

Ranked No. 1
Pediatric Oncology
Hospital by *Parents*
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Promise

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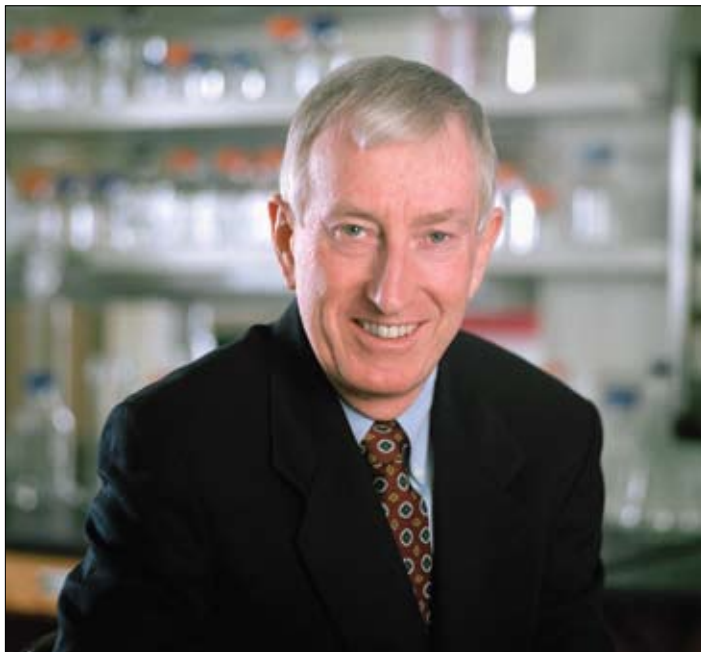
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Highlights

JOHN ZACHER



Another honor for Nobel laureate

Nobel laureate Peter Doherty, PhD, of St. Jude Immunology has been elected to the Institute of Medicine (IOM), a prestigious branch of the National Academy of Sciences. Doherty, who holds the Michael F. Tamer Chair of Biomedical Research at St. Jude, is among 65 new members of the organization.

"This is a terrific honor for Dr. Doherty, who of course already has the greatest honor in medicine, the Nobel Prize, and signifies the importance of his basic science to clinical medicine," said Dr. William E. Evans, St. Jude director and CEO.

Other IOM members at St. Jude include Evans; former St. Jude director Arthur Nienhuis, MD, of Hematology; and Charles Sherr, MD, PhD, a Howard Hughes Medical Institute investigator and the St. Jude Genetics and Tumor Cell Biology department co-chair.

A new way to attack tumor cells

St. Jude scientists have shown that it might be possible to make tumor cells more sensitive to irradiation and chemotherapy by treating them with a drug that cripples the cancer cells' ability to repair DNA damage caused by these therapies.

St. Jude researchers demonstrated that a molecule called CP466722 blocks the ATM protein's ability to orchestrate a series of events that ultimately repair DNA damaged by irradiation. ATM's protective role makes it a tempting target for researchers looking for a way to prevent cancer cells from repairing DNA damage caused by therapeutic irradiation. Laboratory tests suggest that treatment with CP466722 would not cause significant or long-term side effects.

Michael Kastan, MD, PhD, St. Jude Comprehensive Cancer Center director, is senior author of a report on this work that appeared in the September 2008 issue of *Cancer Research*.

Scientists gain insight into biological processes

St. Jude investigators have learned that a vast array of the cell's proteins can function properly because of their ability to adapt through accessorizing.

Cells use a set of proteins called ubiquitin-like proteins as accessories that adapt their function as needed in the cell.

"Understanding ubiquitination can give us important knowledge about such biological processes as cell division, embryonic development and immune function," said Brenda Schulman, PhD, of St. Jude Structural Biology and Genetics and Tumor Cell Biology.

Schulman and her colleagues discovered how the function of a protein called cullin-RING changes when it wears the ubiquitin-like protein accessory called NEDD8. A Howard Hughes Medical Institute investigator, Schulman is the senior author of a paper on this topic, which appeared in the September 2008 issue of the journal *Cell*.

"Understanding ubiquitination can give us important knowledge about such biological processes as cell division, embryonic development and immune function."



Conformal radiation earns A+

Children with the brain tumor ependymoma show significant academic advantages when treated with highly focused radiation therapy that spares healthy brain tissue, St. Jude researchers have found.

The findings are the first to demonstrate that conformal radiation therapy not only achieves a high success rate in treating the tumor, but when compared to conventional whole-brain irradiation, also preserves children's academic abilities.

"Now, we can make sure that, beyond survival, these children have the best possible quality of life once their cancer is successfully treated," said the paper's first author, Heather Conklin, PhD, of Behavioral Medicine.

Results of this study were published in the August 2008 issue of the *Journal of Clinical Oncology*.

Drug combo protects hearing

A team of St. Jude researchers have established that the drug amifostine is effective in preventing deafness in children with localized medulloblastoma, a type of brain tumor.

Cisplatin, the chemotherapy drug traditionally used to treat medulloblastoma, can cause permanent hearing loss. Amifostine is used in cancer treatment to protect blood, kidney, neural and mucosal cells against damage from chemotherapy and radiation.

"By using amifostine along with cisplatin, we have greatly reduced the incidence of clinically significant hearing loss in patients with average-risk medulloblastoma," said the study's principal investigator, Amar Gajjar, MD, St. Jude Oncology co-chair. "This reduction in the side effect will go a long way toward helping these children lead productive lives as adults."

The researchers published their findings in the August 2008 issue of *Journal of Clinical Oncology*.



SETH DIXON



Andy Saunders of Radiological Sciences talks with 9-year-old Andrew Morlen, as he prepares to receive conformal radiation therapy. This treatment provides high doses of radiation to the tumor, while sparing surrounding normal brain tissue. New research indicates that conformal radiation preserves children's academic abilities, when compared to conventional whole-brain irradiation.

