focus on Pediatric Oncology
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cancer committee

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Hospital Representatives:
Zona Akbari, Director, Regional Cancer Center
Tom Bekkers, Case Management
Sara Biese, Cancer Registry
Jolene Cheslock, Clinical Research
Brenda Hella, Outpatient Rehabilitation
Dale Herold, Pharmacy
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Sally Luehring, Executive Director, Cancer Services
Peter Safranski, Green Bay Oncology
Jen Thompson, American Cancer Society
John Viste, Pastoral Care
Heidi Warpinski, Pediatrics
Marilyn Wilson, Cancer Care Coordinator
Connie Worzala, Cancer Care Coordinator
Barb Zenker, Palliative Care Specialist
Welcome to the 2009 Regional Cancer Center Annual Report for St. Vincent Hospital. The focus of this report is on pediatric oncology services for Northeast Wisconsin and the Upper Peninsula of Michigan. In this report, we will provide you with statistics and information from our region and the services provided for our Pediatric Oncology Program.

St. Vincent Hospital has a long history of providing pediatric oncology services. We took it to a new level in 2000 with the arrival of Pediatric Oncology Specialist, Dr. Jon Brandt. That year, we saw the diagnosis of 15 new cancer cases. Sadly, the numbers have not slowed down since then. In 2008, there were 25 cases of newly diagnosed pediatric cancers treated at St. Vincent. The cumulative numbers from 2000 through 2008 indicate 188 newly diagnosed pediatric cancer cases. The good news is that pediatric cancer survivorship has improved in most diagnoses over the years. That success comes in part because many of the children with cancer treated here follow a treatment plan that is part of ongoing national research through the Children’s Oncology Group (COG).

Pediatric oncology patients have received support from several generous organizations including The Angel Fund for Children with Cancer, Inc.; Families of Children with Cancer; Bryan Wulf Angel Classic; A Noble Cause, and the Jerry Parins Cruise for Cancer. Parins has generously donated to the St. Vincent Pediatric Center with a special focus on meeting the needs of all oncology patients and their families.

Since 2000, St. Vincent Hospital has enjoyed an affiliation with Children’s Hospital of Wisconsin, with specialty physicians from the Milwaukee facility historically traveling at regular intervals to join the team to provide care to pediatric patients at St. Vincent Hospital and the Pediatric Hematology/Oncology Clinic.

The Future of Cancer Care
In the 2008 Cancer Center Annual Report, readers were introduced to the new Regional Cancer Collaborative, a network of seven hospitals, stretching from Marinette to Sheboygan. Various components of the St. Vincent Regional Cancer Center are extended to these sites either through common physicians, shared clinical staff, clinical research affiliations or through specific care integration. This relationship of independent organizations, brought together to meet the needs of our patients with cancer, continues to be unprecedented in our region.

Led by Sally Luehring, Executive Director of Cancer Services, HSHS Division (Eastern Wisconsin), the Collaborative spent its first year focused on setting priorities for integration, sharing resources and developing common clinical outcome measures.

The clinical research department of St. Vincent Hospital has evolved to become the Cancer Research Institute under Director Jolene Cheslock. The year 2009 saw the writing and re-submission of the National Cancer Institute-supported Community Clinical Oncology Program (CCOP) grant to do prevention as well as treatment research. We place high value on the ability to provide patients access to ongoing research. Research protocols available through our organization are accessible online via the St. Vincent Hospital Web site, www.stvincenthospital.org.

Cancer survivorship has been a focus over this past year as we have expanded and organized our offerings of educational and support classes. Massage as a therapeutic intervention is offered to our patient population helping to reduce anxiety, lower blood pressure and relieve pain.

New technology this past year included the implementation of Rapid Arc to our radiation therapy techniques. For selected patients, Rapid Arc uses precise anatomic imaging prior to, or during treatment, through the use of high quality imaging x-rays and on board CT scanning. Treatment is delivered dynamically as the linear accelerator completes 1-2 rotations around the patient in a matter of minutes. This shortened treatment time improves patient comfort and can reduce the risk of unintended internal or external patient motion.

As of January 2010, St. Mary’s Hospital will house an expansion of the St. Vincent Regional Cancer Center program. The new complex will offer treatment with the same leading medical and radiation oncology specialists found at St. Vincent Hospital. A significant number of cancer program elements will be shared and integrated between the two sites including leadership through a combined Department of Oncology. Specialized services such as Pediatric Oncology and Gynecologic Oncology will remain centered at St. Vincent Hospital.

St. Vincent and St. Mary’s hospitals currently provide nearly three-fourths of all cancer-related services in the greater Green Bay area and, for our youngest cancer patients, St. Vincent Hospital will continue to provide the highest quality, child-centered cancer care that research, technology and loving providers have to offer.

Zona Akbari, RN, BSN, OCN
Director, Regional Cancer Center
St. Vincent Hospital
• About one in 300 boys and one in 333 girls will develop cancer before the age of 20. Although uncommon, cancer is the second leading cause of death due to disease in children, exceeded only by accidents.

Between 2000 and 2008, St. Vincent hospital diagnosed and/or treated 188 newly diagnosed pediatric cancer patients.

• Since the mid-1950s, cooperative research has improved the survival rates for pediatric cancer from less than 10% to almost 80% overall. Cure rates vary according to each specific type of cancer. Some types continue to be very difficult to cure.

• The Surveillance, Epidemiology, and End Results (SEER) Program of the National Cancer Institute (NCI) is an authoritative source of information on cancer incidence and survival in the US. Five-year relative survival rates describe the percentage of patients with cancer that are alive five years after their diagnosis divided by the percentage of the general population of corresponding age that are alive after five years.

