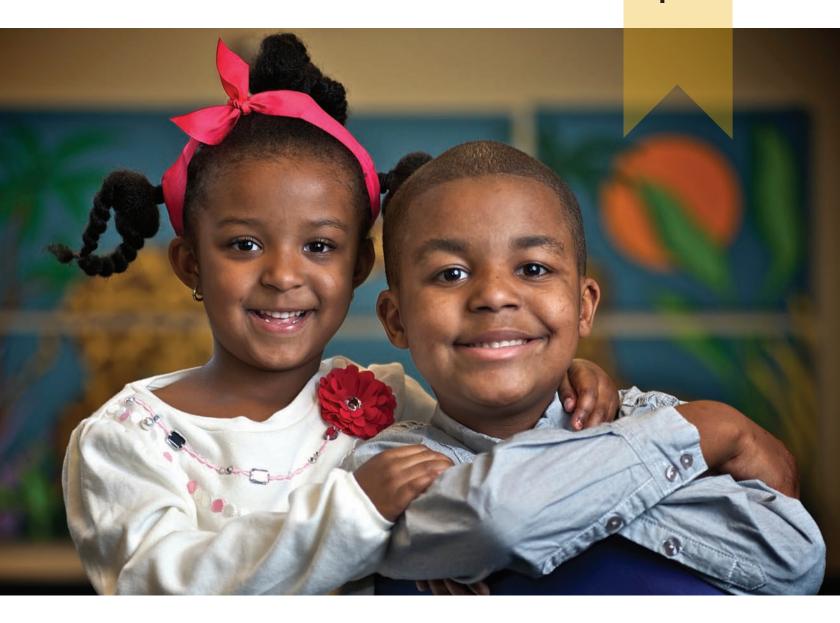
Annual Report



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



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From the Chairperson

HILDREN'S
HOSPITAL'S
LaNasa-Greco
Center for Cancer
and Blood Disorders provides
comprehensive,
compassionate
"total care" for

children with leukemia, lymphoma, tumors, anemia, hemophilia, and other childhood cancers and blood disorders. Our physicians have access to the most modern therapies for treatment of malignancies and blood disorders in children. We treat more than 1,100 children with cancer or blood disorders each year.

Our state-of-the-art inpatient unit, which overlooks Audubon Park, has 18 large, private rooms, with beds for family members, too. It 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. It's no wonder that we treat more Louisiana kids with cancer than all other facilities combined.

As the leading Pediatric cancer, hematology and blood and marrow transplant program in Louisiana, we continually provide advanced clinical care, educational programs, innovative treatments and research options for the children of our fine state.

In addition to our comprehensive hematology-oncology & Hematopoietic Stem Cell Transplantation (HSCT) services, we have added two specialty clinics this year. The Survivorship/Late Effects Clinic and the Bleeding/Thrombosis Clinic. Both clinics offer multidisciplinary care to address the unique needs of these cohort of patients.

2012 has been quite eventful for our patients. They were able to participate in a number of activities, including Unforgettable Prom, Curesearch Walk, Memorial and summer Camp Challenge. Photos reflecting these activities are included in this report.

The Unforgettable Prom was held on April 6th, 2012, at the Champion's Square. Patients age 12 to 21 were invited to participate. It was great seeing them all dressed up in their prom dresses or tuxedoes, driven into the site in limousines and walking on the red carpet. They celebrated the night with good food, electrifying music and great company. They danced the night away without a care in the world and forgot all about their illnesses for at least a few hours. We are immensely grateful to the Friends of Scott Foundation who totally sponsored & organized this event.

We had our third Curesearch Walk, which continued to be a complete success through the outstanding efforts of patients, families and the Heme-Onc team led by Drs. Morrison, Velez and Yu. As with other years, Mayor Mitch Landrieu and his lovely wife, Cheryl, were our honorary guests. We are very fortunate to have them continue to support this endeavor. More than a thousand walkers took part in this walk, and we were able to raise more than \$95,000.

Our yearly Camp Challenge took place last July and predictably, it was a very big turnout. Close to 100 campers came, probably the largest group since its inception. They enjoyed a week away from home and the hospital. None of the campers had to interrupt their time in camp to be admitted to the hospital, mainly due to the exceptional care and supervision given by the camp director, Dr. Jaime Morales.

We held our second Memorial this year to remember and celebrate all the children who sadly passed on to a better place from 2009-2011. We will continue to be inspired by these children whose tenacity and resilience influenced their short lives. Remarkably, it was very well attended, and it was nice to visit with their families and loved ones again.

Other achievements for our program this year include the Spirit Award given to Dr. Jaime Morales in August 2012 by the American Cancer Society. This award is given to a healthcare professional in the community who has made significant con-

tributions to the fight against cancer. Past recipients of this award include Dr. Velez in 2008, Dr. Gardner in 2009 and Dr. Yu in 2010

We also received the Hyundai Hope on Wheels award in the amount of \$75,000 for work being performed to fight childhood leukemia. This research project aims to determine potential mechanism of resistance to therapies for childhood lymphoblastic leukemia so more effective treatments can be developed. Dr. Ofelia Crombet, Heme-Onc fellow, was one of 43 recipients of the Hope on Wheels 2012 Hyundai Scholar grant. The work is in collaboration with her mentor, Dr. Paulo Rodriguez at the LSUHSC Stanley Scott Cancer Center.

Finally, for this 2012 cancer annual report, we have included our Lymphoma study reviewing the outcome for children with lymphoma diagnosed from 2001-2010. The results revealed two important findings that survival for lymphoma in children has improved significantly compared to the last era and despite having more advanced disease with our patient population, our results compared favorably with the national trend.

We will continue to strive to improve and enhance the quality of life of our patients by promoting the most advanced treatment options available for their cancer. It is with this goal in mind that we can offer patients the best opportunity for a cure and healthy survivorship.



Lolie Yu, MD
Professor of Pediatrics,
Cancer Committee Chairman,
Pediatric Hematology/Oncology

About Children's Hospital

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

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

Today, Children's Hospital is the only full-service pediatric hospital in Louisiana. A 247-bed, not-for-profit regional medical center offering the

most advanced pediatric care, the hospital's more than 300 pediatric specialists care for children from birth to 21 years in more than 40 specialties, including life-threatening illnesses, routine childhood sicknesses and preventive care. In 2011, Children's Hospital recorded 194,339 visits by 59,403 children.

ACCREDITATION

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

MEMBERSHIPS

Child Health Corporation of America, Children's Oncology Group (COG), Louisiana Hospital Association, Children's Hospital Association formerly CHCA, NACHRI, and N.A.C.H., Metropolitan Hospital Council of New Orleans



About the LaNasa Greco Center For Cancer and Blood Disorders

HELANASA
GRECO CENTER
FOR CANCER and
Blood Disorders at
Children's Hospital
offers comprehensive treatment of
all types of malignancies and blood
disorders including leukemia, anemia and
hemophilia, among many others.

Children's Hospital is approved as a Pediatric Hospital Cancer Program by the American College of Surgeons. 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.

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 Department of Pediatrics and the Stanley S. Scott Cancer Center of LSUHSC.

OUR STAFF

The LaNasa Greco Center for Cancer and Blood Disorders at Children's Hospital comprises the largest group of hematology and oncology physicians and nurses in the Gulf South dedicated exclusively to pediatrics. They are specially trained to care for the unique needs of children and work side by side with a medical staff of more than 300 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, who provide compassionate "total care" for the child and family.

ONCOLOGY SERVICES

Leukemia/Lymphomas

A full range of treatment options, including chemotherapy, stem cell transplantation and radiation therapy is available for children. Our medical staff develops a 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 evaluated and treated according to the specific subtype and stage of the disease.

The LaNasa Greco

Center for Cancer

and Blood Disorders

(504) 896-9740

Soft tissue and solid tumors

Children's Hospital treats a variety of tumors including neuroblastoma, tumors of the brain and spine, soft tissue and 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 neuro-oncology, genitourinary oncologic surgery, orthopaedic oncologic surgery, pediatric ocular surgery, radiation oncology and pediatric pathology.

Bone Marrow/Hematopoietic

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

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

in Louisiana for COG protocol studies.

A multidisciplinary team of physicians, nurses, social workers, nutritionists, pharmacists, physical therapists, psychologists and blood bank personnel is available, with experience

and commitment to the clinical practice and basic science of hematopoietic stem cell transplantation.

Children's Hospital is accredited by the National Marrow Donor Program (NMDP) as a transplant center. Through the NMDP, Children's Hospital has access to the largest worldwide registry of hematopoietic stem cell donors. This affiliation provides patients with the best chance of finding a suitable donor for transplantation.

In December 2008, our clinical HSCT program, our cellular therapy collection and processing facility obtained accreditation from the Foundation for the Accreditation of Cellular Therapy (FACT). We are only one of 20 pediatric HSCT programs in the United States to receive FACT accreditation.

In keeping with our willingness to innovate in order to provide patients the benefit



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

For additional information regarding our hematopoietic stem cell transplant program, please contact Dr. Lolie Yu in the Hematology/Oncology department at (504) 896-9740.