New treatment lowers risk of side effects

A new combination of anti-cancer drugs, when integrated into an existing treatment for non-Hodgkin lymphoma, offers a lower risk of side effects than does the conventional regimen, St. Jude researchers have found. Non-Hodgkin lymphomas are tumors of the peripheral lymph nodes, thymus or abdominal organs.

The administration of dexamethasone, cytarabine and carboplatin gives clinicians a treatment option for children who have significant potential for heart dysfunction and infertility—side effects of the conventional therapy.

"The new combination offers a foundation for improving treatment by adding to the drug cocktail so-called monoclonal antibodies, which are immune proteins designed to target cancer cells," said John Sandlund, MD, of St. Jude Oncology. Sandlund is the first author of a report on this work that was published in the August 2008 issue of the journal *Cancer*.

Highlights

Team finds new approach to killing cancer cells

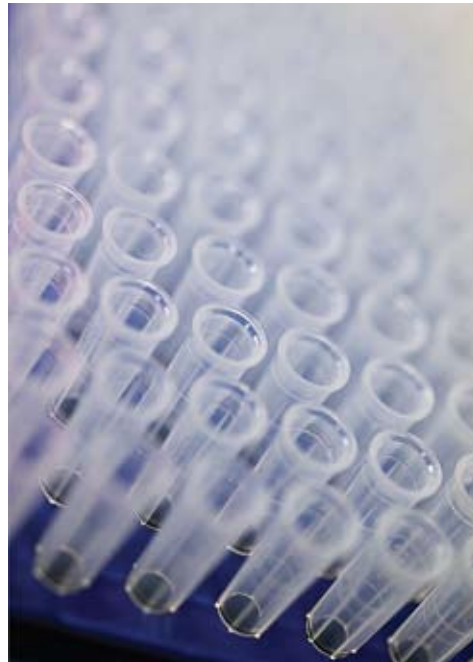
St. Jude scientists have gained new insight into the function of an enzyme called DNA topoisomerase 1 (Top1). The finding may yield a new approach to anti-cancer drugs that can jam the function of this enzyme and kill cancer cells.

Understanding Top1 is clinically important, because the enzyme is the target of anti-cancer drugs called camptothecins. These drugs prevent Top1 from performing its job, thus keeping the replication machinery from working and killing proliferating cancer cells.

Mary-Ann Bjornsti, PhD, of Molecular Pharmacology and her colleagues published a paper on the discovery in the October 2008 issue of the *Journal of Biological Chemistry*.

Bjornsti, senior author of the paper, said the findings might lead to the design of anti-cancer drugs that trap Top1 while it is attached to DNA, forming a roadblock to DNA replication in cancer cells.

“The finding may yield a new approach to anti-cancer drugs that can jam the function of the enzyme and kill cancer cells.”



Scientists unveil secrets of thiopurines

St. Jude researchers have discovered that the reason anticancer drugs called thiopurines destroy the body's ability to continually replace old, worn-out blood cells is that an important cellular pump is either missing or not installed properly in some children. The pump rids the cells of thiopurines' breakdown products.

A team led by John Schuetz, PhD, of Pharmaceutical Sciences showed that a type of small gene variation called a single nucleotide polymorphism (SNP) can prevent this pump from being properly “installed.”

The findings give insight into why thiopurines cause anemia and suppress the immune systems in some children being treated for leukemia. “More than 18 percent of Japanese individuals have this SNP that disrupts proper installation of the pump in the cell membrane,” Schuetz said. “That seems to explain why some Japanese patients are so sensitive to the toxic effects of thiopurines.”

Schuetz is the senior author of a report on this study, which appeared in the July 2008 issue of *Cancer Research*.

Scientists uncover secrets of wily pathogens

St. Jude scientists have discovered one method intracellular pathogens use to shut down one of the body's key chemical weapons against them: nitric oxide. The researchers found that microbes block nitric oxide production by destroying the biochemical machinery that immune cells called macrophages use to produce the chemical.

Macrophages attack and consume bacteria and parasites, shredding them with enzymes and poisoning them with nitric oxide. But some pathogens, such as those that cause tuberculosis and toxoplasmosis, deploy an arsenal of weapons to avoid and counterattack the macrophage's own weapons.

“This discovery reaffirms the notion that pathogens have an incredibly diverse way of manipulating their hosts,” said the paper's senior author, Peter Murray, PhD, of Infectious Diseases and Immunology. “And it reveals a new pathway by which a pathogen can induce an enzyme that is normally not present in those macrophages and use the induction of that enzyme to its advantage.”

A report on this topic appeared in the November 2008 issue of the journal *Nature Immunology*.





Parents magazine ranks St. Jude as No. 1

Parents magazine has named St. Jude as the No. 1 pediatric cancer care hospital in the country. The results, based on the magazine's survey of more than 100 children's hospitals, appear in the February 2009 issue on newsstands nationwide.

"This is wonderful recognition of what goes on every day at St. Jude," said Dr. William E. Evans, St. Jude director and CEO. "One thing that distinguishes St. Jude is how we seamlessly blend quality, innovation and compassion for patients and families. It also reflects the culture of collaboration that allows St. Jude to translate discoveries into better patient care in an incredibly effective manner."

All hospitals surveyed are members of the National Association of Children's Hospitals and Related Institutions. In the fall of 2008, St. Jude faculty and staff completed Parents magazine's extensive survey. Parents ranked St. Jude and other participating hospitals on their responses to detailed questions in specific areas.

"It is great not only to know that we are the best but also to be recognized as such by a publication that benefits the parents of our patients," said Joseph Laver, MD, St. Jude clinical director and executive vice president.

The magazine also chose the top five hospitals for pediatric emergency care, heart care, neonatal care, orthopedic care and pulmonary care.