• Chart compares the relative survival rate of St. Vincent’s top four pediatric cancers to SEER survival rates. Patients diagnosed and/or treated at St. Vincent show survival rates above the SEER rates.
**2000-2008 Analytic Pediatric Case Referrals by County of Residence**

Total Cases = 188

**2008 Combined Registry; All Analytic Cancer Case Referrals by County of Residence**

Other States
- Florida: 2
- Illinois: 1
- Indiana: 1
- Oklahoma: 1
- Oregon: 1
- Washington: 1

Total: 1225
2008 Combined Registry Analytic Cases*

Breast
Lung/Respiratory
Prostate
Corpus Uteri
Hematopoietic
Colon
Non-Hodgkin Lymphoma
Bladder
Ovary
Other
Stomach/Esophagus
Thyroid
Kidney
Biliary
Rectal/Anal
Melanoma
Cervix Uteri
Pancreas
Unknown Primary
Head & Neck
Brain (Malignant)
Vulva
Hodgkin Lymphoma
Soft Tissue
Larynx
Testis

*Analytic cases: Patients diagnosed (clinically or pathologically) at St. Vincent or St. Mary’s or cases diagnosed elsewhere with first course of treatment at either hospital.
Pediatric Incidence by histology/site

2000-2008 Pediatric Incidence by Histology/Site

Total Cases=188

*Benign Tumors
The most common adult cancers are breast, prostate, lung and colorectal. Unlike adults, the most common pediatric cancer types are blood and bone marrow, lymph tissue, kidney, brain and bone.

**Acute lymphoblastic leukemia (ALL)** is the most common pediatric cancer, accounting for 35% of all cancers in children. There are about 7,000 new cases in the US each year.

**Acute myeloid leukemia (AML)** is more common in adults. But each year, approximately 500 new pediatric cases are diagnosed in the US each year.

**Non-Hodgkin lymphoma (NHL)** is a general term for cancer of the lymphoid system. Approximately 7% of all pediatric cancers are NHL. NHL occurs more frequently with increasing age and twice as many boys are diagnosed than girls.

**Hodgkin lymphoma** is also a cancer of the lymphoid system. Hodgkin lymphoma accounts for 5% of cancers diagnosed in children less than 15 year of age in the US. The number of cases increases significantly in the second decade of life, making it most common in teenagers, comprising 16% of cancers in adolescents.

**Brain tumors** are the most common solid tumors in children less than 15 years. They account for approximately 20% of all cancers diagnosed in this age group. Most brain tumors tend not to spread to other parts of the body outside the brain and/or central nervous system (CNS). However, they tend to recur locally or spread to other areas of the CNS.

**Neuroblastoma** is the most common solid tumor outside of the brain in children. Approximately 650 cases are diagnosed in the US annually. Most children are diagnosed as toddlers, but neuroblastoma can present in infants and older teenagers.

**Wilms’ tumor (nephroblastoma)** is the most common form of kidney cancer in children. Usually, Wilms’ tumor arises in one kidney, but sometimes can occur in both. A Wilms’ tumor may grow without being detected until it becomes quite large. However, most are discovered before they have spread to other parts of the body.

**Osteosarcoma** is a cancer of the bone. It usually occurs in adolescents and young adults, but can occasionally occur in younger children. Osteosarcoma most often starts in the bones around the knee joint, in the upper or lower leg next to the knee, or in the thigh.

**Ewing sarcoma** is the second most common tumor of the bone. It most often affects bone of the pelvis, tibia, fibula and femur, and can also start in the soft tissues. The disease most often occurs in adolescents, with nearly half the cases between the ages of 10 and 20.

The most common liver cancers in children are hepatoblastoma and hepatocellular carcinoma (HCC). Together hepatoblastoma and HCC account for about 1-2% of pediatric cancers.

**Germ cell tumors** are growths that arise in young children and teens, as well as adults. Germ cell tumors are rare only 2.4 children out of one million will develop a germ cell tumor. They make up only 4% of all pediatric cancers.

**Rhabdomyosarcoma** is a soft tissue sarcoma that develops in the muscles. In the US, about 350 new cases are diagnosed annually in children less than 15 years of age. Almost two-thirds of rhabdomyosarcoma cases develop in children under the age of 10.

**Retinoblastoma** is a rare cancer with approximately 300 children diagnosed with the US. It occurs most often in children under 4 and is 2.8% of all cancers in children ages 0 to 14.

Source: CureSearch.org
Childhood Cancer: The Innocent Victims

Pediatricians like Jon Brandt, John Hill and Renee Madden from the St. Vincent Pediatric Hematology/Oncology Clinic on St. Vincent Hospital’s 2nd floor have taken on a medical specialty that many of their peers might choose not to handle day after day.

As the only provider of pediatric hematology/oncology services in Northeast Wisconsin, the trio treats youngsters, from those newly born to age 21, who have been diagnosed with cancer and blood disorders.

“Children with cancer are the ultimate innocent victims of an undeserved, life-limiting illness,” Brandt said. “My career in this field is the opportunity to combine passion for the care of young people and a fascination with a genetic basis for disease.

Brandt serves as Medical Director for the Pediatric Hematology/Oncology inpatient program and outpatient clinic. He launched the program 10 years ago with three core characteristics that would drive patient care which he outlines here:

**Competence:** An excellent background in training for all three physicians and nursing staff certified in Pediatric Oncology Nursing; an affiliation with our colleagues at the Children’s Hospital of Wisconsin, and uninhibited communication with specialty providers around the country. “Participation in the Children’s Oncology Group (COG), links us to the largest pediatric clinical trials group on the planet. It offers patients access to care through clinical trials, examining the best possible treatment for a child’s cancer and brings further opportunities for expert oversight and contribution to their care. We are pleased to participate in COG as a member of only 63 Community Clinical Oncology Programs (CCOPs) in the country,” Brandt said.