Children's Oncology Group (COG)

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 more than 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.

Late Effects Clinic

With advances in current therapy, 80% of childhood cancer patients will be cured of their disease and become survivors. Currently, there are more than 270,000 pediatric cancer survivors living in the United States. Research has demonstrated that some survivors are at risk for physical and psychological issues related to cancer diagnosis and its therapy. Radiation, chemotherapy and surgery are used to successfully treat childhood cancers and can lead to "late effects." The Treatment after Cancer and Late Effects Clinic is Louisiana's first dedicated Cancer Survivorship Clinic. The clinic Director is Dr.

Pinki Prasad; throughout her fellowship at Vanderbilt University she conducted research specific to late effects in childhood cancer and trained with Late Effects guru Dr. Smita Bhatia. The main goals of the Treatment after Cancer and Late Effects Clinic is to improve the health and well being of childhood cancer survivors by promoting adherence to a schedule of follow up appointments and routine screening tests, to educate patients, families and healthcare professionals about the long term effects of cancer treatment, to provide referrals to specialists as needed, offer psychological counseling and neurocognitive testing and transition patients to adult care when they are ready. Survivors seen in this clinic will receive an individualized treatment summary and learn about the effects of treatment they received. It is important for every cancer survivor to know about their treatment and to understand how that treatment may have the potential for long-term complications. In addition, survivors should know how to keep themselves as healthy as possible as they grow older.

Team Members

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Sherry Troquille, RN, CPON, Pediatric Nurse Coordinator
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Roxanne Stegall, LCSW
Kristin Haugen, Child Life Specialist

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HEMATOLOGY SERVICES

The hematology/oncology service treats a wide variety of hematologic disorders including sickle cell disease and other anemias, neutropenias, platelet and bleeding disorders. More children with blood disorders come to Children's Hospital for treatment than to any other hospital in the state. They receive the highest level of care from a medical staff experienced in the latest treatments for a full spectrum of disorders.

Hemophilia and other blood disorders

Patients with hemophilia, von Willebrand's disease, and other bleeding disorders are evaluated and treated with the most current therapies. Appropriate support for patients and parents is offered as needed. Nurse coordinators educate and coordinate the patient's care in clinic as well as at home. We have partnered with manufacturers of Factor to secure for our patients mobile devices that permit electronic data and therapeutic management. This has allowed parents of patients with bleeding disorders to record bleeding episodes and infusion details that enable the physician to better manage the

acute and chronic complications of the disorder. We also were participants in the Hemophilia and Thrombosis Research Society Registry. The registry provided insight into the differing management strategies employed by hemophiliacs, into the natural history of patients with inhibitors, and assessment of alternative therapies for acute bleeding episodes (NovoNordisk).

Outpatient clinic

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

Patients visiting our outpatient clinic are closely monitored by their pediatric hematologist/oncologist and nurses trained in chemotherapy administration and receive

a variety of treatments, including blood transfusions, platelet transfusions and gammaglobulin infusions.

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

The clinic sees on average 40 patients per day and is open Monday through Friday, 8 a.m. to 4:30 p.m.

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

Sickle cell anemia

Comprehensive management of sickle cell disease is available at Children's Hospital. Currently, we care for between 250 and 300 patients with sickle cell disease. Satellite clinics are located in Baton Rouge and Lake



Charles. From the time the patients are first identified as having a hemoglobinopathy, they are offered the most progressive treatment available for stroke prevention, oral chelation, retinopathy screening and monitoring for long-term complications of sickle cell disease. In addition to sickle cell disease, we also treat individuals who are diagnosed with other hemoglobinopathies, (e.g., CC Disease or thalassemia). Our involvement in the National Marrow Donor Program and the National Cord Blood Registry permits us to offer this treatment modality to greater numbers of patients who might otherwise have had to forego this treatment option for want of an eligible donor. We are currently in an agreement with Viacord (Celgene) that will enable patients to bank cord blood—a service often beyond the financial means of many of our families.

RESEARCH

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

Our staff has been active as mentors for the summer cancer and/or genetics research

programs offered at LSUHSC and, as such, have studied subjects such as problems had by children in school re-entry, knowledge of and acceptance of HPV vaccine, brain tumors and late effects and prevention of nosocomial infection, etc. Studies aimed at insuring quality control improvement in the hospital setting have been very important to us, with the overreaching goal of improving patient care. We have recently completed a study on the use of chlorhexidine wash to prevent nosocomial infection. The preliminary findings have been published in our 2010 cancer annual report. These results were so encouraging which prompted us to proceed with a follow-up study on using chlorhexidine wash for all prospective oncology patients admitted to the hospital. The current group of patients were compared to historical controls. Preliminary results suggest that the rate of nosocomial infection was higher among patient who did not get chlorhexidine wash. These results were presented to the 2011 SSPR meeting. Similarly, central line infections on the Hematology/ Oncology unit now have a prevalence that is lower than the national average. Another study led to the introduction of sample labeling practices in the operating or recovery room during procedures that promise to reduce error rates. All of these studies have resulted in the institution of new intervention for the improvement of patient care.

LANASA GRECO CENTER FOR CANCER AND BLOOD DISORDERS INPATIENT UNIT

The LaNasa Greco Center for Cancer and Blood Disorders is 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. This 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.

Support Services

SOCIAL SERVICES

Pediatric cancer is a devastating diagnosis that affects the entire family. Social workers help patients and families identify their concerns, consider effective solutions, and better cope with the child's illness. They assist families dealing with cancer by providing emotional support; guiding them to the most appropriate sources of monetary assistance for the child's medical care; directing them to transportation services that might be used and helping find temporary housing in New Orleans during treatment, when this is suitable.

PSYCHIATRY/PSYCHOLOGY

The Child Psychiatry and Psychology departments provide comprehensive evaluation and management of emotional and behavioral disorders stemming from the diagnosis of cancer. They work closely with the hematology/oncology physicians and social workers pioneering multidisciplinary psychosocial conference to ensure the stability of mental health of these patients under stressful conditions. 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.

CHILD LIFE

The Child Life department is dedicated to improving the quality of life for children facing the many challenges of cancer treatment while they remain hospitalized. Using developmentally appropriate play, music and recreation therapists promote opportunities for children to understand a new diagnosis, adjust to the hospital experience, learn coping skills, express themselves, and maintain normal growth and development. An attractive playroom, with a view of Audubon Zoo is located on the unit. Playroom activities include unstructured and structured activities during the evening hours, such as bingo night and movie night.

REHABILITATION MEDICINE

The Rehabilitation Medicine team provides a comprehensive approach to the treatment of

patients who may have experienced a temporary or permanent loss or impairment of functional abilities as a result of their disorder or treatment. Rehabilitation Medicine integrates physical, occupational and speech therapy services, nursing, nutritional and other services to improve and strengthen the patient's functional capabilities.

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.

DIETARY/NUTRITIONAL SERVICES

Children undergoing chemotherapy or bone marrow transplantation may suffer lack of appetite, so the Dietary and Nutritional Services department provides a complete nutritional assessment and crafts an individualized nutritional care plan to meet each patient's specific needs. Parents are thoroughly counseled on diets meeting their child's needs. Safe food handling is emphasized for the immune compromised patient and the nutritionist meets with the family as much as necessary.

PHARMACY

The pharmacists work closely with the physicians, nurses and other healthcare team mem-

bers 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.

PASTORAL CARE

When a child is diagnosed with cancer, the child and his/her family can experience 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. 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 assist Child Life staff with activities 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 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.

STARBRIGHT WORLD

Starbright World (SBW) is an online social network/community where teens can con-

nect with other teens who also have cancer. Through videos, moderated chat rooms, games and bulletin boards they help each other confront the challenges they face every day. SBW is a safe environment where teens can express fears and frustrations, share experiences and laugh. Teens are able to hang out with peers who understand the realities of living with a serious or chronic illness. The Child Life department has laptops with webcams available for checkout to patients who are interested in SBW.

CAMP CHALLENGE

Camp Challenge is 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. It provides recreation and the camaraderie of associating with other children who have undergone similar experiences with cancer and chronic or serious illnesses. The children look forward to the opportunity to swim, ride horseback, engage in competitive sports, and generally have a ball while forgetting the all-too-present concerns of sickness and hospital.

AMERICAN CANCER SOCIETY'S PATRICK F. TAYLOR HOPE LODGE

The Hope Lodge houses our patients and caregivers who need to travel a long distance to New Orleans for cancer treatment. It offers

temporary lodging in a warm, caring, supportive environment so they can focus on fighting the disease.

RONALD MCDONALD HOUSE

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



The Jazz Half Marathon raises funds to help support The Cancer Program at Children's Hospital.

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.

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. Many of our patient's

fondest dreams have come true due to the dedicated work of these special wish granters.

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 such as a trip to Walt Disney World, a shopping spree or a remodeling of their room.

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.