"I believe that the intricate link between broad-based research efforts and patient care is what makes St. Jude stand out among its peers," said Michael Kastan, MD, PhD, St. Jude Comprehensive Cancer Center director. "It is satisfying to see these efforts recognized in this way."



Getting to the root of ALL relapse

St. Jude scientists have identified distinctive genetic changes in the cancer cells of children with acute lymphoblastic leukemia (ALL) that cause relapse.

Researchers compared the genomes of the cancer cells of 61 childhood ALL patients when they were initially diagnosed and after they had relapsed.

"In more than 90 percent of the cases, we found differences in the genetic alterations present at the time of diagnosis and at the time of relapse," said Charles Mullighan, MD, PhD, of Pathology. Mullighan was first author of a report on this work, which appeared in the journal *Science* in November 2008.

"The key finding in our work is that in the majority of cases, relapse is arising from a cell already present at the time of diagnosis," said the paper's senior author, James Downing, MD, St. Jude scientific director. "That cell is selected for during treatment and then subsequently emerges as basis for relapse."

The researchers' findings offer a pathway to designing treatments for ALL relapse in children and, ultimately, in adults.

Identity crisis

St. Jude scientists have discovered that a certain differentiated cell type is so ready to change its identity that it requires the constant expression of a gene called *Prox1* to dissuade it.

The researchers showed that *Prox1* acts as a two-way switch whose inactivity is sufficient to reprogram a specialized type of cell, called a lymphatic endothelial cell. In the absence of active *Prox1*, the lymphatic endothelial cell actually loses its identity and assumes characteristics of a blood endothelial cell, which plays a different role in the body.

"The new finding adds to a growing body of evidence showing that some fully differentiated cell types can exhibit great plasticity and upon reprogramming revert back to their previous identity," said the paper's senior author, Guillermo Oliver, PhD, of Genetics and Tumor Cell Biology. Results of this study appeared in the December 2008 issue of *Genes & Development*.

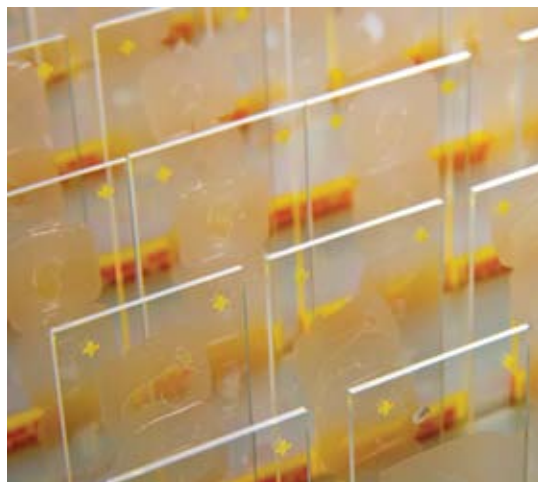
Highlights

Pinpointing the source of tumors

St. Jude scientists have shown for the first time that normal stem cells can act as the source of tumors in mature solid tissues. Stem cells are immature cells that can renew themselves and give rise to mature, differentiated cells that compose the range of body tissues.

Normal and cancerous stem cells display on their surface characteristic proteins, including Prominin1 or CD133. In the December issue of the journal *Nature*, St. Jude investigators show that Prominin1 marks normal intestinal stem cells and that these cells, when mutated, give rise to intestinal tumors. The finding could also aid in identifying the source of cancer stem cells in the lung, kidney, brain, pancreas and other tissues.

“Until now, the link between normal and cancer stem cells in solid tissues like the intestine was not known,” said the paper’s senior author, Richard Gilbertson, MD, PhD, of the Developmental Neurobiology and Oncology departments. “Our work provides the first direct link between normal solid tissue stem cells and cancer.”



New insight into a go-to enzyme

Scientists at St. Jude have gained new insights into regulation of one of the body’s enzyme workhorses called calpains.

Calpains function in many cellular processes, including the movement of cells in tissues, the death of damaged cells, insulin secretion, and brain cell and muscle function. The downside of this broad set of responsibilities is that defective or overactive calpains have been linked to an array of disorders, including a form of muscular dystrophy, Type 2 diabetes, gastric cancers, Alzheimer’s and Parkinson’s diseases, cataracts, and the death of both heart muscle in heart attacks and of brain tissue in stroke and traumatic brain injury.

“Our basic findings on calpain regulation could add useful pieces to the puzzles of these disorders and perhaps reveal targets for drugs to treat them,” said Douglas Green, PhD, chair of Immunology. Green was senior author of a report on this work, which was published in the November 2008 issue of the journal *Nature*.

“The results demonstrate for the first time that it is possible to correct sickle cell disease with genetic therapy to produce fetal hemoglobin.”

Gene therapy corrects sickle cell disease

St. Jude scientists have alleviated sickle cell disease pathology by using a harmless virus to insert a corrective gene into blood cells of laboratory models.

Researchers have long known that symptoms of sickle cell disease could be alleviated by persistence in the blood of fetal hemoglobin in red blood cells. Fetal hemoglobin contains a protein component known as gamma-globin.

Derek Persons, MD, PhD, of Hematology and his colleagues developed a technique to insert the gene for gamma-globin into blood-forming cells using a harmless viral carrier. Those cells generated red blood cells that contained fetal hemoglobin, alleviating the disease.

“The results demonstrate for the first time that it is possible to correct sickle cell disease with genetic therapy to produce fetal hemoglobin,” Persons said. Although applying the gene therapy to humans presents significant technical obstacles, scientists believe that the new therapy will become an important treatment for the disease.

Persons is senior author of a report on this work, which appeared in the journal *Molecular Therapy* in December 2008.



Outreach through Oncopedia

Through Oncopedia, health care professionals worldwide collaborate and learn from each other.