**Consistency:** “There is great value in being small, and in our clinic that value translates into a limited number of people with whom patients and providers have to become familiar,” he suggested. “Navigating a child’s journey through cancer treatment can be stressful enough without adding a myriad of providers to the mix. By maintaining a small cohort of physician and RN care providers, we hope to ease patient and parent stress and promote familiar communication to enhance our ability to sustain a prolonged and productive relationship.”

**Compassion:** “Those darn cute little bald-headed kids will get to you every time,” Brandt said. “Child Life eases their burdens through distraction and artful expression, Palliative Care helps in the toughest of times and nurses who go to great lengths to choreograph entire days of procedures, studies and sedations in a way that minimizes time in the clinic or at the hospital and maximizes patient comfort are just a few of the ways we express compassion for our patients and their families.

“I believe we all love what we do, work hard to do it well and most of all, do it for those to whom life has not been fair,” Brandt concluded.
Getting to Know You

Like his partners at the Prevea Hematology/Oncology Clinic at St. Vincent Hospital, Dr. John Hill was drawn to children during his clinical rotations in medical school. Together with his intrigue with biochemistry, specifically the failure of regulation of cell proliferation in the development of cancer, and his interest in the molecular causes of brain tumors, Hill was on his way to a career in pediatric oncology.

He was drawn to Prevea Health and St. Vincent Hospital in Green Bay where he would establish his practice and continue his journey toward helping children in their fight against cancer.

“During my clinical rotations in medical school, I found I enjoyed working with and for children. I discovered I would gladly go an extra mile in the care of a child,” Hill said.

“I wanted to practice in a small group where I would have the opportunity to get to know patients and families better than at a larger institution, and I wanted to raise my family in a small city in the north,” Hill said.

He was drawn to Prevea Health and St. Vincent Hospital in Green Bay where he would establish his practice and continue his journey toward helping children in their fight against cancer.

“In our practice, we provide routine chemotherapy and acute care to our oncology patients in northeast Wisconsin and in the Upper Peninsula of Michigan in a timely manner and minimize family travel time.”

Hill said he and his partners and the rest of the clinical staff in the clinic, as well as the pediatric nursing staff in the pediatric unit of St. Vincent Hospital are committed to providing current therapy for children with cancer in as compassionate a way as possible.

“Heart and Soul”

Pediatric oncology, as any other field of medicine, is constantly changing, Hill observed. Researchers are striving to find better treatments for pediatric cancers. As a result, new treatments and updates of current treatment protocols are coming out constantly.

Besides the pediatric oncology patients he and his partners treat, Hill noted, “We also care for pediatric patients with hematological diseases including bleeding disorders, clotting disorders and abnormalities in either over or underproduction of white blood cells, red blood cells and/or platelets.” That is also challenging and rewarding work that keeps his passion for his profession alive.

“I occasionally hear from some people who, when they learn what I do, say they would not be able to do my job,” the physician said. “It is true this profession can be very difficult at times. But the rewards of getting to know our wonderful young patients and their families and sharing in their lives far outweigh the bad days, and that’s what gets me through the difficult times.”
Home Again

Central Wisconsin native Renee Madden’s training and career had taken her south and west – to Tennessee, Kentucky, Texas and Arizona – but when she was ready to settle down, Wisconsin still seemed like the place to hang her stethoscope.

“I joined the Pediatric Hematology/Oncology team at Prevea Health, located in St. Vincent Hospital, in March of 2009,” Dr. Madden said. “I was looking for a practice with a passion for caring for children with hematologic disorders and pediatric patients with cancer, and I feel fortunate to have found such a group at St. Vincent Hospital in Green Bay.”

She was impressed with the big city level of care she found in this community-centered clinic, Madden said. “Just seeing Dr. Brandt, Dr. Hill and the rest of the staff here, so committed to taking care of the kids with cancer and hematologic issues – that is what drew me here.”

She brought her own expertise to the team and fit right in. “I have always had the desire to care for children with oncologic and/or hematologic disorders,” Dr. Madden said. After her medical training, she worked at the renowned M.D. Anderson Cancer Center as an assistant professor in the Department of Pediatrics, focusing her practice on the care of pediatric patients with leukemia.

But her education expanded. “I had the opportunity to pursue a second fellowship in Pediatric Hematopoietic Stem Cell Transplant at St. Jude’s Children’s Research Hospital in Memphis, TN; and afterward I spent several years on staff as an assistant member at St. Jude’s in the Division of Stem Cell Transplant,” she explained.

Her work with youngsters in need of stem cell transplants continued at the Cancer and Blood Disorders Center in Phoenix Children’s Hospital in Arizona. It is that excellent experience and insight that Dr. Madden brings to the children at St. Vincent and Prevea.
Terri Lewis, RN, MSN, CPON, APNP

Education: Bachelor of Science degree in Nursing Education – University of Wisconsin-Eau Claire
Master of Science in Nursing, Pediatric Nurse Practitioner – University of Alabama, Birmingham
Certified Pediatric Oncology Nurse
Advanced Practice Nurse Prescriber

From Diagnosis to Empowerment
After 25 years in Pediatrics, from staff nurse at the University of Wisconsin Hospital and Clinics fresh out of college to Nurse Practitioner in the region’s busiest Pediatric Hematology/Oncology practice, Terri Lewis says, “My career has actually come full circle.”