CLINICAL TRIALS CENTER

The Clinical Trials Center at Children's Hospital was established in 1999 to improve health- care for children and adolescents through the development of new medications and treatments. Our efforts help to create a culture in which safer and more effective drugs are available for a wide range of health problems. The Clinical Trials Center organizes community and hospital-based physicians into a multi specialty research network. Our goal is to set the standard for



Actor Will Ferrell, serving as Bacchus XLIV, visits Children's Hospital Hematology/Oncology patients.



Patients and families celebrating birthdays on the Hematology/Oncology Unit.

excellence in clinical trials by providing effective administrative expertise and a staff experienced in the conduct of clinical trials.

THE S.M.I.L.E. PROJECT

For over a decade now, Children's Hospital has had the only successful SMILE Program in the city. The SMILE Program is a collaboration between Children's Hospital, LSU, and the American Cancer Society. The goal is to pair first-and-second year medical students as "buddies" with children with cancer. The buddies then maintain a relationship with the

children that are non-medical but emotionally supportive through difficult hospitalizations and treatment. Additionally, each month there is a SMILE party in the outpatient clinic that all children are invited to attend. This has proven to be a very rewarding program for both patients and medical students alike.

SPERM BANKING SERVICES

Since January 2011, we have actively been looking at our Sperm Banking Services and whether families have taken advantage of

the services. Eleven males were possible candidates. Three young men choose to pursue this option. Cost did not appear to be a prohibitive factor in making the decision.

The Cancer Committee

HE MISSION OF the Cancer Committee 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

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 orthopaedic surgeons, radiation oncologists, pediatric radiologists and pathologists, these professionals combine their specific outlooks to view

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

DID YOU KNOW?

Cancer Awareness Ribbons







Neuroblastoma



All pediatric cancers



CNS tumors



Leukemia and Lymphoma

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 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

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 LSU Health Sciences Center. 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 the 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 Members

Lolie C. Yu, MD, Professor of Pediatrics, Cancer Committee Chairman, Pediatric Hematology/ Oncology

Evans Valerie, MD, Physician Liaison, Pediatric Surgery

Simone Bienvenu, RN, Quality Assessment and Improvement

Rachel D. Bufkin, CTR, Cancer Registrar

Kay Casey, MSW, Social Services Department

Chittalsinh Raulji, MD, Hematology/Oncology Fellow

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Renee V. Gardner, MD, Professor of Pediatrics, Hematology/Oncology

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Kristen Haugen, Child Life Specialist

Marie-Louise Haymon, MD, Radiology

Wendy Huval, RHIA, Director of Medical Records

Dana Leblanc, Pediatric Hematology/Oncology Fellow

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Jaime Morales, MD, Assistant Professor of Pediatrics, Hematology/Oncology

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Stephanie Sonnier, Clinical Trials

Matthew Stark, MD, Pathology/Laboratory Department

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Claudette Vicks, RN, Pediatric Hematology/Oncology Nurse Coordinator

Jennifer Walgamotte, Medical Records Coordinator

Peggy Williams, LSCW, Social Services Department

Lynn Winfield, RN, Nurse manager

Ellen L. Zakris, MD, Radiation Oncology

Committee recently incorporated programs on cancer prevention trials such as the FreshStart program, a comprehensive approach to the cessation of smoking during pregnancy and after delivery. We are involved in providing information to the families of children in Louisiana through our Web site, addressing their concerns about long term environmental and toxic hazards that might be encountered upon

their return to New Orleans and its environs after Hurricane Katrina.

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 Hematology/ Oncology Department at (504) 896-9740.

Advances in the Treatment of Pediatric Lymphoma: A Single Center 10-Year Review

MATTHEW FLETCHER, MD; MEGHAN JONES, MS; CRUZ VELASCO-GONZALES, PHD; AND MARIA C. VELEZ, MD

INTRODUCTION

Lymphomas are malignant neoplasms of the lymphatic system, a part of the immune system, and can arise from any area of the body where lymphatic tissue aggregates, such as lymph nodes, bone marrow, liver or spleen. As a group, they constitute the third most common malignant neoplasms in children, after leukemia and brain tumors, and they account for 15% of all malignancies^[1]. Lymphomas are currently one of the most treatable and curable types of pediatric cancer, with overall cure rates approaching 90%. Classically, lymphomas have been divided into two groups, Hodgkin's and non-Hodgkin's. However, these two entities are clinically and biologically distinct, and modern treatments for these two groups are vastly different.

Hodgkin's disease (HD), or Hodgkin's lymphoma, is one of the few cancers that affects both adults and children. It has a bimodal distribution in its incidence, with one peak in the 15-34 year old age group and a second peak in the older than 60 group. There are ~800 new pediatric cases of HD in United States per year, for an incidence of 7 cases/million persons/year.[2] Hodgkin's lymphoma arises from a type of immune cells known as B-cells. While in most cases the cause is unknown, recent studies have implicated Epstein-Barr virus (EBV), the causative agent in infectious mononucleosis, in a significant proportion of cases of HD.[3] Treatment for HD is similar in both children and adults, usually consisting of multiagent chemotherapy for 4-6 months ± radiation. Prognosis depends primarily upon initial staging (See Table 1), with long-term survival >95% for early (stage la) disease and 75-80% for advanced (stage IVb) disease. [4] Cure is still possible after relapse, with ~50% of patients able to achieve a durable remission after high-dose chemotherapy with autologous stem cell rescue.[5] Given the high rates of cure, more recent studies have examined using less intensive treatment regimens, such as the elimination of radiation therapy, to minimize late effects.

Non-Hodgkin's lymphomas (NHL) are a diverse collection of malignant neoplasms which includes all malignant lymphomas not characterized as Hodgkin's disease. It affects primarily adults, with only 1.7% of all cases affecting individuals <20 years old. There are ~500 new pediatric cases of NHL in the United States per year, for an incidence of 6.6 cases/million persons/year. [6] NHL is classified by the type of cell from which it arises, with the most common subtypes including Burkitt's lymphoma (see Figure 3), T-cell lymphoblastic lymphoma and anaplastic large cell lymphoma. Numerous clinical factors can predispose to the development of NHL, including immunosuppression from either drugs or HIV infection,

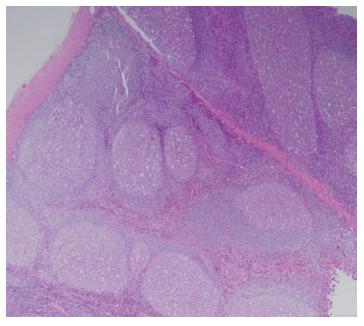


FIGURE 1: Normal lymph node consisting of well defined germinal centers. Image courtesy of Dr. Matthew Stark.

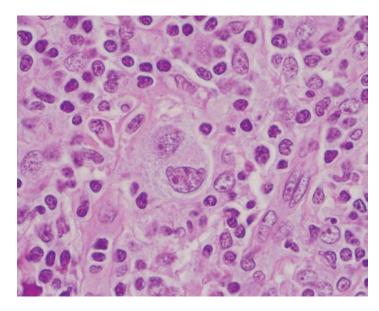


FIGURE 2: Bi-nucleate Reed-Sternberg cells (center) are pathognomonic for Hodgkin's lymphoma. Image courtesy of Dr. Matthew Stark.

TABLE 1 - ANN ARBOR STAGING CLASSIFICATION FOR HODGKIN'S LYMPHOMA

STAGE DESCRIPTION

- Involvement of a single lymph node region (I) or a single extralymphatic organ or site (IE)
- II Involvement of two or more lymph node regions on the same side of the diaphragm (II) or localized contiguous involvement of only one extralymphatic organ or site and its regional lymph node(s) on the same side of the diaphragm (IIE)
- III Involvement of lymph node regions on both sides of the diaphragm (III), which may also be accompanied by involvement of the spleen (IIIS) or by localized contiguous involvement of an extralymphatic organ or site (IIIE) or both (IIISE)
- IV Diffuse or disseminated involvement of one or more extralymphatic organs or tissues, with or without associated lymph node involvement
 - Designations applicable to any stage
- A No B symptoms
- B symptoms, defined as presence of fever (>38° C [100.4° F]) for 3 consecutive days, drenching night sweats, or unexplained loss of 10% or more of body weight in the preceding 6 months
- E Involvement of a single extranodal site that is contiquous or proximal to the known nodal site
- S Involvement of the spleen

viral infections such as EBV or human T-cell lymphotrophic virus-1 (HTLV-I),or genetic disorders such as X-linked lymphoproliferative disease (XLP) or Wiskott-Aldrich syndrome.^[7] Treatment for NHL is dependent on the subtype, but consists primarily of chemotherapy for 2-32 months. Radiation is typically only used in emergency or high-risk situations, and surgery is not curative. Prognosis depends upon subtype and staging (See Table 2), but overall long-term survival is ~60-90%.^[8] Relapsed NHL carries a poor prognosis, with <20% of patients able to achieve a second remission, though recent studies using either autologous or allogeneic stem cell transplants have had promising results, with 3-year event free survivals of 70-75%.^[9,10]

The advent of monoclonal antibodies in the treatment of cancer, while still in its earliest stages, offers hope for cure with less toxicity than traditional cytotoxic chemotherapy. Rituximab, a human/murine chimeric monoclonal antibody against CD20, was first approved in 1997 for the treatment of non-Hodgkin's lymphoma. It is indicated for the treatment of B-cell lymphomas and leukemias, and early results of studies in adults are very promising. [11] Data for its safety and efficacy in pediatrics is lacking, but the limited evidence available shows response rates up to 70% in relapsed and refractory B-cell lymphoma, [12] and prospective trials are currently ongoing.