BY HEATHER GUESS

The mission of St. Jude Children's Research Hospital extends far beyond the borders of the United States. An interactive Web site known as Oncopedia helps health care providers in the world's most remote regions access St. Jude knowledge and research with the click of a computer mouse.

In a modern, online twist on encyclopedias, health care professionals can submit patient cases and discuss them through Oncopedia, which is devoted solely to pediatric hematology and oncology. An expert panel reviews all content submitted to the site. These experts also describe how they would handle cases, engage in online discussions with participants and respond to queries.

"Oncopedia has two important dimensions," says Raul Ribeiro, MD, St. Jude International Outreach director. "First, it creates a space for health care providers to interact and discuss specific pediatric hematology and oncology issues. Secondly, it provides a forum for pediatric hematologists and oncologists to describe their most interesting cases and share them with peers around the world."

Oncopedia is an outgrowth of www.cure4kids.org, the hospital's highly successful Web-based educational resource for health care professionals who treat kids with cancer and other catastrophic diseases. For six years, *Cure4Kids* has been offering courses and seminars and hosting live meetings. The site's 16,000 users have downloaded more than 2 million educational items. These users encouraged *Cure4Kids* to enhance the interactive aspects even more. And Oncopedia was born.

"We thought if a few hundred people participated in Oncopedia, it would be useful," says Yuri Quintana, PhD, director of education and informatics in International Outreach. "Thus far, more than 3,000 people have visited the Oncopedia site, so it's exceeded our expectations."

Pediatric oncology affects a much smaller population than adult oncology. "To have 3,000 people across the

"We thought if a few hundred people participated in Oncopedia, it would be useful. Thus far, more than 3,000 people have visited the site."

world who are treating kids and participating in online discussions is quite a high number," Quintana says.

Discussions and cases come from around the globe. The resulting networking opportunities offer several benefits to professionals in the field.

"A lot of these cases don't get published because they're in parts of the world where people don't have access to the published literature, or they have language challenges," Quintana says. "Medical journals sometimes don't want to publish a case that's too rare until there's more data, but nonetheless, that case needs attention."

Physicians who treat the eye cancer retinoblastoma have greatly benefited from Oncopedia. Several retinoblastoma cases and discussions are present on the site. New features, especially the addition of videos, also offer educational resources to doctors at St. Jude partner sites in Central America. As the service helps clinicians provide more lifesaving treatments, Oncopedia is destined to expand to serve their needs.

"These retinoblastoma programs are treating many children," Quintana says. "Hopefully, that success will also occur with other diseases as we have more and more content available."

To learn more about Oncopedia or *Cure4Kids*, visit www.cure4kids.org. ●

Tiny Dancer

BY CARRIE L. STREHLAU



Even during cancer treatment, Sarah Marchbank (seated, at right) continued to dance. Her dance company in Louisiana filmed their rehearsals so that Sarah could practice in Memphis. “I feel powerful, strong and graceful when I dance,” Sarah says.

It was like a *Nutcracker* dream sequence, in which the Mouse King and his minions attack Clara. But this performance was real—a production fraught with uncertainty and hope. In the midst of chemotherapy and radiation, Sarah Marchbank knew exactly what she had to do: *Dance on.*

In the cool, blue glow of the spotlight glides a thin figure adorned in a glistening tutu. Her arms flow from her sides, slow and graceful like an ocean wave rolling in on a sandy beach. *Jete. Pas de bourrée. Rond de jambe à terre. Arabesque.* The normally shy ballerina’s confidence is strong as she bows to her audience. *Une forte ballerina.*

The curtain rises

Not quite two years ago, the body of this graceful dancer was gearing up for a performance that would rival any *Nutcracker* battle scene.

Amid the sweltering Louisiana heat and intense ballet classes several days a week, Sarah Marchbank spent the summer of 2007 like a normal pre-teen—with one difference.

“That summer, Sarah was walking around the house saying ‘I don’t want cancer. I don’t want cancer,’” recalls her mother, Laura. “We told her that we would always be vigilant and for her not to worry.”

The Marchbank family was no stranger to cancer. Sarah’s dad, Johnnie, had battled stage III Hodgkin lymphoma when he was 21 years old. As a result, the couple had always closely monitored the health of Sarah and her twin brother, Blake.

One August evening, Laura, a fourth-grade teacher, told her husband about a student who had complained of a bump on his neck. Overhearing the conversation, Sarah said, "Mom, I have a lump on *my* neck."

"She bent toward us and there was a lump under her earlobe," Laura recalls.

When 10 days of antibiotics did not eliminate the lump, Sarah visited a specialist, who initially suspected that the problem stemmed from an infection.

A nasty infection it was not. The diagnosis was stage IV Hodgkin lymphoma. Characterized by the progressive enlargement of affected lymph nodes, this cancer occasionally spreads to the spleen, liver, bone marrow, bones or lungs. Laura was terrified. The next week, Sarah had an appointment at the St. Jude Children's Research Hospital affiliate in Shreveport, Louisiana. Soon the family was at the hospital's main campus in Memphis, Tennessee.

"We felt so far away from home when we arrived," Laura says. "The first day, though, we met a young patient waiting for his check-up. He was in remission and full of confidence. He told us we were at St. Jude, the best place in the world."

The battle begins

"I remember my first encounter with Sarah and her parents," recalls Monika Metzger, MD, of St. Jude Oncology. "Initially I could see the fear in their eyes and then disbelief when I said that chemotherapy would only be 12 weeks and that I expected her to continue dancing and going to school. This lightened not only Sarah's eyes, but Johnnie's, whose chemotherapy experience had been vastly different.

"I could also see confusion in Johnnie's eyes," Metzger continues. "While for the most part Hodgkin

is not hereditary, it can be familial in up to 5 percent of the cases. We can neither predict it, nor do we understand the genetics and environmental factors responsible for it."

Although Sarah's first round of chemotherapy occurred at St. Jude, she was able to continue her treatment at the hospital's affiliate, located just two hours from her home.

