been attempting to identify those measures that need to be taken to facilitate or smooth the way for the child's resumption of school activities. A concerted effort is being made to systematize our efforts and maintain close and supportive relationships with parent and child.

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## NICOLE DUPONT

Playing in the schoolyard one day, one of Nicole DuPont’s classmates noticed an unusual bump on the right side of her neck and pointed it out to her. When the 12-year-old showed her parents that night, they immediately scheduled an appointment with her pediatrician. He advised the DuPonts to keep an eye on it and keep him posted if it made any changes. Instead, they took her to their ear, nose and throat doctor, who ordered a biopsy. On the day before her 13<sup>th</sup> birthday, she was diagnosed with stage four Hodgkin’s lymphoma.

“I remember crying for hours. Then I said to myself, ‘Stop crying. You’ve got to face it. There’s no way of getting around it,’” Nicole said.

Nicole’s doctor referred the DuPonts to Children’s Hospital’s Oncology Department and she began her battle against cancer.

“We wanted the best, and Dr. Velez was the best for my type of cancer,” Nicole, now 21, said. “Dr. Velez is an empowered woman. That meeting was pretty intense, but we were told it was a very curable cancer. I was given a good chance to beat it,” she said. “Dr. Velez inspired me and made everything comfortable. After my first meeting with her I was ready to kick this thing. It was a complete change from my initial reaction.”

While Nicole was gearing up for the fight of her life, the first question she asked her doctor was typical of a girl about to enter her teenage years.



***Lee, Nancy and Nicole Dupont with boyfriend, Brian Perry, Jr.***

“My first question was will I lose the hair on my legs,” she says with a laugh. “Wow, what perspective!”

Nicole underwent an intense three-month chemotherapy session that killed her cancer and changed her outlook on life. “I was a brat,” she said of her pre-cancer days. “I wanted my way and threw tantrums if I didn’t get it. But once I got in the hospital, my attitude changed. I didn’t complain. I just wanted to beat it.

“It also strengthened us as a family. It made us more aware of the love we had for one another. I focused more on others and how they felt. Superficial things didn’t seem to matter. I changed. I didn’t want to be cool. I just wanted to be me.”

In 2008, Nicole will celebrate the 10-year anniversary of her cure.

“I wouldn’t be the person that I am today had I not had cancer,” she said. “It was a positive experience overall. It focused me, made me grow up. My life is totally different. I don’t take anything for granted. I’m thankful for the little things and thank God for everything — an A on a test or no spiders in the trees when I ride my horse, Honey.”

Nicole just finished her first year at the Louisiana State University School of Nursing. She wants to go into pediatric oncology because of her experiences.

“I want to pay back my dues,” she said. “I love it. I want to help people. I don’t want to do anything else.”

# 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.

## **Music, Recreation and 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, whether temporary or permanent, such as stroke in sickle cell or hemiparesis in brain tumor. Working with physical, occupational and speech therapy services, nursing, nutritional and other services, Rehabilitation Medicine, under the capable guidance of physiatrist Dr. Maurice Sholas, has integrated these and other services to improve or 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 nutrition-

ist 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 health care 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.

### **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 con-

nects 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 annually 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 which is 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.

## SHIVAS GILOTRA

It seems Shivas Gilotra has known cancer his entire life. Diagnosed with Acute Lymphoblastic Leukemia (ALL) at 3 years old, he immediately underwent treatment to battle his cancer. He was pronounced cured at 8, but relapsed a year later and began his second bout against the disease. His life was saved when his younger sister donated bone marrow for the transplant performed here at Children’s Hospital under the care of Dr. Lolie Yu. Once cured, he dedicated his life to helping others beat cancer and became an advocate for the “miracles” that occur daily at Children’s Hospital.

Shivas grew up thinking his condition was universal for everyone.

“Being so young that was the only perspective I had, so it was normal to me,” Shivas said. “I call Children’s Hospital my second home. I was here as often as I was at home. It was only when I got older and realized I was missing school and stuff like that when I realized I wasn’t the same as the other kids.”

The Gilotras grew closer as a result of his disease, he said. “My family was my base. My mom, dad, sister and brother pulled me through. My sister’s blood runs through my body. I hug them every chance I get. I hope they know how much they are appreciated.”

Today Shivas is looking forward to graduating from the Louisiana State University School of Nursing in December 2009 and hopes to work in pediatric oncology.

“Being a survivor I feel like I’ll have an advantage helping those who are going through it now,” he said. “I understand the consequences of treatments, how it feels and how it helps. I want to utilize that. I want to help someone else who is suffering by easing their fears and letting them and their family know what to expect.”

Shivas credits the nurses who cared for him as his reason for wanting to join their ranks.