She admits that her first job in that teaching atmosphere in Madison was exciting, “but also very difficult on my young mind and heart because not everyone got better and went home.”

In hindsight, she has learned, “One’s career really does evolve over time and results in a perfect balance of one’s skills, interests and strengths, combined with opportunities that lead you down exciting new paths.”

In the intervening years, marriage and career tracks have taken her family to Germany, Alabama, Illinois, and finally back to Appleton and Green Bay, her hometown. Here she found Prevea Health and a chance to help develop an obesity program for children, work as a clinical preceptor for nursing students there and for the School of Nursing at Madison’s Nurse Practitioner Program.

Then, two years ago, Prevea’s Pediatric Hematology/Oncology team beckoned. “I am responsible for daily rounding on the kids who are hospitalized for chemotherapy and those who are hospitalized for infusions, procedures or illness,” Lewis said. “A whole new world has opened up for me professionally.”

All three of the physicians with whom she works “are great teachers and they allow me to develop my own practice style,” Lewis said. “I have brought a different assortment of skills and knowledge from primary care with me and have gained a wealth of new knowledge, recently passing the national Certification in Pediatric Oncology Nursing.”

And that full circle? “Unlike my first experience with Hematology/Oncology as a young staff nurse, I now bring a maturity in dealing with those families whose children face a life-threatening disease. Parents will do anything ‘to make it all better’ for their kids. The special thing about this team is that we support and empower parents to do just that for their children.”

The news that a child has cancer “makes no sense in anyone’s universe and we strive to give families the knowledge and tools they need to help them cope with such news and regain some control in their lives,” Lewis said. “I am proud to be a part of this caring team.”

“I am proud to be a part of this caring team.”

Regional Pediatric Center staff: Paula Allen, Terri Haese, Sheila Franz, Rosa Kugel, Barb Colborn, Sue Schauland, and Director, Heidi Warbinski.
A Passion for Pediatric Oncology Nursing

Across the United States, approximately two classrooms of children are diagnosed with cancer every day.

Within the walls of St. Vincent Hospital, “We have an exceptional team that is qualified to provide the kind of care that can make a difference in the lives of those children, adolescents and young adults faced with just such a challenging diagnosis,” said Lori Vertz.

Vertz is a pediatric oncology nurse and clinic manager at the St. Vincent Pediatric Hematology/Oncology Clinic located on St. Vincent’s 2nd floor. Her clinic works hand-in-hand with the inpatient team on St. Vincent’s 10th floor Pediatric Unit.

“My role is to provide hands-on patient care, patient and family education, and assist with coordinating patients’ care to assure that the timeline of therapy and testing meets the expectations of the treatment program and study recommendations.”

Experience in working with patients, self-directed learning and ongoing education through participation in specialty nursing organizations have allowed her to become certified in the specialty field of pediatric oncology nursing.

Certification in Pediatric Oncology Nursing (CPON) is a voluntary process. Testing is based on current professional practices and validates that a nurse’s knowledge is up to date.

“Educating patients, families and my colleagues, teaching and mentoring upcoming nurses who choose to dedicate their profession to pediatric oncology nursing is a rewarding accomplishment,” Vertz said. “As I mentor nursing staff within our clinic, I encourage certification as a way to acquire additional knowledge to be confident in their work and gain respect as a leader within their profession.” In January of 2009 she was selected to write questions for the 2010 CPON exam.

Melissa Paasch, RN, Terri Lewis, APNP, and Barb Zenker, APNP, are other members of the CPON-certified nursing team.

As a member of the Children’s Oncology Group (COG), the team has access to a network of clinical trial information and a panel of national and worldwide experts. “A patient diagnosed here or in California, would likely be offered the very same care,” Vertz said.

Over the past 10 years, she has been involved in the Children’s Oncology Group nursing discipline, participating in the planning committee for nursing workshops in 2003, 2005 and 2007, and co-chairing the poster session in 2005 and 2007. Currently, she is a member of the nursing committee dedicated to revising the Cure Search Family Handbook.

“Pediatric oncology nursing is my passion. The kindness, gratitude and love expressed by our patients and families during the continuum of their care is inspirational. The courage of our young patients and their parents in the face of uncertainty, their vitality in the wake of every new storm and their laughter at the simple pleasures in life inspire me, deepening my commitment and strengthening my compassion for my profession.”

Her commitment is heartfelt. “When patients survive; I rejoice. When patients relapse; I feel their distress, offering hope for the next remission. When patients die; I grieve, offering comfort to the family, gaining satisfaction in knowing that my nursing skills may have eased the dying process.”

“I am passionate about the work I do, I am committed to providing the best care to every patient every day. I have dedicated my professional life to the pediatric oncology specialty.
“It’s amazing what picking out a Band-Aid means to a child,” said Kim Kostichka, a registered nurse and Team Leader in the Pediatric Unit at St. Vincent Hospital. She is also a member of the Pediatric Sedation Team. These are the people that provide comfort and care for children undergoing diagnostic or painful procedures.

That Sedation Team is a key group in a child’s hospital experience. “Following procedures, most kids tell us they had no pain, and they weren’t scared,” Kostichka said.

That is the team’s goal. And it does not happen by accident. These children meet the Pediatric Sedation team in advance of their procedure, and in a soothing environment. The Team is made up of a physician specialist skilled in pediatric procedural sedation and intensive care, a nurse like Kostichka with Pediatric Advanced Life Support training and Pediatric ICU experience, and a Child Life Specialist trained in relaxing and distracting children in a hospital setting.

Unlike in the adult patient world, pediatric patients typically have parents at their bedside during the sedation process. “Sometimes, the Child Life Specialists may be calming the parents as much as the child,” Kostichka said.