"After school Wednesday afternoons, we would drive to the affiliate," Laura says. "Sarah would get treatment Thursday, and then we would drive back home. Sarah slept in the car and went straight to ballet class Thursday evenings."

This hectic schedule continued throughout the course of chemotherapy. "That is what kept her going and kept her energy up," Laura says. "She had a goal of performing, and she wanted to stay on that goal."

"I feel powerful, strong and graceful when I dance," Sarah explains.

After her third week of chemotherapy treatments, Sarah traveled from Louisiana to Houston, Texas, for a performance and then participated in a dance recital.

"She was bald, but she danced," Laura says.

Stage fight

Then the family had a scare.

"When I saw Sarah for her post-chemotherapy evaluation, she had a spot in her spleen that lit up, and I was very concerned about relapse," Metzger says. Fortunately, a biopsy revealed Sarah had an infection. With the infection treated, she underwent





CAMILLE MARCHBANK

When she's not dancing or hanging out with her friends, Sarah enjoys spending time with her mom, Laura; her twin brother, Blake; her dad, Johnnie; and their golden retriever, Beaux. During Sarah's treatment, St. Jude physicians educated Johnnie about the health risks he faces as a result of his own bout with Hodgkin lymphoma. "The doctors not only helped Sarah, but they also helped Johnnie to be aware," Laura says.

11 weeks of radiation at St. Jude.

Despite slowly losing her hair and her strength, Sarah's confidence never faltered.

"Sarah did great during radiation," Laura says. "She continued to dance and did not miss any school work. She graduated valedictorian from her sixth grade class with an A average."

Like the Land of Sweets dancers supporting their Sugar Plum Fairy, Sarah's dance company filmed their rehearsals so Sarah could practice in her room at the Ronald McDonald House. She also auditioned by DVD for her middle school's dance squad. She made the team.

"I love it so much," Sarah says. "I could not have come home after radiation and watched my friends dance. I just had to dance also. God gave me the strength to make it through."

When Laura's strength waned, Sarah was her rock.

"If there were days I would fall apart or was depressed, she would look at me and say, 'Mom, it's in God's plan, and there's something I'm supposed to do with this.'"

In good company

Even with the strength of the Nutcracker Prince himself, Sarah still had some fears.

Child Life specialist Amy Kennedy helped calm Sarah's nerves. "She had the hardest time with needle sticks," Kennedy says. "I helped

Sarah develop a coping plan. That was what worked best for her."

Kennedy also distracted Sarah at times when anxiety surfaced. "I needed some help making sure I had what patients wanted in the radiation clinic Child Life areas," Kennedy says. "I gave Sarah the job of creating a list of things she wanted to see there. Giving patients a role in their treatment and environment—making them feel like they are in control of something—allows them to take ownership of their hospital experience."

Each day, Kennedy would ask Sarah if she had done her "homework."

"It made her laugh, which led to her talking and engaging more with me," Kennedy says. "Sarah is an amazing girl."

"St. Jude took such good care of Sarah at every step to make sure there was no way she would feel uncomfortable," Laura says. "If we had to be anywhere, St. Jude was where we needed to be. They took away the fear we had."

Standing ovation

Before the Marchbanks came to St. Jude, Johnnie had agonized about the hardships his daughter would surely endure. In the 1980s, his treatment had been grueling. "He had 16 rounds of chemotherapy over a 10-month period and had to postpone graduating from college for a year," Laura says.

Johnnie was amazed that Sarah continued with her life as normally as she did.

"To my surprise, the protocol had changed so much that it made Sarah's chemo a walk in the park compared to what I had," Johnnie says. "Sarah had two to three bad days a month, whereas I had two to three good days a month."

St. Jude physicians also helped Johnnie understand health risks he faces as a result of chemotherapy drugs administered during his treatment. "The doctors talked to him at great length about the cancer survivor guidelines to ensure he stays healthy," Laura says. "They not only helped Sarah, but they also helped Johnnie to be aware."

Because Sarah is still at risk for relapse, Metzger continues to monitor her condition carefully.

"I am thrilled that Sarah is doing so well, and while I know every visit is stressful for her and her family, I always look forward to seeing my little dancer," Metzger says.

Sarah's ensemble has grown from family and friends in Louisiana to a troupe of new faces at the hospital.

"I made a lot of new friends at St. Jude," Sarah says. "Some of us call ourselves 'The Fab Five.'"

After months of treatment and being more than 250 miles from home, the ballerina's spirit has never been stronger.

"She never questioned that she would not be OK," Laura says. "Sarah performed seven pieces when we came home, and she never complained of being tired. To see her on that stage still dancing is a blessing." ●

A Global MISSION

One international company recognizes a kindred spirit in St. Jude.

BY JANICE HILL



(From left) Chris Kearsley, B.K. Im and Michael Lyle chose to make St. Jude the sole focus of their company's philanthropic giving.

St. Jude Children's Research Hospital takes a global approach to saving children's lives through such initiatives as its International Outreach Program, Oncopedia and the St. Jude surgery training program (*see related stories, pages 5 and 16*). That mission is especially compelling for employees of one international corporation.

InfinityQS International Inc. takes a global approach to its business of providing software, hardware and consulting services to manufacturers aimed at reducing waste, improving productivity and identifying production problems before they occur.

Two years ago, the company's leaders—President and CEO Michael A. Lyle, Executive Vice President Christopher Kearsley and Chief Financial Officer B.K. Im—chose to make St. Jude the sole focus of their philanthropic giving.

"We wanted to pool our gifts for the benefit of one organization so we could make more of a difference," Lyle says. At his mother's suggestion, they took a look at St. Jude. "I have five boys, all very healthy, and for that I'm very appreciative," Lyle says. "I considered what it must be like to have a child with a catastrophic illness, and it really hit home."