***Pictured, clockwise from top left, Shivas Gilotra with his father, Sudhir; sister, Shivani; mother, Madhu, and brother, Shakti.***

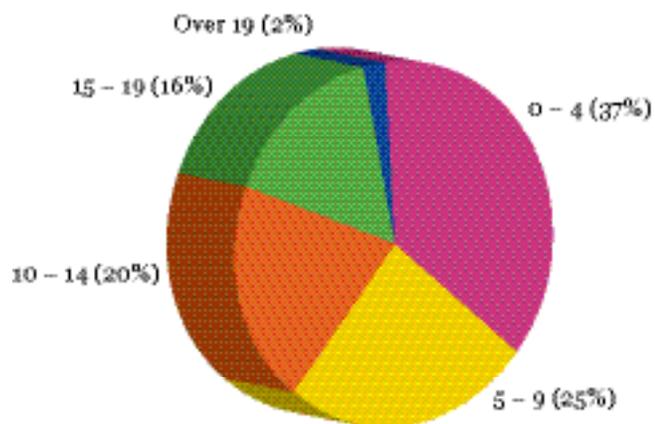
“They acted like an extended family and provided so much support,” he said. “My mom was in nursing school and my dad was in the process of opening his own business. There were times when my parents had to go to work, and my nurses were always there going out of their way to show they really cared about me. They made me comfortable. They made me smile. They held me when I needed it. They tucked me in when I was sleepy. They made all the difference. It made me forget about being sick and provided motivation. Without the support I got, I wouldn’t be here, and I want to give back by providing support to all I can.”

If he has his way, he’ll have a homecoming of sorts when he finishes his schooling.

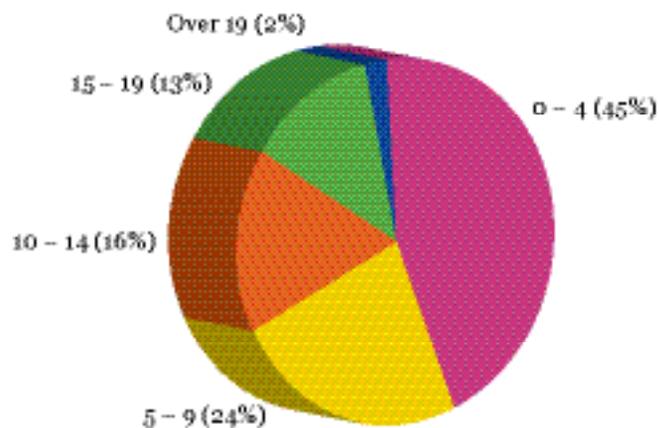
“I love Children’s Hospital and would love to work there eventually. I’ve got a deep attachment to the hospital and the people here. The atmosphere here promotes a better outlook. It’s a happy place, calming. It’s got a good aura,” he said. “There’s definitely a sense of love here. You can’t get around it.”

# Cancer Statistics

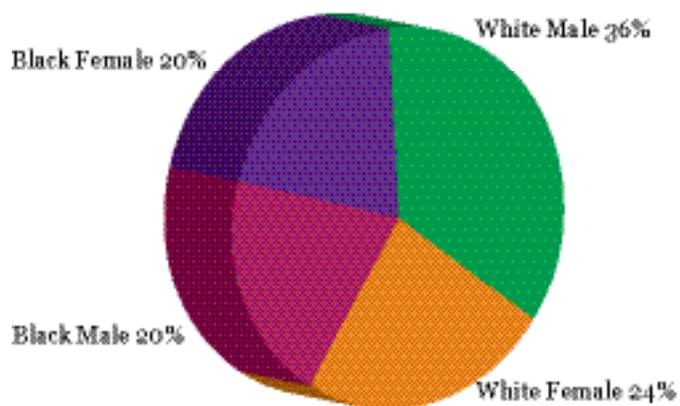
**Age at Diagnosis**  
2004 - 2005



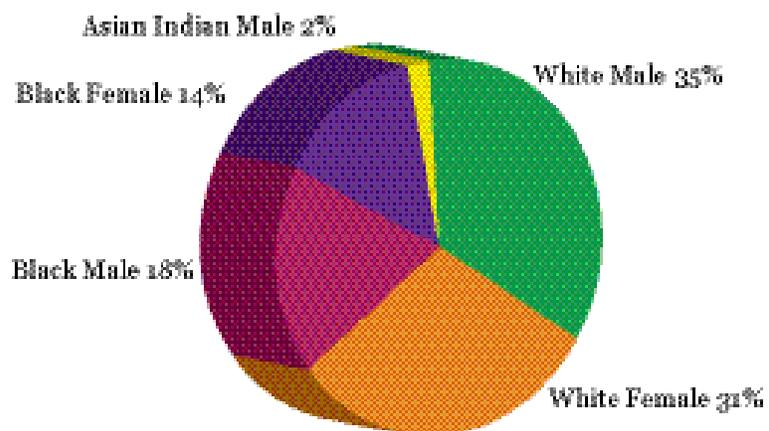
**Age at Diagnosis**  
2006



**Distribution**



**Distribution  
by Sex and Race**



# 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 Précis Hospital. 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, 2006, the cancer registry has accessioned 1,413 cases. A comparison of Children’s Hospital data from 2004, 2005 and 2006 is presented in the Cancer Statistics section (page 18) of this report. The following discussion will focus primarily on Children’s Hospital analytic case

data from 2006. In 2006, a total of 67 cases were accessioned:

- 82 percent (n=55) being analytic and 18 percent (n=12) being non-analytic.
- 56 percent (n=31) were male and 44 percent (n=24) were female.
- 7 percent (n=4) of our patients resided in Orleans parish.
- The median age at diagnosis of our patients was 6.
- 35 percent (n=19) were white males with the highest incidence of cancer.
- 27 percent (n=15) were white females with the second highest incidence of cancer.
- 16 percent (n=9) were ALL patients which was our most common histology in 2006.