As soon the sedative takes effect, the patient is prepared for the procedure. When the child awakens, it is in the same familiar room, surrounded by parents and a familiar nurse. The child is typically unaware of the procedure, and proceeds to happily select “loot” from the Treasure Chest, accept a “bravery bead” or pick out a Band-Aid.

“It’s family-centered and pediatric friendly,” Kostichka said.

All the equipment used in a child’s journey in the hospital are sized for that little one, from needles to resuscitation equipment. “Medication is based upon the individual weight of each pediatric patient,” said Kostichka. Pharmacists are trained to scale dosages of chemotherapy and other drugs to a child’s needs, and laboratory staff use minimal blood volumes for pediatric testing. Lab technologists are skilled in obtaining specimens from the littlest patients. The dieticians on the Pediatric Floor understand the special dietary needs of an ill child, or a child on dietary restrictions.

Many procedures which several years ago were done only in operating rooms, are now routinely done by interventional radiologists, with much faster recovery times. At St. Vincent Hospital, these physicians are skilled at caring for children of all ages including infants.

**Topnotch team**

At St. Vincent Hospital, pediatric patients are fortunate to have the most experienced and trained staff in the region caring for them. This includes the only Pediatric Intensive Care physician group in all of Northeastern Wisconsin and the Upper Peninsula of Michigan, and the area’s only Child Life Service, along with the most experienced pediatric and pediatric ICU nurses in the region. This includes those who are certified in chemotherapeutics and extensive care of pediatric cancer patients.
The Pediatrics Department has pediatric floor beds, a pediatric step-down unit, and a pediatric intensive care unit. As many patients are from out-of-town, every effort is made to accommodate overnight stays for parents.

Because of the Pediatric ICU, kids with cancer do not have to travel to distant cities for their care, even when they become very ill, in need of a high level of hospital care. This issue was discussed by Dr. Joel Ament, one of the pediatric intensivists at St. Vincent Hospital. “Proximity to an ICU is key,” he said. “At times Dr. Brandt may have a patient not in immediate need of ICU care, but there exists concern for deterioration. Without our PICU, he would be faced with potentially transferring the child to a hospital in another city.”

Ament, who shares work with two other Pediatric Intensivists, Dr. Ralph Vardis, and Dr. John Taylor, described his role as threefold: “I work as an ICU attending physician, as a pediatric hospitalist, and as a provider of pediatric procedural sedation.” He expressed delight in the fact that so many regional parents entrust the St. Vincent Hospital pediatric team of physicians, nurses, dieticians, pharmacists, child life specialists and respiratory therapists, to care for their children. “It is a trust we never take for granted.”

Pediatric Tumor Boards, shared via videoconferencing between St. Vincent Hospital and Children’s Hospital of Wisconsin, are an essential forum that adds to the services already provided to our young oncology patients at St. Vincent.

The first videoconferenced Pediatric Tumor Board was held at St. Vincent Hospital on August 22, 2002. Videoconferencing uses telecommunications - audio and video - to bring staff from Children’s Hospital in Milwaukee and St. Vincent Hospital in Green Bay together to discuss pediatric cases. St. Vincent participants save time and money by not having to drive to Milwaukee and back every week.

Tumor Boards provide multidisciplinary consultative services for patients. Visual information is an important component of these discussions. Through videoconferencing, medical images, presentations, shared documents and photos can be shared by key staff at both hospitals.

This pediatric multidisciplinary team met 44 times in 2008. The team includes: pediatric oncology, radiation oncology, radiology, pathology, surgery, nursing, clinical research and Child Life Specialists. The Pediatric Tumor Board convenes every Thursday at 7:30 a.m. in the St. Vincent Cancer Center Conference Rooms.

In addition to the more commonly known childhood cancers of leukemia, lymphoma and brain tumors, many other conditions were presented in 2008: Pheochromocytoma; Osteosarcoma; Choroid Plexus cancer; Infantile Fibrosarcoma; Mesenchymal Chondrosarcoma; Angiomatoid Fibrous Histiocytoma; Fibromatosis; Ependymoma; Langerhans Cell Histiocytosis and Hemophagocytic Lymphohistiocytosis. Special presentations have included Morbidity and Mortality and Bone Lesion Anomalies.

In addition to Pediatric Tumor Board, Weekly Tumor Board meets every Tuesday, Breast Tumor Board meets every Friday and Gynecologic Tumor Board meets the fourth Wednesday of each month except December.
St. Vincent Cancer Research Institute offers clinical trials to pediatric cancer patients as a member institution of the Children’s Oncology Group (COG). COG is one of the cooperative group research bases that receives support from the National Cancer Institute (NCI). The St. Vincent mission is closely aligned with the mission of the Children’s Oncology Group: “To cure and prevent childhood and adolescent cancer through scientific discovery and compassionate care.”

The COG consists of more than 2,000 physicians who provide multi-specialty care to children with cancer. St. Vincent has six physician investigators with specialties in medical oncology, radiation oncology and pathology who are listed on the COG membership roster. By treating children in clinical trials, COG members have increased the cancer cure rate for children from less than 10 percent in the 1950s to nearly 80 percent at present in COG-member hospitals.

COG conducts over 150 concurrent studies covering all the principal cancers of infants, children and adolescents. Over 40,000 patients nationwide are being treated according to COG research protocols. These clinical trials compare the best available treatment to one or more experimental treatments, which are carefully developed with the goal of yielding even better results.