Kearsley says everything the three company leaders have learned about St. Jude since that time confirms their choice.

"First and foremost is the fact that there is no selfishness in St. Jude's approach to research," he says. "When St. Jude comes up with solutions, they make them available for the world."

"The fact that St. Jude is trying to move the body of

"We wanted to pool our gifts for the benefit of one organization so we could make more of a difference."

knowledge forward by sharing their research is noble and really is the key to me," Lyle adds. "It results in saving many more lives, which makes a gift to St. Jude a heck of an investment."

InfinityQS provides software that allows production supervisors and management to see what is occurring worldwide on their manufacturing lines, as well as those of their suppliers. This quality assurance information helps manufacturers make decisions in real time, so that quality issues are addressed before final products are produced. When the InfinityQS executives toured St. Jude, they recognized processes that mirrored their own approach to designing solutions for quality control issues.

During their visit to St. Jude, the colleagues learned about the process for developing new drugs and biologics at the Children's GMP, LLC. Located on the St. Jude campus, the facility is a dynamic biomedical workshop for making vaccines, drugs, proteins, gene-based molecules and other biological products.

"We were awed by all we saw walking around St. Jude," Kearsley says. "We have a true heartfelt appreciation for all that is being done in research and care for children at St. Jude and worldwide."

"The three of us are blessed, and we are happy to be in a position where we can help children and families who must go through an incredibly difficult time." ●

The Hunt for

Puma

BY MIKE O'KELLY

While stalking *Puma*, investigators learned that this protein is suppressed in one type of cancer. This discovery opens the door for the creation of drugs that switch on the *Puma* gene.

Nine-year-old Matthew Fox doesn't talk much about the fact that he was found to have cancer when he was 4 years old. His mother, Freda, says most people have a hard time believing that the third-grader battled Burkitt lymphoma, a cancer in which immune cells called B lymphocytes turn malignant and proliferate uncontrollably.

When an egg-shaped knot developed on his neck and Matthew complained of a sore throat, Freda took her son to a specialist. Surgeons removed Matthew's abscessed tonsils, but a biopsy revealed cancer. The physician referred Matthew to St. Jude Children's Research Hospital.

"It floored me when I found out," Freda says. "My family had no dealings with cancer. It was something new to me."

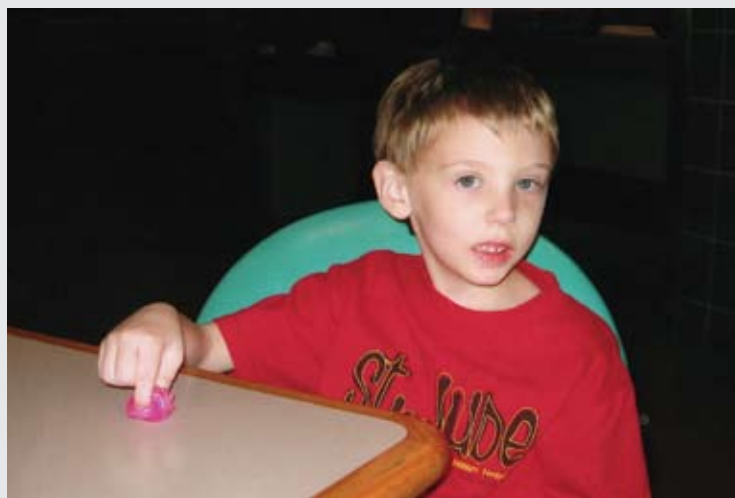
In the past few years, the Fox family has learned much about the clinical aspects of Burkitt lymphoma. Meanwhile, in a research laboratory, one biochemist has been exploring the gene that contributes to this disease. Gerard Zambetti, PhD, of St. Jude Biochemistry and his colleagues recently made a discovery that may someday help kids like Matthew. The research centers around a gene with a feline name: *Puma*.

When *Puma* runs silent

Although cases such as Matthew's are rare in the United States, Burkitt lymphoma is the most widespread form of childhood cancer throughout the African

continent. St. Jude researchers recently made a discovery that could lead to the treatment of this cancer by using drugs to switch on the *Puma* gene. The Puma protein usually protects the body by triggering cancer cells to self-destruct. But Zambetti and his team found that Puma is suppressed in Burkitt lymphoma.

Puma is an acronym for "p53 upregulated modulator of apoptosis." Apoptosis is the process by which cells undergo programmed death. The p53 protein prevents cancer by functioning as a tumor suppressor. One way p53 performs this function is by inducing genes such as



Nine-year-old Matthew Fox began his battle with Burkitt lymphoma when he was only 4 years old. A recent St. Jude discovery may someday help other kids with this disease.



Gerard Zambetti, PhD (at right), and postdoctoral fellow Sean Garrison, PhD, both of Biochemistry, examine the *Puma* data. The researchers recently made a discovery that could lead to the treatment of Burkitt lymphoma by using drugs to switch on the *Puma* gene.

Puma to target abnormal cells to commit suicide.

In addition to regulating *Puma*, *p53* is responsible for modulating the expression of more than 100 other genes. “*p53* can control whether an abnormal cell is halted or killed through the regulation of a series of downstream target genes,” Zambetti explains.

In search of *Puma*

In Burkitt lymphoma, the protein-encoding *c-Myc* gene swaps places in the chromosome with an antibody-producing immunoglobulin gene and becomes abnormally expressed.

“When the *c-Myc* gene is moved into the immunoglobulin position on the chromosome in B cells, it is constantly expressed at high levels,” Zambetti says. Although the elevated level of *c-Myc* inappropriately drives the growth of these blood cells, it also triggers *p53*-mediated killing. To fully develop into tumors, these abnormal B cells must overcome the death response.

As they studied *Puma* production in Burkitt lymphoma, the researchers found that in models created to overexpress *c-Myc*, *Puma* inactivation accelerated the cancer’s growth and development.