Our institution previously described the lymphoma cases treated at Children's Hospital in New Orleans between 1995 and 2000. [13] The current study will examine the cases of lymphoma treated at our institution from 2001 to 2010, with additional emphasis on the role of monoclonal antibodies in the treatment of non-Hodgkin's lymphoma. Comparison to national survival data from the 2008 Survival, Epidemiology and End Results (SEER) study will also be presented.

METHODS

A 10-year retrospective analysis of medical records for all patients diagnosed with lymphoma at Children's Hospital in New Orleans between 2001 and 2010 was performed. Institutional Board Review (IRB) was obtained following the compliance regulations of the institutions. Demographic information collected included: age, sex,

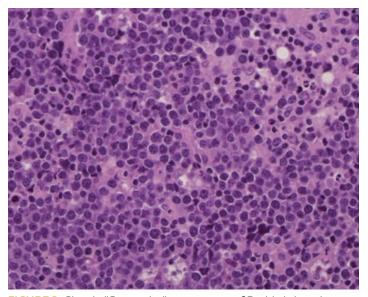


FIGURE 3: Classic "Starry sky" appearance of Burkitt's lymphoma. Image courtesy of Dr. Matthew Stark.

race and date of diagnosis. Clinical information collected included: disease, stage, location, bone marrow involvement, central nervous system involvement, chemotherapy received, including the use of rituximab, underlying immunodeficiencies, hematopoietic stem cell transplant, including type and date, date of relapse, and date of death. Statistical analysis using Cox regression was performed to determine correlation between clinical variables and overall/disease-free survival.

RESULTS

From January 1, 2001 through December 31, 2010, 97 patients were treated for lymphoma at Children's Hospital in New Orleans. Complete records were available for review for 71 patients, with 38 cases of HD and 33 cases of NHL. Mean duration of follow-up was 3.6 years. Demographic and presentation information from the cohort is presented in Table 3. Of note, NHL was significantly more prevalent in younger patients, males and those with immunodeficiency,

TABLE 2 - ST. JUDE STAGING SYSTEM FOR PEDIATRIC NON-HODGKIN'S LYMPHOMA

Stage Description

- A single tumor (extranodal) or involvement of a single anatomic area (nodal), with the exclusion of the mediastinum and abdomen A single tumor (extranodal) with regional node involvement

 Two or more nodal areas on the same side of the diaphragm
- II Two single (extranodal) tumors, with or without regional node involvement on the same side of the diaphragm
 A primary gastrointestinal tract tumor, with or without involvement of associated mesenteric nodes, that is completely resectable
 Two single tumors (extranodal) on opposite sides of the diaphragm
 Two or more nodal areas above and below the diaphragm
- III Any primary intrathoracic tumor (mediastinal, pleural, or thymic)
 Extensive primary intra-abdominal disease
 Any paraspinal or epidural tumor, whether or not other sites are involved
- IV Any of the above findings with initial involvement of the central nervous system, bone marrow, or both

consistent with national norms. In addition, patients with NHL were significantly more likely to present with advanced disease (stage III/IV) than those with HD (60% vs. 50%).

Overall survival (OS) of all cases was 93% (See Figure 4), with 95% OS for HD and 91% for NHL. There was a significant improvement in 5-year OS among NHL patients compared to the prior cohort (91% vs. 72%) and slight improvement in 5-year OS among HD patients compared to the prior cohort (95% vs. 94%). Advanced stage disease (Stage III/IV) at presentation was more common in our population than the national average (55% vs. 37%), though this was an improvement compared to the prior cohort (63% advanced stage disease). Relapse rates remained stable (17% in both cohorts), and among the clinical variables analyzed, only relapse was associated with increased mortality (hazard ratio 18.2, [95% Cl 2.0-163.2], p=0.002). Fourteen patients received a monoclonal antibody (13 NHL patients received rituximab and 1 HD patient received brentuximab), and the use of monoclonal antibodies did not improve survival among patients with NHL (See Figure 5). Kaplan-Meier survival curves for overall survival by stage for both HD and NHL are presented (Figures 6 and 7). Disease stage was not significantly associated with survival.

DISCUSSION

In the last decade we have witnessed remarkable progress in the treatment and cure of children with lymphoma. Overall survival of this cohort of patients reflects the current trend towards excellent outcome in pediatric lymphoma, with 93% of the patients treated at our institution in the last decade becoming cancer survivors, compared with an 85% overall survival in the latter half of the 1990s. Multiple factors likely contributed to this improvement. Our ongoing participation in national clinical trials through the Children's Oncology Group (COG) seeks to continually improve outcomes by offering state-of-the-art therapy and accessibility to the most up-to-date treatment options and modalities. Additionally, increasing cancer awareness among the general pediatricians and family physicians in the community has translated into earlier detection and prompt

FIGURE 4: Comparison of outcomes of current cohort with prior cohort and SEER data. Improvements in overall mortality and disease specific mortality are noted compared to prior cohort. Relapse rates remain stable, while fewer patients present with advanced disease in the current cohort.

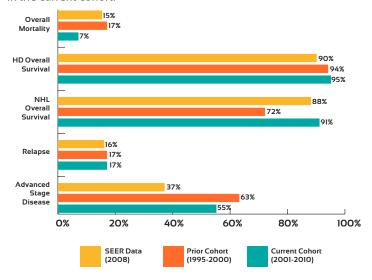


FIGURE 5: Overall survival among non-Hodgkin's lymphoma patients by use of monoclonal antibody. No significant difference in survival was noted in patients receiving monoclonal antibody thereon.

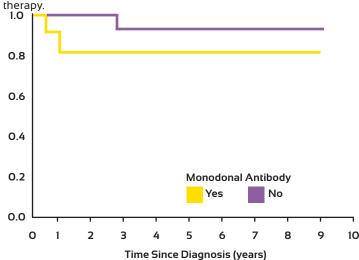


TABLE 3 – DEMOGRAPHIC AND CLINICAL INFORMATION OF COHORT

		DISEASE		
	TOTAL N (%)	HD N (%)	NHL N (%)	P-VALUE
SEX				0.0266
Female	25 (35)	18 (72)	7 (28)	
Male	46 (64)	20 (43)	26 (56)	
RACE				0.7334
African American	36 (50)	21 (58)	15 (41)	0./554
White	28 (39)	14 (50)	14 (50)	
Other	7 (9)	3 (42))	4 (57	
	, ()	3 (42))	4(3)	
PRIMARYSITE				0.1461
Head/neck	33 (46)	19 (57)	14 (42)	
LN, multiple sites	10 (14)	6 (60)	4 (40)	
Mediastinum	16 (22)	9 (56)	7 (43)	
Below diaphragm	10 (14)	2 (20)	8 (80)	
Other	2 (2)	2 (100)	0 (0)	
STAGE				
I	5 (7)	4 (80)	1 (20)	0.0089
II	27 (38)	15 (55)	12 (44)	
III	20 (28)	5 (25)	15 (75)	
IV	19 (27)	14 (73)	5 (26)	
MEDIASTINAL MASS				0.0963
No	37 (52)	16 (43)	21 (56)	
Yes	34 (47)	22 (64)	12 (35)	
MARROW INVOLVEMENT				0.5941
No	69 (OE)	37 (54)	21 //E)	0.5941
Yes	68 (95) 3 (4)	1 (33)	31 (45) 2 (66)	
	5 (4)	1 (55)	2 (00)	
MONOCLONAL ANTIBODY				0.0001
No	56 (80)	36 (64)	20 (35)	
Yes	14 (20)	1 (7)	13 (92)	
TRANSPLANT (TYPE)				1.0000
Allogeneic	3	2	1	
Autologous	9	8	1	
IMMUNODEFICIENCY				0.0182
No	66 (92)	38 (57)	28 (42)	0.0102
Yes	5 (7)	0 (0)	5 (100)	
	3 (,)	3 (3)	3 (100)	
RELAPSE				0.0285
No	59 (83)	28 (47)	31 (52)	
Yes	12 (16)	10 (83)	2 (16)	
AGE				0.0113
Mean (years)		13.8	11	

FIGURE 6: Overall survival by stage for Hodgkin's disease. No significant difference was found in survival among those presenting with early stage disease.

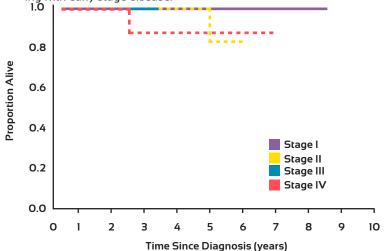
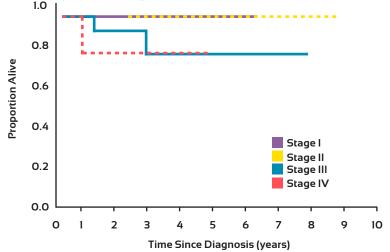


FIGURE 7: Overall survival by stage for non-Hodgkin's lymphoma. No significant difference was found in survival among those presenting with early stage disease.



referral to our cancer treatment center, which is reflected in the decrease in the percentage of patients presenting with advanced stage disease.