In order to evaluate cancer care outcomes, the cancer registry maintains long-term follow-up on eligible patients included in the registry. The American College of Surgeons (ACoS) requires an 80 percent follow-up rate on eligible patients (both living and deceased) for survival analysis. The cancer registry has

been able to successfully maintain the required follow-up rate.

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.

## Top Five Sites

<i>Site</i>	<i>Number of Cases</i>	<i>Percentage of Cases</i>
Bone Marrow	13	23%
Brain & CNS	12	22%
Lymph Node	8	15%
Adrenal	5	9%
Kidney	2	4%

# About The LaNasa-Greco Center for Cancer and Blood Disorders

## Physicians and Staff

### **Lolie C. Yu, MD**

*Division Chief,  
Pediatric Hematology/Oncology  
Director, Bone Marrow  
Transplantation Program  
Professor of Pediatrics*

### **Renée V. Gardner, MD**

*Director, Sickle Cell Clinics  
Professor of Pediatrics*

### **Tammuella C. Singleton, MD**

*Assistant Professor of Pediatrics*

### **Maria C. Velez, MD**

*Director, Fellowship Program  
Associate Professor of Pediatrics*

### **Fellows**

Faisal Razzaqi, MD  
Corey Morrison, MD  
Quan Zhao, MD

### **Nurses**

Cherie Hadley, RN  
*Pediatric Nurse Coordinator*  
Lisa Patterson, RN  
*Bone Marrow Transplant Nurse  
Coordinator*  
Sherry Troquille, RN, CPON  
*Pediatric Nurse Coordinator*  
Claudette Vicks, RN  
*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 (MC-COP), 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.

### **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.

**In 2006, Children's Hospital recorded 138,804 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 4,369 clinic visits, 3,042 of which were for the treatment of children with cancer, and 718 for the care of sickle cell patients.**

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 approach in the treatment of malignant diseases for many patients. For some diseases, the five-year survival rate surpasses that of chemotherapy alone. The list of diseases for which hematopoietic stem cell transplantation has been considered grows almost daily. Hematopoietic stem cell transplantation allows administration of cytoreductive therapy with curative intent, without regard to the lethal effects to the marrow of this treatment regimen. The sources of stem cells are bone marrow, peripheral blood stem cells mobilized by growth factors or chemotherapy, and cord blood.

The Children's Hospital hematopoietic stem cell transplant program began in January 1989. From January 1989 to December 2006, 200 transplants were performed. Of those

performed, 134 were allogeneic and 66 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 here at Children's Hospital with the same protocols as those of the 240 COG institutions (i.e. St. Jude, MD Anderson, Johns Hopkins) adopted throughout the nation. COG has recognized Children's Hospital as the only 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

## Transplants by Disease 1989-2006

Acute Lymphocytic Leukemia	36
Acute Myelogenous Leukemia	33
Chronic Myelogenous Leukemia	5
Acute Undifferentiated Leukemia	5
Aplastic Anemia	8
Brain/CNS Tumors	8
Immunodeficiency	15
Lymphoma	13
Malignant histiocytosis	2
Myelodysplastic Syndrome	14
Fanconi's Anemia	3
Neuroblastoma	34
Thalassemia Major	1
Sarcoma or Other Solid Tumor	8
Sickle Cell	6
Wilms Tumor	3
Metabolic Disorder	6
<b>Total</b>	<b>200</b>

donors. This affiliation provides patients with the best chance of finding a suitable donor for transplantation. Children's Hospital, in collaboration with LSUHSC, is also an approved Children's Oncology Group (COG) hematopoietic stem cell transplant center with Dr. Yu as the principal investigator.

For more information regarding the hematopoietic stem cell transplant center at Children's Hospital, please contact the Hematology/Oncology Department or Dr. Lolie Yu 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, idiopathic thrombocytopenia purpura 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.

### **Outpatient Clinics**

Treatments that once required a child to be admitted are now often given on an outpatient basis. Patients visiting the hematology/oncology outpatient clinic at Children's Hospital are treated in an environment that places the comfort and care of the child and family first. In the hospital's Ambulatory Care Center, a separate patient suite with a 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 hematologist/oncologist and nurses and receive a variety of treatments, including blood transfusions, platelet transfusions and gammaglobulin infusions.

In addition to eight private rooms, a large treatment room provides patients an opportunity to interact with other patients, watch TV, choose videos from a movie library,

play games or simply relax while receiving treatments. With an average of 20 to 25 patient visits a day, the clinic 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 treatment including transfusion therapy, skilled pain management, and chelation therapy is available at Children's Hospital. We currently offer the most progressive protocols for stroke prevention, oral chelation, retinopathy screening, and monitoring for long-term complications of sickle cell disease that are currently in use. We have been involved in clinical trials sponsored by Novartis, Celgene and other pharmaceutical companies; this has often resulted 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., 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 also have entered into a trial agreement with Viacord (Celgene) that will enable patients to bank cord blood—a service often beyond the financial means of many

of our families. We are also currently involved in a study which looks at the inhibition of PLA<sub>2</sub> by a novel agent called Varespladib; this new project will allow us to screen and identify individuals presenting with sickle cell crises who might be at increased risk of developing acute chest syndrome and offers exciting new hope of preventing this devastating complication.