The researchers also discovered that *Puma* expression had been lost in most human Burkitt lymphoma cells. Such a loss had never been shown before in human cancer, according to Zambetti.

Manipulating *Puma*

The next question for the St. Jude researchers to

answer was how the *Puma* gene was being silenced in Burkitt lymphoma. By analyzing the structure of the *Puma* gene and of lymphoma cells, investigators found that while *Puma* was intact, its function was being masked so that it could not be read by the cell’s protein-producing machinery.

This silencing occurs through DNA methylation, which occurs when molecules known as methyl groups attach directly to the DNA.

“The human Burkitt lymphoma cell lines that we grew in the lab were consistent with what we found in the tumors,” Zambetti says. “The cell lines that had low *Puma* message also had *Puma* gene methylation, which would explain why *Puma*

expression is diminished.”

Zambetti and a team that included postdoctoral fellow Sean Garrison, PhD, of Biochemistry used a drug to switch the silenced *Puma* gene back on by inhibiting the cell’s machinery responsible for DNA methylation. This finding suggests that drugs could be developed for clinical use to restore *Puma* expression and activity.

“On the one hand, patients receiving traditional chemotherapy can suffer the loss of immune cells. This loss occurs in part because *Puma* induces the death of these cells,” Zambetti says. “In this case, the goal would be to protect patients’ bone marrow by developing drugs to inhibit *Puma*. On the other hand, for patients with a lymphoma in which *Puma* was inactivated, drugs could be used to reactivate the gene, to trigger apoptosis and kill the tumor cells.”

Taming the beast

During his treatment for Burkitt lymphoma, Matthew received six months of chemotherapy at St. Jude. His check-ups now occur only once a year.

“St. Jude was so overwhelming because everybody there was so nice,” Freda says. “Every time we go for his yearly check-up, he has to go upstairs and see his nurses.”

Now, when the family comes to St. Jude, they will also glance up at the fourth-floor windows of the Danny Thomas Research Center. Matthew and his parents know that in a laboratory high above them, researchers continue their quest to understand—and eradicate—Burkitt lymphoma. ●

Double Jeopardy



ANN-MARGARET HEDGES

During a routine checkup to evaluate Aaron Jackson's sickle cell disease, Nurse Practitioner Amy Cone discovered that the baby also suffered from retinoblastoma, a malignant tumor of the retina. St. Jude oncologist Carlos Rodriguez-Galindo, MD, credits Cone's early detection with saving Aaron's eye and possibly his life.

Imagine finding out that your newborn son has an inherited blood disorder. Still reeling from that diagnosis, you discover that he also has cancer. St. Jude helps one family cope.

BY ELIZABETH JANE WALKER

To watch Aaron Jackson at play is to catch a glimpse of the man he will become. Aaron punches the keys of a computer game with the focus of a top executive typing a proposal. Arranging puzzle pieces, he furrows his brow with the concentration of an artist crafting a masterpiece. And the incandescent smile he bestows

on his doctor and nurse practitioner foreshadow the gratitude of a man who understands just how fortunate he is.

At the seasoned age of 2, Aaron has already endured more hardship than many adults. His trials began with the prick of a needle only minutes after birth. That blood test revealed that he had the most severe form of sickle cell disease, an

inherited blood disorder of the red blood cells.

His mom, Racheal, was shocked at the news. "His dad and I never knew that we had the sickle cell trait," she says.

Rocky beginning

Sickle cell disease arises from a mutation in the gene for hemoglobin. Aaron inherited one copy of the

mutated gene from his mom and another from his dad, giving him a one-in-four chance of developing the disorder.

Sickle cell disease causes red blood cells—normally round and soft—to elongate into hard, boomerang-shaped rods that hook together, clogging blood vessels. The disorder may cause severe pain, organ damage, strokes, seizures and even death.

When he was less than a week old, Aaron was admitted to the ICU in his local hospital. For 21 days he battled meningitis, a life-threatening infection that causes inflammation of the membranes covering the brain and spinal cord.

“I was terrified,” Racheal admits. She soon learned that sickle cell anemia makes her son more susceptible to meningitis and other infections.

Aaron’s doctors referred him to St. Jude Children’s Research Hospital where Jane Hankins, MD, of St. Jude Hematology explained that Aaron would need twice-daily doses of penicillin until age 5 to protect him against further infections.

Double whammy

Racheal spent the next few months grappling with her child’s serious medical condition.

“My other kids had been completely healthy,” she says. “This was the first time that I’d ever had to deal with these kinds of health issues.”

She took Aaron to St. Jude for regular checkups. Peering into Aaron’s eye with an ophthalmoscope during one exam, Nurse Practitioner Amy Cone noticed something odd.

“Have you ever looked at photos where some of the people have red eyes?” she asks. “What you’re seeing is the light reflex. When I looked in Aaron’s eye, I didn’t see that nice,

bright red color. Instead, I saw a solid white area.”

Cone knew that the ominous white reflex could indicate retinoblastoma, a malignant tumor of the retina. She asked Carlos Rodriguez-Galindo, MD, of St. Jude Oncology to examine Aaron. At first glance, the anomaly was almost imperceptible. “In spite of the fact that I knew Amy had seen a white reflex, it was not easy to find,” Rodriguez-Galindo says.

Clinicians at most other sickle cell clinics may not conduct eye exams as part of routine sickle cell checkups.

“Typically, a pediatrician would just focus on the standard problems that accompany sickle cell disease: issues with the spleen, liver, lungs, bones or development,” Rodriguez-Galindo says. “Doing a careful light reflex exam is uncommon.”

Further testing revealed that Aaron did, indeed, have retinoblastoma, a cancer that strikes only 10 to 14 children out of a million.

In retrospect, Racheal recalled a few instances in which she had noticed a fleeting abnormality in her baby’s eye.