St. Vincent Hospital has been participating in NCI-sponsored pediatric clinical trials since 1984 and has enrolled over 300 participants to these studies. During calendar year 2008, St. Vincent Hospital investigators enrolled 43 participants to the following clinical trials coordinated by COG:

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<th>Title</th>
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<td>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</td>
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<tr>
<td>ARST0531</td>
<td>Randomized Study of Vincristine, Dactinomycin and Cyclophosphamide (VAC) versus VAC Alternating with Vincristine and Irinotecan (VI) for Patients with Intermediate-Risk Rhabdomyosarcoma (RMS).</td>
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St. Vincent's participation in COG clinical trials is funded through the Community Clinical Oncology Program (CCOP) grant award that St. Vincent has received from the National Cancer Institute. St. Vincent is one of only 63 community hospitals in the United States to receive this award. As a condition of this award, St. Vincent has made a commitment to not only enroll patients on cancer treatment clinical trials but also to make cancer control trials available. Cancer control trials are designed to examine ways to relieve cancer-related symptoms or to reduce side effects associated with cancer treatment. St. Vincent is currently participating in these five cancer control studies sponsored by COG:

<table>
<thead>
<tr>
<th>Protocol</th>
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<tr>
<td>ACCL0431</td>
<td>A Randomized Phase III Study of Sodium Thiosulfate for the Prevention of Cisplatin-Induced Ototoxicity in Children</td>
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<tr>
<td>ACCL05C1</td>
<td>A Group-wide, Prospective Study of Ototoxicity Assessment in Children Receiving Cisplatin Chemotherapy</td>
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<tr>
<td>ACCL0731</td>
<td>Glutamic Acid to Decrease Vincristine Toxicity in Children with Cancer</td>
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<td>ALTE03N1</td>
<td>Key Adverse Events after Childhood Cancer</td>
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<tr>
<td>ALTE07C1</td>
<td>Neuropsychological, Social, Emotional and Behavioral Outcomes in Children with Cancer</td>
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Another important objective of the COG is to facilitate the translation of important laboratory research to clinical applications to benefit children with cancer. Many of the COG treatment trials incorporate a laboratory research component. Children enrolled on these trials will have tissue samples, bone marrow and/or blood submitted for analysis. In many instances, the participants enrolled to these trials will benefit from the results of these special procedures; the laboratory results may determine their best course of treatment on the trial. The samples may also be stored for the use of COG group members for future research.

Because childhood cancers are much less common than adult cancers, nationwide research studies are needed to better understand causes of cancer in children. For this reason, all St. Vincent pediatric cancer patients and their parents are offered participation in the Childhood Cancer Research Network (CCRN). The Children's Oncology Group has established the CCRN with the goal of collecting clinical and demographic information about every infant, child, adolescent and young adult diagnosed with cancer in the United States and Canada. This information will be used to help physicians and scientists better understand whether childhood cancer is increasing and whether there are some children who may be at greater risk for these diseases. Additionally, the CCRN helps researchers study the causes of specific types of childhood cancers.

St. Vincent Hospital currently has 36 clinical trials available for childhood, adolescent and young adult cancer patients. A list of these active clinical trials, with links to a summary of the trial, may be found on the Regional Cancer Collaborative Web site, www.stateofthearthope.com. Information may also be found on the Children's Oncology Group (COG) Web site, www.childrensoncologygroup.org, or call the St. Vincent Cancer Research Institute at (920) 433-8889.
St. Vincent Hospital is the only hospital in Green Bay to offer Child Life as a service to its pediatric families and the physicians who care for them. The Child Life team includes two providers who hold Certified Child Life Specialist (CLS) credentials.

Colleen Ducke, Program Coordinator, has worked hard to develop what was a fledgling program when she arrived. She and her associate, CLS Ashley Zimmerman, divide their time between the St. Vincent Pediatric Hematology/Oncology Clinic located on the hospital’s 2nd floor, and the 10th floor inpatient pediatric unit. They are aided by Child Life interns and volunteers, all of them intent on making a difference in the lives of the children and families who they serve.

The goal of Child Life, according to Ducke, is to minimize the negative aspects of a child’s treatment and the family’s experience during hospitalization. The two women work to facilitate positive child and family adjustment to the health care experience.

**New Diagnosis**

“When a child is newly diagnosed with cancer, it can be a very stressful and emotional time for both the patients and the families. We try to help the children understand why they have to come into the healthcare setting frequently and also to help the children cope through play,” Ducke said.

“When a patient arrives at our clinic, we always have toys, games, movies or crafts waiting for the patient in their room. We use play as a distraction method during procedures such as lumbar punctures, port accessing, IV’s and chemotherapy treatments. Many of the children get excited to come to Clinic because they look forward to playing with the new and different toys and games.”

When a child has longer chemotherapy treatments, they may be admitted to the hospital’s pediatric inpatient floor. Play is a big part of the child’s daily lives. When they are in the hospital, most children also want to continue to play.

“The CLS helps to facilitate many different play opportunities for patients while they are in the hospital. We use medical equipment, pictures, dolls and age-appropriate explanations to help kids understand the procedures that they are going to be having,” Ducke explained. “Children need this explanation to avoid any misconceptions and to learn to understand and cope with the procedures they are going to be having done.”

**Chemo Duck**

She said a fun medical play tool they use with the Pediatric Hem/Onc patients is ‘Chemo Duck’. Chemo Duck is a stuffed animal that is dressed in doctor’s clothes. It has a line or a port. “Many of the younger patients bring Chemo Duck with them and we can practice the steps of having their ports accessed right on Chemo Duck. By doing this, they are able to ask questions, learn the process of port accessing, and any misconceptions they may have about their ports or lines can be removed,” she said.
Jenny Johnson, child life intern, providing therapeutic play activities for Lilyana, age 6, during her hospital stay.