## 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 those involving translational research:

1. study of the role of arginine in the cellular responsiveness to cancer cells (Drs. Augusto Ochoa and Arnold Zea)
2. the role of acetylated glycation end-products (AGEs) in the development of short- and long-term complications of sickle cell disease (Dr. James Hempe)
3. the use of counterimmunoelectrophoresis in the diagnosis of hemoglobin variants (Dr. James Hempe)
4. the development of ways to more accurately quantitate hemoglobin types and distinguish fetal hemoglobin from aberrant hemoglobin variants (Dr. James Hempe)
5. study of the role of arginine in immunity in sickle cell disease (Drs. Renée Gardner and Lily Leiva)
6. analysis of immune responsiveness to pneumococcal vaccine

among patients with sickle cell disease (Dr. Gardner)  
7. xenotransplantation (Dr. Davila).

However, we have been involved in the conduct of studies looking at new clinical agents for the use in sickle cell disease and cancer.

Trials have included the following:

1. study of a novel molecular transcriptional inhibitor, produced by Biocryst, that has shown potential as an inhibitor of T-leukemia cells in patients with resistant disease.
2. study of the investigational drug, Traumeel, as a possible means of preventing post-chemotherapy mucositis.

The division has maintained a long-time interest in late effects and has investigated the reasons for their development. Studies aimed at ensuring quality control within the hospital are also constantly being carried out, with the goal of improving care. Such studies have included looking at ways to shorten the interval of time to administration of antibiotics to children presenting with possible sepsis; investigation of causes of central line infection on the pediatric inpatient ward that might be inherent to our inpatient ward and patient population, with the intent of reducing the nosocomial infection rate; introduction of novel bone marrow aspiration techniques, etc. All of these studies have resulted in the institution of new interventions and ultimately have been responsible for improving patient care.

## LANASA-GRECO CENTER FOR CANCER AND BLOOD DISORDERS INPATIENT UNIT

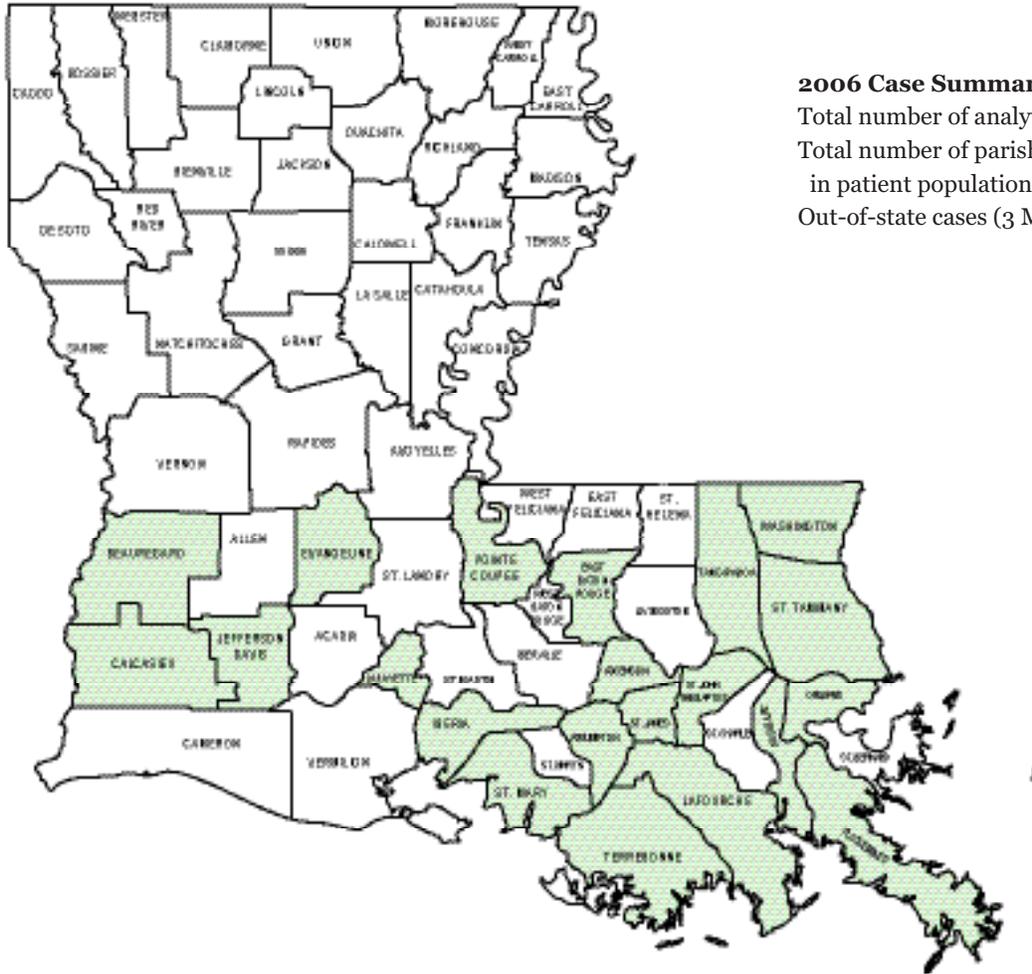
The LaNasa-Greco Center for Cancer and Blood Disorders opened in November 2003 on the fourth floor of Children's Hospital. The inpatient unit boasts 18 private rooms in a

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.