The most significant improvement in survival occurred among patients with non-Hodgkin's lymphoma. Multiple advancements in the treatment of NHL have taken place over the last decade, especially in the most common types of NHL, Burkitt's lymphoma and T-cell lymphoblastic lymphoma (TLL). With regards to Burkitt's lymphoma, advances in supportive care, such as the use of rasburicase in the management of acute tumor lysis syndrome[14], have contributed to a significant decrease in early mortality and morbidity, while in TLL, a transition to regimens based on T-cell leukemia treatment and the advent of newer therapeutic agents such as nelarabine have contributed to significantly improved cure rates. In addition, the emergence of monoclonal antibodies such as rituximab offers an exciting new weapon in the arsenal to fight these devastating diseases.

While this small study did not show a survival benefit among patients receiving rituximab, several limitations should be noted. Most notably, only patients with B-cell and Burkitt's NHL were treated with rituximab in this cohort, while the comparison group of patients who did not receive rituximab consisted primarily of T-cell NHL, thus no appropriate control group is available for comparison. Furthermore, as a new investigational agent, rituximab was initially used in relapsed/refractory cases which had a poorer prognosis. Promising results both from recent Children's Oncology Group trials and from adult clinical trials have led to the incorporation of rituximab into front-line treatment for all B-cell NHL patients. For example, in a trial of young adults with diffuse large B-cell NHL, the addition of rituximab increased 3-year overall survival from 84% to 93%[15], while a pilot study in children with advanced B-cell leukemia and lymphoma showed 95% 3-year overall survival in patients receiving rituximab[16]. The current Children's Oncology Group study for Bcell NHL is examining the effectiveness of rituximab in newly diagnosed patients. Other limitations of our study include the relatively short follow-up period (mean 3.8 years), which does not allow for accurate 5-year survival statistics, and the retrospective, singlecenter nature of the study. Furthermore, the relatively small number of patients do not allow for enough statistical power to find associations which are certainly present, such as improved survival among early-stage disease.

CONCLUSIONS

This 10-year retrospective study showed significant improvements in survival among both Hodgkin's and non-Hodgkin's lymphoma patients treated at our institution from 2001 to 2010 compared to patients treated from 1995-2000. In addition, outcomes of patients treated at our institution continue to outpace national averages, in spite of treating a higher proportion of patients who present with advanced stage disease.

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An Eventful Year

Curesearch Walk



Unforgetable Prom







Hole in the Wall Gang Summer Camp



Fashion Show













An Eventful Year

St. Baldrick's Event





Hematology/Oncology Memorial Service



Histology

	20	009	2	010	2	2011
	#	%	#	%	#	%
Adenocarcinoma	0	0.0%	2	3.8%	0	0.0%
Astrocytoma	5	7.4%	5	9.7%	7	8.4%
Atypical Teratoid Rhabdoid Tumor	1	1.5%	0	0.0%	0	0.0%
Carcinoma, NOS	2	2.9%	1	1.9%	1	1.2%
Chondrosarcoma	0	0.0%	1	1.9%	0	0.0%
Choroid Plexus Carcinoma	1	1.5%	0	0.0%	0	0.0%
Craniopharyngioma	2	2.9%	0	0.0%	1	1.2%
Dermatofibrosarcoma	0	0.0%	0	0.0%	1	1.2%
Dermoid Cyst	1	1.5%	0	0.0%	0	0.0%
Ependymoma	2	2.9%	0	0.0%	1	1.2%
Ewing's Sarcoma	2	2.9%	0	0.0%	4	4.8%
Ganglioglioma, NOS	3	4.4%	0	0.0%	3	3.6%
Germ Cell Tumor	3	4.4%	3	5.9%	1	1.2%
Glioma, NOS	6	8.8%	3	5.9%	3	3.6%
Glioneuronal Tumor	0	0.0%	1	1.9%	0	0.0%
Hemangioma (CNS)	0	0.0%	0	0.0%	1	1.2%
Hepatoblastoma	0	0.0%	2	3.8%	0	0.0%
Hepatocellular Carcinoma	1	1.5%	2	3.8%	0	0.0%
ALL(Acute Lymphocytic Leukemia)	8	11.7%	11	21.1%	22	26.5%
AML (Acute Myelocytic Leukemia)	5	7.4%	4	7.8%	1	1.2%
APL (Acute Promyelocytic Leukemia)	0	0.0%	0	0.0%	2	2.4%
CML (Chronic Myelogenours Leukemia)	0	0.0%	2	3.8%	0	0.0%
Hodgkin Lymphoma	6	8.8%	1	1.9%	7	8.4%
Non-Hodgkin Lymphoma	5	7.4%	2	3.8%	4	4.8%
Langerhans Cell Histiocytois	2	2.9%	2	3.8%	1	1.2%
Liposarcoma	0	0.0%	1	1.9%	0	0.0%
Medulloblastoma	0	0.0%	1	1.9%	0	0.0%
Melanoma	2	2.9%	0	0.0%	0	0.0%
Meningioma	1	1.5%	0	0.0%	0	0.0%
Myelodysplastic Syndrome	1	1.5%	0	0.0%	3	3.6%
Neuroblastoma	4	5.9%	3	5.9%	5	6.3%
Osteosarcoma, NOS	2	2.9%	0	0.0%	6	7.2%
Peripheral nerve sheath tumor, Malignant	1	1.5%	0	0.0%	0	0.0%
Primitive Neuroectodermal Tumor	0	0.0%	1	1.9%	0	0.0%
Refractory Anemia	0	0.0%	1	1.9%	0	0.0%
Rhabdomyosarcoma	1	1.5%	2	3.8%	2	2.4%
Sarcoma	1	1.5%	1	1.9%	0	0.0%
Schwannoma, NOS	0	0.0%	1	1.9%	0	0.0%
Teratoma	0	0.0%	0	0.0%	1	1.2%
Wilm's Tumor	0	0.0%	1	1.9%	6	7.2%
Total	68	100.0%	52	100.0%	83	100.0%

Cancer Registry

NESSENTIAL 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 Elekta Medical Systems software program, called METRIQ. It is a system designed for the collection, management and analysis of the data on cancer patients. The information that is provided by the cancer registry is utilized in research, education, and patient care evaluation. It has also proven to be of financial importance in administrative planning of allocation of hospital resources.

January 1, 1986 was established as our reference date, and as of December 31, 2011, the cancer registry has accessioned 1898 cases. A comparison of Children's Hospital data from 2009, 2010, and 2011 is presented in the Cancer Statistics section of this report. The following discussion will focus primarily on Children's Hospital analytic case data from 2011. In 2011, a total of 100 cases were accessioned:

- 83% (n=83) being analytic and 17% (n=17) being non-analytic.
- 43% (n=36) were male and 57% (n=47) were female.
- 24% (n=20) of our patients resided in Jefferson parish.
- The median age at diagnosis of our patients was 9.
- 35% (n=29) were white females with the highest incidence of cancer.
- 27% (n=22) were ALL patients which was our most common histology in 2011.

In order to evaluate cancer care outcomes, the cancer registry maintains long-term follow-up on eligible patients included in the registry. To successfully achieve survival rates the American College of Surgeons (ACoS) requires an 80% follow-up rate on eligible patients, and a 90% follow-up rate for eligible patients diagnosed within the last 5 years. The cancer registry has been able to successfully maintain the required follow-up rate.

Site	# of Cases	% of Cases
Bone Marrow	25	30.1%
Brain & CNS	19	22.9%
Lymph Nodes	13	15.7%
Bone	8	9.6%
Kidney	6	7.2%

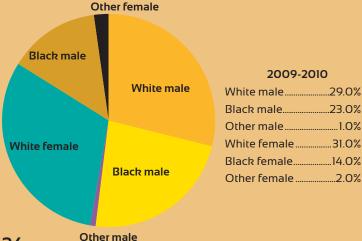
Data is submitted to the National Cancer Data Base (NCDB) and the Louisiana Tumor Registry (LTR). In return, the NCDB provides local, state and national statistics to cancer programs that enables them to benchmark patient care and quality improvement efforts. The LTR also provides local and state statistics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

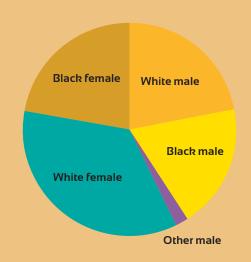
Knowledgeable personnel, including at least one CTR (Certified Tumor Registrar) staff the cancer registry. The cancer registry is located in the Medical Records Department. All inquiries may be directed to Rachel Bufkin, CTR at (504) 894-7381.