“The children are provided with many opportunities either in the playroom or at their bedside to help give them the tools to process and cope with their hospitalization or illness,” said Ducke.

**Family Benefit**

The whole family has the benefit of Child Life services. “Siblings are often the forgotten family members when a child is diagnosed with cancer,” Ducke said. “We offer the Super Sib Program to help recognize what an important role the sibling has in the life of that patient. We also plan an annual Sibling Day for siblings of patients with cancer. During that day we are able to focus on the siblings and provide a fun-filled educational day for them. We can talk with them about their sibling’s cancer as well as play games, do crafts and provide the siblings with several prizes to take home.”

Parents of children with cancer can also use extra support throughout the cancer journey.

The CLS is ready to meet with parents daily to provide breaks for them, behavior modification for patients and siblings, developmental information, relaxation and other tips and ideas for supporting children during hospitalization.

Ducke noted that the Pediatric Hem/Onc patients go through many tests and procedures during their course of treatment. Child Life has developed a program called the “Bravery Bead” program that recognizes what the children have accomplished. The program helps record the cancer journey for patients and families. For every procedure the patient goes through, he or she will get a bead. For instance, a CT scan is a cat bead, sedation is a star and moon bead, and bone marrow is a bone bead. The children see them as their “string of courage.”

**Making Memories**

When a child has to be in the hospital or clinic frequently, it is important that we celebrate the important milestones with them. We mark the occasions with presents, cake, confetti poppers and a camera to help them celebrate. The milestones include last inpatient chemotherapy, last clinic chemotherapy, last radiation and end of therapy. We also celebrate the patients’ birthdays when they are hospitalized or in the clinic near their birthday. All of these events are very important in patients’ and families’ lives.

When the child is newly diagnosed, they may miss school for a while. The Child Life Specialist can meet with the family and teachers to decide how to best help the patient who will be out of school. We are able to meet with the classmates and teach them about the child’s illness, answer questions and give them ideas for how to stay connected with the child while they are out of school for treatment.

Another very important role of the CLS is working with families during grief situations. For families who have a child who is dying, the CLS helps parents, siblings and patients cope. They work with the child and their siblings to help them process and understand what is happening. They work with the family, too, to create memory items such as handprints, canvas handprint pictures, bracelets, bravery beads and the like to keep after the child has passed on.

Child Life is a rapidly growing field offered as a bachelor’s degree program along with related programs such as human development.
When Craig and Deidre Knapp relocated their young family from their native Wausau to Green Bay in 2000, they thought it was a career move for Craig, a pharmaceutical sales representative.

But after the middle child of their trio of boys, Dalton, was diagnosed with Burkitt’s leukemia on Super Bowl Sunday, February 4, 2007, the family came to realize they were in Green Bay for another purpose entirely.

“We didn’t grow up in this community,” Craig said. “God called us here for a reason – so Dr. Jon Brandt could treat Dalton.”

Brandt is one of three medical oncologists and the medical director at the Prevea Health Hematology/Oncology Clinic located on St. Vincent Hospital’s 2nd floor. That clinic and St. Vincent’s 10th Floor Regional Pediatric Unit work in concert to treat young cancer patients like Dalton.

When Dalton arrived on 10th floor at St. Vincent on the day his hero, Peyton Manning, was leading his team to a Super Bowl victory, his young fan was too ill to cheer. The 10-year-old had suffered stomach pain at Christmas time and other vague symptoms, his mother said. Fever and headaches, treatment for a sinus infection and even blood work failed to turn up the correct diagnosis until that fateful day.

“You wouldn’t think in a million years this would happen to your child,” Deidre said. “He was always very healthy and active.”

However, it was happening and Dalton was a sick child, admitted to the Pediatric Intensive Care Unit for testing to determine how far advanced the disease was. Dalton was already at Stage IV, his frightened parents learned. Chemotherapy treatments would follow.

Dalton was never left alone at the hospital; a parent always stayed by his side. Deidre said grandparents stayed with his brothers at the Knapp’s Suamico home so their schooling wasn’t interrupted. The brothers, Drew, older, and Carter, younger, were a comfort to Dalton with their daily visits.

The Knapps felt comfortable immediately at St. Vincent with the staff there. “It didn’t cross our minds to go anywhere else,” Deidre said. “We felt they were really there for us.”

The nursing staff was so skilled and caring with Dalton’s needs during his stay, and “even the cleaning guy put on a yo-yo show for him and did magic tricks,” Craig said. Having Child Life services was wonderful. “They always tried to find something for him to do,” Deidre added.

Dalton was one of the first to benefit from the new laptop computers donated by A Noble Cause, the charitable organization set up by former Green Bay Packer Brian Noble and his wife Cindy to honor their own daughter, Amanda, who is also a childhood cancer survivor. The Nobles still keep in touch with Dalton. Dalton became friendly with Packer player Kabeer Gbaja-Biamila.
and Packer Senior Security Advisor Jerry Parins who were among his hospital visitors. His family shared his story online on the Caring Bridge Web site where school friends, teachers, family and many of his nurses kept up with him.

“There were so many incredible, caring people,” Deidre said, including people at her sons’ schools who conducted fund raisers to help defray expenses by selling “Can’t Stop Knapp” t-shirts and shaving heads when Dalton lost his hair.

Dalton’s leukemia went into remission and he was discharged from the hospital in September 2008, but it wasn’t for long. By the end of that month, the disease was back and Brandt told the family he needed a stem cell transplant in order to recover from the disease. His brothers were tested but, although they were perfect matches for each other, they did not match Dalton.