# 2006 Newly Diagnosed Patients



## 2006 Case Summary

Total number of analytic cases	55
Total number of parishes represented in patient population	21
Out-of-state cases (3 Mississippi, 1 Texas)	4

## Distribution of Analytic Cases by Parish

PARISH	2004	2005	2006	PARISH	2004	2005	2006
Acadia	0	1	0	Pointe Coupee	0	0	1
Ascension	0	0	1	Rapides	2	0	0
Assumption	0	0	1	Red River	1	0	0
Beauregard	0	1	1	St. Bernard	2	2	0
Bossier	0	1	0	St. Charles	0	1	0
Calcasieu	1	3	6	St. James	0	1	1
East Baton Rouge	3	1	1	St. John the Baptist	1	1	2
East Feliciana	1	0	0	St. Landry	2	0	0
Evangeline	0	0	1	St. Martin	0	1	0
Iberia	0	0	1	St. Mary	3	1	1
Jefferson	6	6	10	St. Tammany	3	8	4
Jefferson Davis	0	4	1	Tangipahoa	2	3	4
Lafayette	4	0	2	Terrebone	7	4	2
Lafourche	2	2	3	Washington	2	0	3
Livingston	0	2	0	Out-of-State	4	5	4
Orleans	10	7	4	Out-of-Country	0	1	0
Ouachita	2	2	0	<b>Total</b>	<b>59</b>	<b>58</b>	<b>55</b>
Plaquemines	1	0	1				

# Types of Cancer by Histology

	2004		2005		2006	
	#	%	#	%	#	%
Adenocarcinoid Tumor	0	0.0%	1	1.7%	0	0.0%
Astroblastoma	0	0.0%	1	1.7%	0	0.0%
Astrocytoma	6	10.2%	2	3.5%	3	5.6%
Atypical Teratoid Rhabdoid Tumor	0	0.0%	1	1.7%	1	1.8%
Blastoma, Pleuropulmonary	0	0.0%	0	0.0%	1	1.8%
Carcinoma, NOS	1	1.7%	1	1.7%	1	1.8%
Craniopharyngioma	0	0.0%	1	1.7%	1	1.8%
Desmoplastic Small Round Cell Tumor	0	0.0%	1	1.7%	0	0.0%
Desmoplastic Neuroepithelial Tumor	1	1.7%	1	1.7%	1	1.8%
Embryonal Carcinoma	0	0.0%	0	0.0%	1	1.8%
Ependymoma	0	0.0%	1	1.7%	2	3.6%
Ewing's Sarcoma	1	1.7%	0	0.0%	1	1.8%
Fibrosarcoma	1	1.7%	1	1.7%	0	0.0%
Ganglioglioma, NOS	3	5.1%	1	1.7%	0	0.0%
Ganglioneuroblastoma	0	0.0%	0	0.0%	1	1.8%
Germ Cell Tumor	1	1.7%	0	0.0%	0	0.0%
Glioblastoma	0	0.0%	1	1.7%	0	0.0%
Glioma, NOS	3	5.1%	3	5.2%	2	3.6%
Hepatoblastoma	0	0.0%	3	5.2%	1	1.8%
ALL (Acute Lymphocytic Leukemia)	12	20.3%	12	20.7%	9	16.3%
AML (Acute Myelocytic Leukemia)	3	5.1%	2	3.5%	2	3.6%
JMML (Juvenile Myelomonocytic Leukemia)	1	1.7%	0	0.0%	0	0.0%
Hodgkin Lymphoma	5	8.5%	5	8.7%	3	5.6%
Non-Hodgkin Lymphoma	1	1.7%	4	6.9%	5	9.2%
Langerhans Cell Histiocytosis	0	0.0%	1	1.7%	3	5.6%
Medulloblastoma	1	1.7%	2	3.5%	0	0.0%
Meiningothelial Meningioma	0	0.0%	0	0.0%	1	1.8%
Myelodysplastic Syndrome	0	0.0%	0	0.0%	2	3.6%
Neoplasm, Malignant	1	1.7%	0	0.0%	0	0.0%
Neoplasm, Uncertain Behavior	2	3.3%	1	1.7%	0	0.0%
Neuroblastoma	3	5.1%	1	1.7%	4	7.3%
Neuroectodermal Tumor, Primitive	1	1.7%	0	0.0%	0	0.0%
Oligodendroglioma	0	0.0%	0	0.0%	1	1.8%
Osteosarcoma, NOS	1	1.7%	2	3.5%	1	1.8%
Papillary Carcinoma	1	1.7%	0	0.0%	0	0.0%
Peripheral Nerve Sheath Tumor, Malignant	0	0.0%	1	1.7%	1	1.8%
Pigmented Dermatofibrosarcoma Protuberans	0	0.0%	1	1.7%	0	0.0%
Pineoblastoma	1	1.7%	0	0.0%	0	0.0%
Retinoblastoma	1	1.7%	0	0.0%	1	1.8%
Rhabdoid Tumor, Malignant	0	0.0%	1	1.7%	0	0.0%
Rhabdomyoma	1	1.7%	0	0.0%	0	0.0%
Rhabdomyosarcoma	2	3.3%	2	3.5%	2	3.6%
Sarcoma	1	1.7%	0	0.0%	1	1.8%
Schwannoma, NOS	0	0.0%	0	0.0%	1	1.8%
Teratoma And Embroynal Carcinoma Mix	1	1.7%	0	0.0%	0	0.0%
Wilms Tumor	3	5.1%	4	6.9%	2	3.6%
<b>Total</b>	<b>59</b>	<b>100.0%</b>	<b>58</b>	<b>100.0%</b>	<b>55</b>	<b>100.0%</b>

# 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](http://www.chnola.org).

## 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 2006, a total of 48 conferences were held. On average, approximately 19 physicians, residents, students and other cancer-related supporting staff personnel attended the weekly conferences. A total of 129 cases were presented

in 2006. These cases consisted of prospective, retrospective and follow-up cases. It should be noted that 93% 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 Department 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.