Cancer Statistics

Distribution by Sex and Race

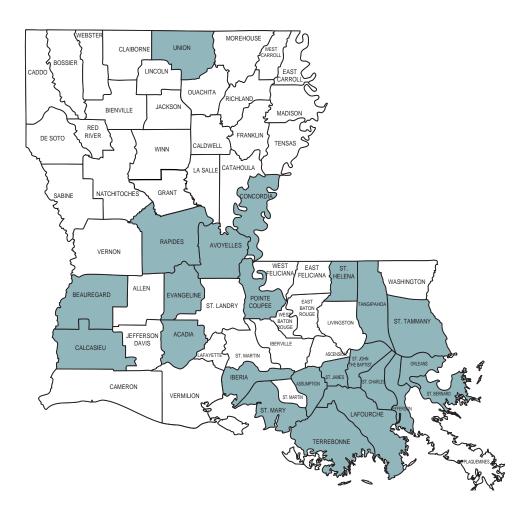
(Analytic cases only)





2011	
White male	22.0%
Black male	19.0%
Other male	2.0%
White female	35.0%
Black female	22.0%
Other female	0.0%

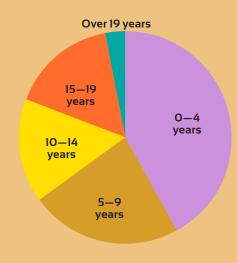
Analytic Cases



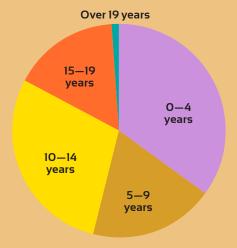
Distribution of **Analytic Cases by Parish**

PARISH	2009	2010	2011
Acadia	0	0	2
Assumption	1	0	1
Avoyelles	0	0	3
Beauregard	0	1	1
Calcasieu	2	4	3
Concordia	1	0	1
East Baton Rouge	2	2	0
Evangeline	0	1	2
lberia	1	0	1
lberville	1	0	0
Jackson	0	0	0
Jefferson	14	8	20
Lafayette	0	1	1
Lafourche	1	1	3
Livingston	1	0	0
Orleans	6	10	13
Ouachita	0	1	0
Plaquemines	1	1	0
Pointe Coupee	0	0	1
Rapides	1	0	2
St. Bernard	3	0	5
St. Charles	1	0	1
St. Helena	0	0	2
St. James	1	0	0
St. John th Baptisit	0	0	4
St. Landry	0	0	0
St. Martin	0	0	0
St. Mary	1	3	2
St. Tammany	10	2	4
Tangipahoa	5	5	4
Terrebone	8	0	1
Union	0	0	1
Vermilion	0	2	0
Vernon	1	0	0
Washington	2	2	0
Out-of-State	4	8	5
Total	68	52	83

Age at Diagnosis (Analytic cases only)



2009-2010	
0-4 years	42%
5-9 years	23%
10-14 years	16%
15-19 years	16%
Over 19 years	3%



2011	
0-4 years	35%
5-9 years	19%
10-14 years	29%
15-19 years	16%
Over 19 years	1%

Bone Marrow/Hematopoietic Stem Cell Transplant Program

HILDREN'S HOSPITAL/LSUHSC PEDIATRIC Hematopoietic stem cell transplantation (HSCT) program is the only approved Children's Oncology Group (COG) transplant program in the state of Louisiana. It offers patients access to all COG transplant protocols without the need to travel far to get this life saving treatment.

We are also a full member of the Pediatric Blood and Marrow Transplant Consortium (PBMTC) which is the largest forum focused on Pediatric BMT and it is a core member of the NIH-funded BMT-CTN network. This affiliation allows our patients to participate in clinical trials aimed at improving the clinical outcomes of BMT.

The transplant patient is treated in the state-of-the-art 18-bed unit with a specialized HEPA air-filtration system. This special environment provides the severely immunocompromised transplant patients the best protection from opportunistic infections.

Our HSCT program applies a multidisciplinary approach to the care of the transplant patient. The HSCT team consists of a highly skilled team of board certified Pediatric Hematologists/Oncologists, Bone Marrow Transplant (BMT) trained nurses, dieticians, child life therapist, child psychologists, pharmacists, social workers, clinical research associates, physical therapists and transplant nurse coordinator.

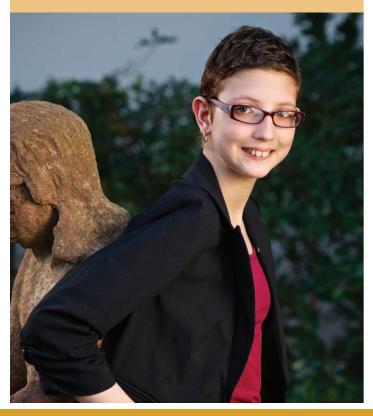
Our HSCT program offers innovative treatment for children with cancer such as leukemia, lymphoma, neuroblastoma, brain tumors and other recurrent cancers as well as for children with non-malignant conditions including immunodeficiency disorders, bone marrow failure syndromes and blood disorders such as transfusion-dependent sickle cell disease and thalassemia major.

Under the leadership of Lolie Yu, M.D., director of the HSCT program, we performed the first human placenta-derived stem cell transplant (HPDSC) in the world in 2008. These HPDSC cells will be used for malignant and non-malignant conditions which can be cured with transplantation. The study is in collaboration with the cellular therapy section of Celgene. We also were the first transplant center in Louisiana to implement the use of Mesenchymal stem cells (MSC) to treat refractory graft versus host disease (GVHD).

Our HSCT is certified by the Foundation for the Accreditation of Cellular Therapy (FACT) for its high quality of patient care and HPC collection/processing laboratory performance. We are one of only 20 pediatric facilities in the U.S. to be FACT- accredited.

Our Pediatric HSCT program provides quality care that is designed to accommodate the full range of a child's unique needs with expertise in both autologous and allogeneic transplants.

TRANSPLANTS BY DISEASE	
DISEASE TYPE	TOTAL
ACUTE LEUKEMIA	
AML/MDS	55
ALL	51
Other	13
SOLID TUMORS	
Lymphoma	22
Neuroblastomas	48
Brain tumor	16
Wilms	3
Histiocytosis	4
Sarcoma	10
Germ cell tumor	2
NON-MALIGNANT CONDITIONS	
BMF	46
Metabolic disorders	5
Immunodeficiency	23
Hemoglobinopathy:	
Sickle cell	11
Thalassemia	2
TOTAL	311



Hematology/ Oncology Program

HE PEDIATRIC HEMATOLOGY/ONCOLOGY AND HSCT section of LSUHSC Department of Pediatrics was formally accredited by the Accreditation Council for Graduate Medical Education (ACGME) in 1989. It remains the only accredited fellowship program between Florida and Texas. We are proud to report that, this year, 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, Morales, Morrision, Prasad 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 Children's Hospital and LSUHSC, New Orleans.

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, James Hempe, Yan Cui, Paula Rodriquez 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.

Cancer Conference

T 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, appropriate staging, 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.

In 2011, a total of 48 conferences were held. On average, approximately 22 physicians, residents, students and other cancer-related supporting staff personnel attended the weekly conferences. A total of 131 cases were presented in 2011. These cases consisted of prospective, retrospective and follow-up cases. It should be noted that 98 percent of the cases presented were prospective and were representative of the major sites of cancer at Children's Hospital.

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

Community Outreach Program

MONG THE GOALS FOR OUR COMMUNITY OUTREACH PROGRAM ARE THE CONTINUING EFFORTS TO EDUCATE AND inform the public and healthcare 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), human papillomavirus (HPV) vaccine 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 website at www.chnola.org.

SUPPORT SERVICES HIGHLIGHT: Beads of Courage

with cancer face many challenging events throughout their treatment path. Beads of Courage is a unique program designed to honor that challenging journey patients and their families take while receiving care for cancer. The Beads of Courage program uses color-

for cancer. The Beads of Courage program uses colorful beads that each symbolize different procedures and milestones for children going through treatment including bone marrow aspirate/biopsy, day of chemotherapy, Port and central line insertion/Removal, and more. Children are then able to tell their courageous story using the beads they collect throughout treatment. Children also receive a handmade glass purple heart bead when they complete their treatment to symbolize their outstanding courage and bravery.







ABOUT THE BEADS OF COURAGE® PROGRAM

The Program is a resilience-based intervention designed to support and strengthen children and families coping with serious illness. Through the program members tell their story using colorful beads as meaningful symbols of courage that they receive to honor and acknowledge each step of their treatment journey. Beads are given according to a specific program bead guide. For milestones in their treatment journey, they receive handmade one-of-a-kind glass beads that are donated by members of the International Society of Glass Beadmakers (ISGB).

PROGRAM AREAS

The Beads of Courage® Program is available for the following:

- Cancer and Blood Disorders
- Cardiac Conditions
- ■Burn injuries
- Neonatal Intensive Care Unit
- Chronic Illness

PROGRAM DEVELOPMENT

All Program bead guides were developed in collaboration with experts in the field (nurses, doctors, child life specialists and social workers) so that each bead guide would reflect meaningful acknowledgment of a member's treatment journey.