To the family’s delight, two perfect matches were found in cord blood stored in Germany. But first, their very ill son had to be strong enough to undergo the transplant.

Brandt was undaunted, Craig said with pride. “Dr. Brandt searched the world over and found a protocol used on one male patient in Europe and got Dalton in remission to be able to do the stem cell transplant.

With the new protocol, Brandt got Dalton well enough to head to Children’s Hospital of Milwaukee to prepare for the stem cell transplant which took place on January 8, 2008.

At Children’s Hospital, the Knapps had another excellent experience, thanks in large part to the excellent communication between the Green Bay and Milwaukee caregivers. “They knew Dr. Brandt and Dr. (John) Hill who conferenced weekly with their physicians,” Deidre said “They knew all about Dalton.”

Thanks to that confidence in Brandt, the family also had confidence in Dalton’s new physician at Children’s, Dr. David Margolis, also a pediatric hematologist/oncologist and director of the Bone Marrow Transplant Program. It didn’t hurt, Deidre said, that at their first meeting Margolis told them, “We’re going to make him well.”

She believed him. “The miraculous part to his recovery is there was no graft versus host disease” which causes rejection of the new stem cells, Deidre said.

Today, Dalton is well. He missed a year-and-a-half of school but he’s back on track with his 8th grade class at Bay View Middle School in spite of spending 244 days in St. Vincent and Children’s hospitals.

During that time, Dalton, the heftiest of the three Knapp kids when he got sick, went from 73 to 54 pounds, his dad said. During his illness, he needed 167 blood transfusions.

This fall when deer hunting season began, Dalton, now 13, was out in the woods with his Dad and brothers, hoping to tag a deer. When his gymnastics team was taking to the parallel bars and riding that pommel horse, Dalton was right there with them, hoping to compete in regionals in North Dakota.

“I’m not as fast as I was but I’m probably as strong,” he said.

Strong enough to weather the worst that leukemia could send his way. Because, like the posters and the t-shirts said, and his legion of family, friends and medical pals at two hospitals and a clinic know, you can’t stop Knapp.
When people hear the words “palliative care,” oftentimes they don’t know what it means or assume it is end-of-life care.

In 2003, the Institute of Medicine stated that palliative care “seeks to prevent or relieve the physical and emotional distress produced by a life-threatening medical condition or its treatment, to help patients and their families live as normally as possible, and to provide them with timely and accurate information and support with decision-making.”

The American Academy of Pediatrics noted, “The goal (of pediatric palliative care) is to add life to the child’s years, not simply years to the child’s life” (AAP, 2000).

It follows, then, that when describing palliative care, especially for pediatric patients, the focus is on quality of life. As a result, the Pediatric Palliative Service at St. Vincent Hospital has been named Quality In Life Team (QUILT) to better explain the purpose of this unique service.

At St. Vincent Hospital, palliative care is part of the healing ministry to help those patients and families meet the goals they wish to accomplish in the face of life-changing health challenges. Nearly all newly-diagnosed pediatric oncology patients receive a QUILT consultation which is periodically reviewed throughout their course of treatment.

**QUILT consults focus on the following:**

a. The patient and family’s understanding of the diagnosis and plan of care.

b. The patient’s physical, social, psychological, emotional and spiritual comfort.

c. Assisting the patient and family in re-defining their medical and personal goals based on the patient’s new diagnosis.

d. Aiding in the attainment of the patient and family’s goals by rounding with the entire medical care team.

e. Linking the patient and family with appropriate resources.

f. Creatively helping the patient and family make the best of each day.

Primary team members are the pediatric social worker/case manager, staff from Pastoral Care and a Child Life Specialist team. Zenker coordinates the team.

Collaborating physicians are Dr. John Taylor, a Pediatric Intensivist with extensive experience in caring for children with chronic and acute health challenges, and Dr. Jon Brandt, Medical Director of the Pediatric Oncology Service at St. Vincent Hospital.
The QUILT might help in situations like these:

a. Helping families talk with their children at developmentally and age-appropriate levels about new diagnoses and treatments;
b. Providing memory-making activities to patients and families;
c. Offering sibling support activities;
d. Use of complementary therapy such as massage therapy and aroma therapy;
e. Creating creative communication tools such as patient Web sites;
f. Completion of advance directives for young adult patients;
g. Arranging family pet visits;
h. Creating a home-like environment in patient rooms;
i. Symptom management for health challenges such as deconditioning, nausea, constipation, pain, fatigue and dyspnea.

Staff members aren't immune to the stress that naturally results from participating in the intense care of these children and their families. Those with compassion fatigue sometimes benefit from Zenker's touch, too. She reaches out to them through informal discussions and formal education. As a Pediatric End-of-Life Nursing Education Consortium (ELNEC) instructor, Zenker has educated over 30 staff at St. Vincent Hospital through the Pediatric ELNEC course.

In summary, QUILT focuses on the patient and family's quality of life as defined by them in conjunction with their medical and personal goals. These goals are then re-enforced with patient’s primary healthcare providers to help define/clarify the plan of care. In addition, QUILT provides assistance to the staff caring for these patients and their families through support and education.

References


Pediatrics, 106 (2), 351-357.

Resources

For additional information regarding pediatric palliative care or the QUILT service at St. Vincent Hospital you may access the following resources:

Center to Advance Palliative Care: www.capc.org
Pediatric Palliative Care Referral Criteria: www.capc.org
Curesearch: www.curesearch.org
Initiative for Pediatric Palliative Care: www.ippcweb.org
Precepts of Palliative Care for Children/Adolescents and Their Families: available online at www.nann.org