# Treatment Protocols

## PHARMACEUTICAL TRIALS

### Novartis Pharmaceuticals

A randomized, open-label, multicenter, phase II study to evaluate the safety and efficacy of oral ICL670 (deferiasirox) 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 Craniospi-

nal 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

**AALLO331** Standard Risk B-Precursor Acute Lymphoblastic Leukemia, Phase III Group-Wide Study (QOL component)

**AALLO3N1** 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**

**AALLo232** High Risk B-precursor Acute Lymphoblastic Leukemia- A Phase III Group-Wide Study

**AALLo331** Standard Risk B-Precursor Acute Lymphoblastic Leukemia, Phase III Group-Wide Study

**AALLo3B1** Classification of Acute Lymphoblastic Leukemia

**AALLo3N1** Understanding the Role of Adherence in the Ethnic Differences in Survival after Childhood

## **ALL**

**AALLo434** 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

**ADVLo4P2\*** 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 Group-wide 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 Neuroblas-

toma: 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

**ARENO3B2** 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

Accelerating 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.

# Publications

## 2006

Kuvibidila S, Sandoval M, Lao J, Velez M, Yu L, Ode D, Gardner R, Lane G, Warriar RP. Elevated Circulating Levels of Vascular Cell Adhesion Molecule –1 (VCAM-1) and Decreased Lymphocyte Proliferation in Children with Sickle Cell Disease with Suboptimal Zinc Status. *J Natl Med Assoc* 98: 1263, 2006

Kuvibidila S, Rayford W. Correlation between serum prostate-specific antigen and alpha-1-antitrypsin in men without and with prostate cancer. *J Lab Clin Med* 147: 174-81, 2006

Davila E, Byrne GW, LaBrecche PT, McGregor HC, Schwab AK, Davies WR, Rao VP, Oi K, Tazelaar HD, Logan JS, McGregor CG. T-cell responses during pig-to-primate xenotransplantation. *Xenotransplantation* 13: 31, 2006

Gardner RV, Correa H, Craver, R, McKinnon E, Sadowska-Krowicka H, Warriar, R. A Rasayana, ICHOR-CR, as a Possible Chemoprotectant against Doxorubicin-Related Toxicity. *Proceedings of the International Conference on Ethnopharmacology and Alternate Medicine*, 2006

Pisharody U, Craver RD, Brown RF, Gardner R, Schmidt-Sommerfeld E. Metastatic perivascular epithelioid cell tumor ((PEComa) of the colon in a child. (IN PRESS)

Kuvibidila S, Ode D, Warriar RP, Yu LC. In Vivo and In Vitro Secretion of Soluble Interleukin-2 Receptor (sIL2R) in Children with Acute Lymphoblastic Leukemia During the First Four Weeks of Treatment. (IN PRESS)

Scaradavou A, Castellino S, Stevens C, Brochstein J, Wagner J, Kletzel M, Yu LC, Rubinstein P, Kurtzberg

J. Acute Lymphoblastic Leukemia in Infancy: Improved Outcome with Unrelated Placental Cord Blood (PCB) Transplants. (IN PRESS)

Murray RA, Thom G, Gardner R, Craver R. Infant acute lymphoblastic leukemia: A 20-year Children's Hospital Experience. (Submitted)

Scavella A, Leiva L, Monjure H, Zea AH, Gardner RV. T-cell subsets and T-cell receptor zeta chain expression in sickle cell disease and the effects of L-arginine supplementation. (In Preparation)

Scavella A, Leiva L, Monjure H, Zea AH, Gardner RV. Lymphocyte blastogenic response to mitogen and antigen in steady state sickle cell patients. (In Preparation)

## 2005

Occhipinti E, Correa H, Yu L, Craver R. Inclusion of secondary chronic myelomonocytic leukemia and myeloproliferative disease, unclassifiable, in classification of pediatric myeloproliferative disorders [comment]. *J Pediatr Hematol Oncol* 27: 192, 2005

Adams R, Brambilla D, Baredo J, and Stop 2 Investigators (including Drs. RP Warriar and Ode D). Discontinuing prophylactic transfusion used to prevent stroke in sickle cell disease. *N Engl J Med* 353: 26: 2769, 2005

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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.

## DEVIN LEBOEUF

Three days after Daryl and Tanya LeBoeuf learned his mother had cancer, their 4-year-old son, Devin, was diagnosed with Acute Lymphoblastic Leukemia (ALL). It was a devastating time for their family, but Devin was destined to live. He beat his cancer with the help of Children’s Hospital’s oncology team, and today he’s an avid artist and outdoorsman.

“I don’t remember too much about my time at the hospital because I was so young,” said Devin, now 11. “But I like my doctors. They made me feel better.”