OUTCOMES

Ongoing evaluation of the Beads of Courage® program indicates that the program helps to decrease illness-related distress, increase the use of positive coping strategies, helps members find meaning in illness, and restore sense of self in those coping with serious illness. The program also provides something tangible the member can use to tell about their experience during treatment and after.

CURRENT PROGRAMS

Currently, the Beads of Courage program is provided to 130+ sites in 6 countries. By the end of 2012, the program will have 150+ member hospitals.

FACT SHEET 2012

- Beads of Courage, Inc. was founded in 2004 by Jean Baruch, RN, a pediatric oncology nurse who was inspired to care for children and their families with an arts-in-medicine program.
- Beads of Courage, Inc. headquarters are in Tucson, Arizona.
- In February 2004, Phoenix Children's Hospital became the first Beads of Courage Member Hospital providing the Beads of Courage program to families being cared for in their cancer center. Today, Phoenix Children's provides the program to all families coping with serious illness.
- In 2010, Dr. Jean Baruch completed her doctoral study on the Beads of Courage Program and received her PhD from the University of Arizona, College of Nursing.
- Today, Beads of Courage, Inc. is providing innovative support programs to children in 130+ hospitals across the United States, Canada, Ireland, Japan, New Zealand and the United Kingdom.
- The Signature Beads of Courage Program is available for children coping with cancer/blood disorders, cardiac conditions, burn patients and for families in the Neonatal Intensive Care Unit (NICU). Late in 2011, the Program expanded to support children with chronic illness.
- Beads of Courage has a multitude of programs available for our member hospitals encouraging family-centered care, these include: Beads of Courage Sibling Program; Creative Courage Journal; Workshop Series; Bereavement Support; and coming soon...Touch for Strength, a journal for Parents and Caregivers.
- In 2010, Beads of Courage launched a pro-

gram to support clinicians caring for children with serious illness. The Bead Caring Program provides support and encouragement over time using a Round of Caring with beads to recognize professional milestones and provide the staff time to reflect on the work they do caring for children with serious illness.

- Beads of Courage, Inc. is proud of its partnership with the International Society of Glass Beadmakers (ISGB) who provide the handmade one-of-a-kind glass beads for the Beads of Courage Program. Over 50,000 beads are donated annually to honor the COURAGE of our members in the Beads of Courage Program.
- Beads of Courage, Inc. is proud to collaborate with local and national organizations and non-profits to support families at each member hospital. Each member hospital has a Program Sponsor providing the financial support for the Beads of Courage Program and is committed to supporting the maintenance of the program.
- Beads of Courage, Inc. is a Proud Member of the Society for the Arts in Healthcare and has partnerships with nursing and child life organizations.

Treatment Protocols

DISEASE CLASSIFICATION: ACUTE LYMPHOBLASTIC LEUKEMIA

AALLO8B1, Classification of Newly Diagnosed Acute Lymphoblastic Leukemia (ALL)

AALLO433, Intensive Treatment for Intermediate-Risk Relapse of Childhood B-Precursor Acute Lymphoblastic Leukemia (ALL): A Randomized Trial of Vincristine Strategies

AALLO434, Intensified Methotrexate, Nelarabine (Compound 506U78; IND#526II) and Augmented BFM Therapy for Children and Young Adults with Newly Diagnosed Tcell Acute Lymphoblastic Leukemia (ALL) or T-cell Lymphoblastic Lymphoma

AALLO631, A Phase III Study of Risk Directed Therapy for Infants with Acute Lymphoblastic Leukemia (ALL): Randomization of Highest Risk Infants to Intensive Chemotherapy +/- FLT3 Inhibition (CEP-701, Lestaurtinib; IND#76431, NSC#617807)

AALLO7P1, A Phase II Pilot Trial of Bortezomib (PS-341, Velcade, IND# 58,443) in Combination with Intensive Re-Induction Therapy for Children with Relapsed Acute Lymphoblastic Leukemia (ALL) and Lymphoblastic Lymphoma (LL)

AALLO932, Treatment of Patients with Newly Diagnosed Standard Risk B-Precursor Acute Lymphoblastic Leukemia (ALL)

AALLI131, A Phase III Randomized Trial for Newly Diagnosed High Risk B-precursor Acute Lymphoblastic Leukemia (ALL) Testing Clofarabine (IND# 73789, NSC# 606869) in the Very High Risk Stratum

DISEASE CLASSIFICATION: ACUTE MYELOID LEUKEMIA

AAMLO8B1, Biology Study of Transient Myeloproliferative Disorder (TMD) in Children with Down Syndrome (DS)

AAML1031, A Phase III Randomized Trial for Patients with de novo AML using Bortezomib and Sorafenib (IND#114480; NSC# 681239, NSC# 724772) for Patients with High Allelic Ratio FLT3/ITD

ACCLO933, A Randomized Open-Label Trial of Caspofungin versus Fluconazole to Prevent Invasive Fungal Infections in Children Undergoing Chemotherapy for Acute Myeloid Leukemia (AML)

DISEASE CLASSIFICATION: NEUROBLASTOMA

ANBLOOB1, Neuroblastoma Biology Studies

ANBLO032, Phase III Randomized Study

of Chimeric Antibody 14.18 (Ch14.18) in High Risk Neuroblastoma Following Myeloablative Therapy and Autologous Stem Cell Rescue

DISEASE CLASSIFICATION: WILM'S TUMOR / RENAL

9442, National Wilms Tumor Late Effects Study

ARENO3B2, Renal Tumors Classification, Biology, and Banking Study

ARENO321, Treatment of High Risk Renal Tumors

AREN0532, Treatment for Very Low and Standard Risk Favorable Histology Wilms Tumor

ARENO533, Treatment of Newly Diagnosed Higher Risk Favorable Histology Wilms Tumors

ARENO534, Treatment for Patients with Bilateral, Multicentric, or Bilaterally-Predisposed Unilateral Wilms Tumor

DISEASE CLASSIFICATION: BRAIN TUMOR

ACNSO2B3, A Children's Oncology Group Protocol for Collecting and Banking Pediatric Brain Tumor Research Specimens

ACNSO331, 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 Double Randomized Trial

ACNSO332, Efficacy of Carboplatin Administered Concomitantly With Radiation and Isotretinoin as a Pro-Apoptotic Agent in Other Than Average Risk Medulloblastoma/PNET Patients

ACNSO333, Treatment of Atypical Teratoid/Rhabdoid Tumors of the Central Nervous System with Surgery, Intensive Chemotherapy, and 3-D Conformal Radiation

ACNSO831, Phase III Randomized Trial of Post-Radiation Chemotherapy in Patients with Newly Diagnosed Ependymoma Ages 1 to 21 years

ACNS1123, Phase 2 Trial of Response-Based Radiation Therapy for Patients with Localized Central Nervous System Germ Cell Tumors (CNS GCT)

ALTEO7C1, Neuropsychological, Social, Emotional and Behavioral Outcomes in Children with Cancer

DISEASE CLASSIFICATION: RARE TUMOR

ABTROIBI, A Children's Oncology Group

Protocol for Collecting and Banking Pediatric Research Specimens Including Rare Pediatric Tumors

DISEASE CLASSIFCATION: HEPATOBLASTOMA

AHEP0731, Treatment of Children with All Stages of Hepatoblastoma

DISEASE CLASSIFICATION: EWING SARCOMA

AEWSO331, European Ewing Tumor Working Initiative of National Groups Ewing Tumor Studies 1999 (EURO-E.W.I.N.G. 99)

AEWS1031, A Phase III Randomized Trial of Adding Vincristine-Topotecan-Cyclophosphamide to Standard Chemotherapy in Initial Treatment of Non-metastatic Ewing Sarcoma

DISEASE CLASSIFICATION: SARCOMA

ARST0531, Randomized Study of Vincristine, Dactinomycin and Cyclophosphamide (VAC) versus VAC Alternating with Vincristine and Irinotecan (VI) for Patients with Intermediate-Risk Rhabdomyosarcoma (RMS)

ARST08PI, A Pilot Study to Evaluate Novel Agents (Temozolomide and Cixutumumab [IMC-Al2, Anti-IGF-IR Monoclonal Antibody, IND #100947, NSC #742460]) in Combination with Intensive Multi-Agent Interval Compressed Therapy for Patients with High-Risk Rhabdomyosarcoma

ARSTO921, A Randomized Phase II Trial of Bevacizumab (IND# 7921, Avastin) and Temsirolimus (IND# 61010, Torisel) in Combination with Intravenous Vinorelbine and Cyclophosphamide in Patients with Recurrent/Refractory Rhabdomyosarcoma

D9902, A COG Soft Tissue Sarcoma Biology and Banking Protocol

CANCER CONTROL STUDIES

ACCRNO7, Protocol for the Enrollment on the Official COG Registry, The Childhood Cancer Research Network (CCRN)

ALTEO3NI, Key Adverse Events after Childhood Cancer

ACCL1031, A Randomized Double Blinded Trial of Topical Caphosol to Prevent Oral Mucositis in Children Undergoing Hematopoietic Stem Cell Transplantation

ACCLO934, A Randomized Trial of Levofloxacin to Prevent Bacteremia in Children Being Treated for Acute Leukemia (AL) or Undergoing Hematopoietic Stem Cell Transplantation (HSCT)