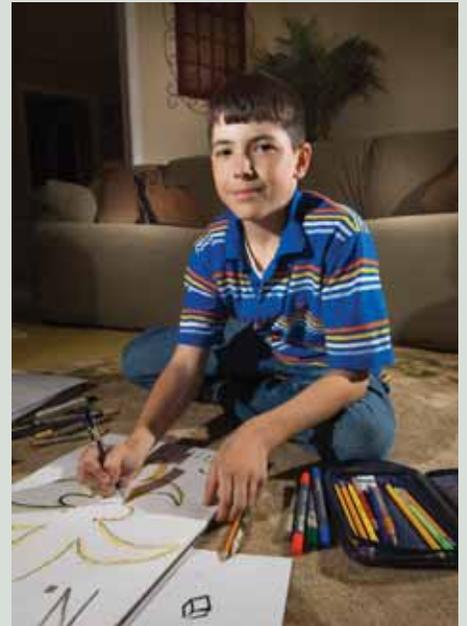
Though his memories of his battle with cancer are vague, Tanya said Devin and her family are very fortunate to receive the care they did.

“At the time we didn’t know how we were going to get through it,” Tanya said. “But the experience we had at Children’s Hospital was wonderful. We had such great people working with us. Everybody made us feel at home. There was so much going on that helped him to feel like a kid. At times we almost forgot that he was sick.”

During his treatment Devin lost his hair, but he never got sick as a result of his chemotherapy and didn’t have to undergo any transplants.

“That was a blessing because he was happy to go to the hospital,” his mom said. “He wasn’t scared. He loved it, and still gets excited about seeing Dr. Gardner in clinic.”

While he was in the hospital for treatment, Devin developed a penchant for art. He picked up a pencil, began drawing and it developed into his main interest. Once he was released from the hospital, Daryl began taking his son hunting. Devin harvested his first deer when he was 6, and joins his dad in the tree stand practically every weekend during the season. His time in the outdoors heavily influences his art.



***Pictured, clockwise from bottom left, Devin LeBoeuf with his father, Darryl; mother, Tanya; and sister, Misty.***

“I love to draw,” he said. “I focus mostly on wildlife and nature scenes.”

Devin recently won an art competition in which each fifth grader in the state was asked to draw a scene of indigenous trees for the Department of Agriculture. His drawing of cypress and oak trees is now on its way to Washington, D.C., where it will be judged against 49 other entries from around the country.

His mom credits Children’s Hospital with making the difference in her son’s life.

“His treatment was amazing. They did wonders for us,” she said. “I tell people all the time that if they have to go to a hospital, go to Children’s Hospital. They’re wonderful ... wonderful.”

In February, Devin will be cancer free for five years. The South Thibodaux Elementary fifth-grader said he enjoys his science classes best, and wants to be an artist, an architect, a policeman or fire fighter when he grows up.

“I want to help people. It makes me feel good to know I’m helping. I’d like to do that for a living,” he said.

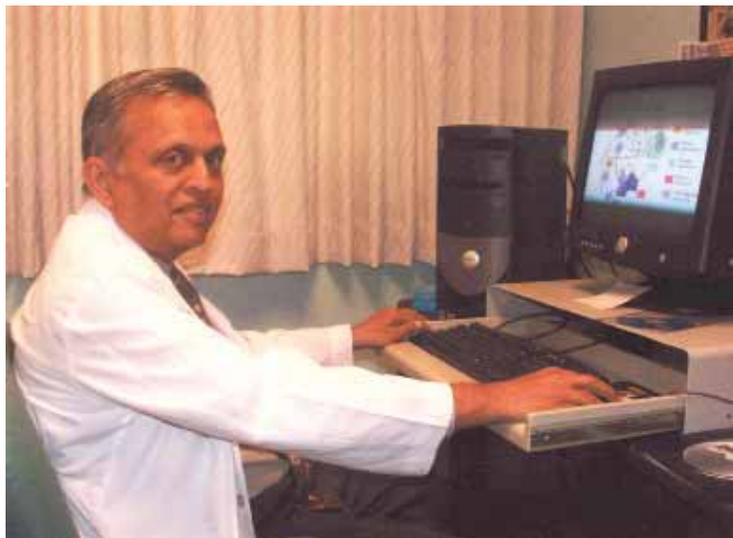
“We’re excited about his future,” Tanya said. “He’s not your typical boy. He’s not rough and tough, but we know he’ll accomplish something big. We can’t wait to see him grow up into manhood to see what he’ll become.”

# Missing a Friend

**R**ajasekharan P. Warrier. We never knew what the “P” stood for and since Rajasekharan was a mouthful for most, Dr. Warrier has been simply and fondly referred to as “Raj” by all. I first met Raj in 1993. I admit that I did not immediately recognize as prepossessing any specific trait about the man who walked and talked too fast, but I quickly learned that Raj was a man of many special talents and accomplishments.

Raj received his medical degree in 1968 from Kasturba Medical College in Manipal, India. He completed advanced studies at the same medical college, gaining a master’s degree in pediatrics (the equivalent of an M.D. from an American medical school) and diploma in child health in 1973. Having taught medicine in India, Raj took a “demotion” of sorts to come to the United States to assume a position as pediatric resident at Henry Ford Hospital in Detroit. His superior knowledge and clinical acumen were readily and quickly perceived and within a year of his arrival in Michigan, he was asked to serve as chief resident in pediatrics. He then went on to complete a fellowship in hematology/oncology at the Children’s Hospital of Michigan (Wayne State University) in Detroit. Imagine all these accomplishments in the midst of a cultural adjustment and adaptation to a completely foreign medical education system – and the snow-covered, wintry streets of Detroit, too.