HSCT OR NON-COG EXPANDED ACCESS STUDIES

Expanded Access of Prochymal® (Ex-vivo Cultured Adult Human Mesenchymal Stem Cells) Infusion for the Treatment of Pediatric Patients Who Have Failed to Respond to Steroid Treatment for Acute GVHD (Osiris Therapeutics Inc. Protocol No. 275, BB-IND No. 7939)

Defibrotide for Patients with Severe Hepatic Veno-Occlusive Disease (VOD): A Treatment IND Study (Under CFR 312.34) (Gentium S.p.A. Protocol Defibrotide 2006-05)

A Study of Hematopoietic Stem Cell Transplantation (HSCT) in Non-malignant Disease Using a Non-myeloablative Preparatory Regimen with Campath-1H, Fludarabine and Melphalan (Washington University 01-0923)

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

NATIONAL MARROW DO-NOR PROGRAM RESEARCH SAMPLE REPOSITORY

A Multicenter Access and Distribution Protocol for Unlicensed Cryopreserved Cord Blood Units (CBUs) for Transplantation in Pediatric and Adult Patients (NMDP 10-CBA)

Unrelated Donor Reduced Intensity Bone Marrow Transplant for Children with Severe Sickle Cell Disease (BMT CTN 0601)

PHARMACEUTICAL SPONSORED STUDIES

A Single-arm Study to Assess the Safety of Transplantation with Umbilical Cord Blood Augmented With Human Placental-derived stem cells From Partially- or fully-HLa Matched Related Donors in Subjects with Certain Malignant Hematologic Diseases and Non-malignant Disorders (Celgene Cellular Therapeutics)

A Randomized, placebo-Controlled, Multisite Phase 2 Study Evaluating the Safety and Efficacy of Preemptive Treatment with CMXOOI for the Prevention of Adenovirus Disease Following Hematopoietic Stem Cell Transplantation (The ADV HALT Trial), Chimerix Protocol CMXOOI-202

A Multicenter, Open-Label Study of CMX001 Treatment of Serious Diseases or Conditions Caused by dsDNA Viruses, Chimerix Protocol CMX001-350 Pathfinder 2; A Multi-National Trial Evaluating Safety and Efficacy Including Pharmacokinetics, of NNC 0129-0000-1003 when Administered for Treatment and Prophylaxis of Bleeding in Patients with Haemophilia A (NovoNordisk)

Efficacy and Safety of NNC 0129-0000-1003 during Surgical Procedures in Patients with Haemophilia A, NovoNordisk Protocol # NN7088-3860

A 3-year, Prospective, Non-interventional, Multicenter Registry in Sickle Cell Disease patients (Novartis)

COG STUDIES THAT WERE ACTIVE IN FOLLOW-UP BUT CLOSED TO ACCRUAL IN

2012 (if study closed to accrual in 2012, the date follows the study title)

COG 0501: Multi-center, Open Label, Randomized Trial Comparing Single Versus Double Umbilical Cord Blood (UCB) Transplantation in Pediatric Patients with Leukemia and Myelodysplasia (BMT CTN 0501) (02/29/2012)

9905, ALinC 17: Protocol for Patients with Newly Diagnosed Standard Risk Acute Lymphoblastic Leukemia (ALL): A Phase III Study

9904, AlinC17 Treatment of Patients with Newly diagnosed low risk acute lymphoblastic leukemia: A Phase III Study

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

AAMLO531, 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

9404, Intensive Treatment for T-Cell Acute Lymphoblastic Leukemia and Advanced Stage Lymphoblastic Non-Hodgkin's Lymphoma (T-Cell #4)

A5971, Randomized Phase III Study for the Treatment of Newly Diagnosed Disseminated Lymphoblastic Lymphoma or Localized Lymphoblastic Lymphoma

AHODOO3I, A Phase III Groupwide Study of Dose-Intensive Response-Based Chemotherapy and Radiation Therapy for Children and Adolescents with Newly Diagnosed Intermediate Risk Hodgkin Disease

AHODO431: Phase III Study for the Treatment of Children and Adolescents with Newly Diagnosed Low-Risk Hodgkin Disease

COG AHODO831: A Non-Randomized Phase III Study of Response Adapted Therapy for the Treatment of Children with Newly Diagnosed High Risk Hodgkin Lymphoma (01/19/2012)

P9645, Phase II Protocol for the Treatment of Children with Hepatoblastoma

A3973, A Randomized Study of Purged versus Unpurged Peripheral Blood Stem Cell Transplant Following Dose Intensive Induction Therapy Following Dose Intensive Induction Therapy for High Risk Neuroblastoma

COG ANBLO532: Phase III Randomized Trial of Single vs. Tandem Myeloablative Consolidation Therapy for High-Risk Neuroblastoma (02/27/2012)

ANBLO931: A Comprehensive Safety Trial of Chimeric Antibody 14.18 (ch14.18) with GM-CSF, IL-2 and Isotretinoin in High-Risk Neuroblastoma Patients Following Myeloablative Therapy: A Limited Institution Study

AOSTO331: 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 (IND# 12697)

9440, National Wilms Tumor Study - 5: Therapeutic Trial and Biology Study

ARSTO331: Vincristine, Dactinomycin, and Lower Doses of Cyclophosphamide With or Without Radiation Therapy for Patients with Newly Diagnosed Low-Risk Embryonal/Botryoid/Spindle Cell Rhabdomyosarcoma

ASCTO431: A Randomized Trial of Sirolimus-Based Graft Versus Host Disease Prophylaxis after Hematopoietic Stem Cell Transplantation in Selected Patients with CR1 and CR2 ALL

ASCTO521: Soluble Tumor Necrosis Factor Receptor: Enbrel (Etanercept) for the Treatment of Acute Non-Infectious Pulmonary Dysfunction Idiopathic Pneumonia Syndrome) Following Allogeneic Stem Cell Transplantation

Publications & Selected Manuscripts

2012

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ABSTRACTS

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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.

Resources

Children's Hospital Main Number	(504) 899-9511	FINANCIAL	
Oncology Department	, ,	Medicaid – Enroller	(504) 896-9152
Oncology Department Fax		Office of Family Security	(504) 599-1700
Oncology Unit – inpatient		Social Security	(800) 772-1213
Oncology – outpatient clinic		Children's Hospital Assistance	
Neurosurgery Department		Program (CHAP)	(504) 894-5166
Social Services Department		American Cancer Society	(504) 469-0021
Surgery Department		Leukemia/Lymphoma Society	(504) 887-0945
Orthopaedics Department		Optimist Leukemia Foundation	(800) 685-9611
	(504) 896-9585	J.L Foundation	(225) 698-1010
Administration		National Children's Cancer Society	(314) 241-1600
Diagnostic Radiology	(504) 896-9565	Cancer Recovery Fund	(717) 564-4100
Pathology Department		First Hand Foundation	(816) 201-1569
Bone Marrow Transplant Program		Cancer Association of Greater New Orleans	(504) 733-5539
Lolie C. Yu, MD		Total Community Action	(504) 304-6676
Cancer Committee Chairman	(504) 896-9741	Kids Kicking Cancer	(504) 455-7754
Cancer Program Liaison	(504) 896-3977		
Evans Valerie, MD		HOUSING	
		Ronald McDonald House	(504) 468-6668
CANCER INFORMATION/RE	SOURCES	American Cancer Society Patrick F.	
American Cancer Society	(800) ACS-2345	Taylor Hope Lodge	(504) 219-2202
American Cancer Society,		Hotels – medical rates list available	
New Orleans Chapter	(504) 469-0021	in Social Services Department	
National Cancer Institute	1-800-4CANCER		
		WISHES	
CANCER INFORMATION WE	BSITES	A Child's Wish	(504) 367-9474
American Cancer Society,	www.cancer.org	Make-A-Wish	(504) 846-9474
National Cancer Institute	www.cancer.gov	A Special Wish	(614) 575-9474
Children's Hospital, New Orleans	www.chnola.org	CURRORT	
National Childhood		SUPPORT	
Cancer Foundation	.www.curesearch.org	Candlelighters	` '
Cancer Care	.www.cancercare.org	Sperm Bank Reproductive Services	, ,
Cancer Surviors Projectwww.cance	rsurvivorsproject.org	Camp Challenge	, ,
National Children's		Sunshine Kids	
Cancer Societywww	.children-cancer.com	Caps for Kids	(504) 891-4277
		MENTAL HEALTH	
			(50 () (00 0 (15
		Rehabilitation Program/RTC	
		Via Link (24 hour counseling)	
		Angel's Place (Respite Care)	
		COPELINE - Suicide Prevention	(800) 2/3-8255
		Children's Hospital Behavioral Health Unit,	(50/) 60/ 7067
		Calhoun Campus	
		Family Service of GNO	(504) 822-0800
		DEATH	

 Compassionate Friends
 (504) 454-5078

 Seasons – The Center for Caring
 (504) 834-1453

 St. Joseph Hospice
 (504) 734-0320

 Serenity Hospice
 (504) 366-3996



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