Then, Dr. Warrier came to New Orleans. With Dr. Rafael Ducos, he founded, just over 25 years ago, the Division of Pediatric Hematology/Oncology at the Louisiana State University Medical Center (now LSU Health Sciences Center). He never looked back. During his tenure as chief, the division became a member of the Children’s Oncology Group (COG), was commended by the American College of Surgeons Commission on Cancer, became a key element of the Minority CCOP, and built a strong fellowship program which has produced many world-class hematologist/oncologists who have gone on to practice all over the world. The author of many published papers and journal editor, his drive for academic excellence is well-recognized. His abilities as a teacher are notable. Three times, he was named “best professor” by medical students and residents of the school of medicine. He also received the Continuing Medical Education Committee Award of Excellence and in 2006 was awarded a Fulbright Fellowship.



But I would have to say that his crowning achievement is, and will always be, the many individuals who can be counted among cancer survivors as a result of his skills as a physician. Many of us have, at one time or another, asked “Does this man have a photographic memory?” Photographic memory or not, all of us know plenty of smart people who are not good physicians. Dr. Warrier has been a compassionate caregiver who consistently demonstrated excellence in care. Now adults, but then just kids, so many patients can remember the Boudreaux and Thibodeaux jokes (perhaps some will quibble now at the political correctness (or incorrectness) of such jokes but all were uplifted at the funny but sometimes “corny” punchlines that helped get one through the difficult times of treatment. So, it is said that in 20-30 years or so, one out of 250 young adults will be a cancer survivor. This annual report’s emphasis will be on those who have survived, and tribute can be given to a man who did so much for so many throughout his time here in New Orleans. This included giving this program a solid start.

Raj has left us for greener pastures, and a more illustrious position of vice-chancellor at Manipal University. He is doing a lot there in India, including putting together a cancer therapy cooperative group, standardizing medical educational standards and programs, and establishing a fellowship in pediatric hematology/oncology. We can anticipate a continuation of many good and excellent things from Dr. Warrier. His legacy, however, lives on here, and Raj remains for us all a very good teacher, role model, mentor and friend.

# Telephone Directory & Referral List

Children's Hospital Main Number	(504) 899-9511	<b>Financial</b>	
Oncology Department	(504) 896-9740	Medicaid – Enroller	(504) 896-9152
Oncology Department Fax	(504) 896-9758	Office of Family Security	(504) 599-1700
Oncology Unit – inpatient	(504) 896-9442	Social Security	(800) 772-1213
Oncology – outpatient clinic	(504) 896-9848	Children's Hospital	
Neurosurgery Department	(504) 896-9568	Assistance Program (CHAP)	(504) 894-5166
Social Services Department	(504) 896-9367	American Cancer Society	(504) 469-0021
Surgery Department	(504) 896-9478	Leukemia/Lymphoma Society	(504) 887-0945
Orthopaedics Department	(504) 896-9569	Optimist Leukemia Foundation	(225) 925-8926
Medical Records/Tumor Registry	(504) 896-9585	Easter Seals (wheelchair loans)	(504) 455-5622
Administration	(504) 896-9450	National Children's Cancer Society	(314) 241-1600
Diagnostic Radiology	(504) 896-9565	Cancer Recovery Fund	(717) 564-4100
Pathology Department	(504) 896-9873	First Hand Foundation	(816) 201-1569
		Cancer Association of	
Bone Marrow Transplant Program	(504) 896-9740	Greater New Orleans	(504) 733-5539
Lolie C. Yu, MD		Total Community Action	(504) 821-2000
		<b>Housing</b>	
Cancer Committee Chairman	(504) 896-9741	Ronald McDonald House	(504) 468-6668
Renée V. Gardner, MD		American Cancer Society	
		Patrick F. Taylor Hope Lodge	(504) 219-2202
Cancer Program Liaison	(504) 896-3977	Hotels – medical rates list available	
Evans Valerie, MD		in Social Services Department	
		<b>Wishes</b>	
<b>Cancer Information/Resources</b>		A Child's Wish	(504) 367-9474
American Cancer Society	(800) ACS-2345	Make-A-Wish	(504) 314-9474
American Cancer Society, New Orleans Chapter	(504) 465-8405	Starlight	(323) 634-0080
National Cancer Institute	1-800-4CANCER	A Special Wish	(614) 575-9474
		Troop "B" State Police	(504) 450-7143
<b>Cancer Information Web sites</b>		<b>Support</b>	
American Cancer Society	<a href="http://www.cancer.org">www.cancer.org</a>	Candlelighters	(301) 657-8401
National Cancer Institute	<a href="http://www.cancer.gov">www.cancer.gov</a>	Sperm Bank Reproductive Services	(504) 454-7973
Children's Hospital, New Orleans	<a href="http://www.chnola.org">www.chnola.org</a>	Camp Challenge	(504) 347-2267
		Sunshine Kids	(713) 524-1264
		Hip Hop Hats	(813) 229-2377
		Locks of Love	(888) 896-1588
		<b>Mental Health</b>	
		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
		<b>Death</b>	
		Compassionate Friends	(504) 887-4599
		Seasons – The Center for Caring	(504) 834-1453
		Hospice Care of Louisiana	(504) 484-6161



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