“For a second, it would look like a lazy eye that would straighten out,” she told Cone. “If we were in a dim light, I could see something like a white cloud in his eye. But I never dreamed it was cancer.”

Rodriguez-Galindo says Cone’s thorough examination definitely saved Aaron’s eye and possibly his life.

“At least 90 percent of kids who have retinoblastoma in one eye must have that eye removed,” he says. “The 5 to 10 percent of patients whose eyes can be saved are the ones who are noticed very early. Aaron’s was a rare case of unilateral retinoblastoma that was diagnosed early.”

Teamwork in action

St. Jude clinicians designed a treatment plan specifically for Aaron. Within a few days, he was receiving his first round of chemotherapy.

Aaron underwent seven courses of chemotherapy and three laser treatments to eradicate the cancer. Initially, the dual diagnosis was a concern to clinicians.

“Chemotherapy can put a child at risk for infection and require transfusions. Having sickle cell disease gives you those same problems,” says Amber Yates, MD, Oncology fellow. “But Aaron was



Occupational Therapist Jessica Sweeney evaluates Aaron’s progress during a Rehabilitation Services appointment. During the session, Sweeney offers his mom, Racheal (pictured at left), creative tips to help Aaron avoid treatment-related developmental delays.

extremely fortunate. During all of his treatments, he had no infection and only had to undergo one blood transfusion, which is impressive.”

Throughout the process, St. Jude clinicians allayed Racheal’s fears and taught her how to assist in her son’s care, which instilled a sense of empowerment.

“I couldn’t have found a more caring hospital for Aaron, because they were so compassionate,” she says. “They also taught me a lot. Parents at St. Jude receive a kind of medical education.”

“I couldn’t have found a more caring hospital for Aaron. They also taught me a lot. Parents at St. Jude receive a kind of medical education.”

Although Aaron has finished his cancer treatment, he returns to St. Jude every eight weeks for follow-up care. Clinicians in the sickle cell and solid tumor clinics coordinate appointments to minimize the amount of time that Aaron must spend at the hospital. “It’s highly unusual for one patient to have two different diseases and to be seen by two separate clinics at St. Jude,” Yates says.

Looking ahead

In the hospital’s Rehabilitation Services department, Aaron carefully inserts large plastic coins into a piggy bank. Occupational Therapist Jessica Sweeney watches Aaron closely, offering encouragement and checking for any problems he may encounter.

“Because Aaron has some visual limitations related to his cancer, he’s at risk for some developmental delays,” Sweeney explains. “We monitor his progress and educate his mom about ways to facilitate his development at home. Right now we want to make sure that this little guy can play and just be a kid.”

Occupational therapy is just one of many appointments Aaron keeps on a regular basis. During exams under anesthesia, physicians look through the pupil of Aaron’s eye into the actual tumor bed. Any new tumors that arise can be removed immediately with a laser. Racheal breathes a sigh of relief after each exam, when she learns that Aaron’s eye shows no further evidence of cancer.

“The main goal of

retinoblastoma treatment is to save Aaron’s life. The secondary goal is to try to save his vision,” says Mary Ellen Hoehn, MD, of St. Jude Ophthalmology.

In the St. Jude Eye Clinic, Hoehn shows Aaron a card whose face is divided into halves—one containing wide, black stripes and the other printed with a bland, gray background. “I watch him to see which way he looks,” explains Hoehn, who checks Aaron’s vision every few months. “If children see the stripes, they will look at the stripes. If they just look away, you know that they’re not seeing them.”

As the test progresses, Hoehn uses cards with thinner stripes. “This test gives us a rough correlation of his level of acuity,” she explains. Aaron currently has about 75 percent usage of the affected eye.

Tiny tornado

Aaron runs through the house scattering toys in his wake. Decidedly independent, the toddler insists on dressing himself and frequently asserts his desires by repeating his favorite mantra: “No!” Aaron’s

curiosity, mercurial temper and boundless energy both delight and exhaust his family.

Aaron has endured only two pain crises thus far as a result of his sickle cell anemia. If the duration and severity of his pain crises increase significantly, St. Jude clinicians will determine whether he is a candidate for hydroxyurea, a drug that causes the body to produce healthier blood cells. For the past decade, St. Jude researchers have been evaluating the effectiveness of hydroxyurea in children. The hospital is heading a national trial to determine the drug’s ability to limit organ damage in infants.

“If the results of current St. Jude research confirm the benefit of hydroxyurea, then all infants with sickle cell anemia may be given the drug in the future,” Hankins says.

With his blood disorder currently under control and his cancer in remission, Aaron spends his day in nearly constant motion. He rides toy trucks, tosses balls with abandon and begs his mom to go outside and play. It’s tough work being a 2-year-old, but this phase won’t last long. Before he knows it, Aaron will be an adult—perhaps pursuing a career, perhaps raising a family. But one thing’s for certain: He will be living a life made possible by St. Jude. ●

ANN-MARGARET HEDGES



Aaron Jackson plays with the stethoscope of Amber Yates, MD, Oncology fellow. Although Aaron has finished his cancer treatment, he returns to St. Jude every other month for follow-up care in the sickle cell and solid tumor clinics.

Sound Fundraisers

BY TARA MILLIGAN

Country music radio stations have made Country Cares for St. Jude Kids®, now in its 20th year, a big hit with listeners and a successful fundraiser for St. Jude.

Country music radio stations often play songs that tell stories of heartbreak, hard times and bad luck. But once a year, hundreds of these stations substitute songs of woe with real-life stories of hope from St. Jude patients who battle deadly diseases like cancer.

As hosts of Country Cares for St. Jude Kids radiothons, these radio partners enable St. Jude to continue its mission by garnering the support of millions of listeners across the nation. Their efforts have generated more than \$345 million for the kids of St. Jude, making Country Cares for St. Jude Kids one of the nation's largest radio fundraising programs.

In 2009 St. Jude will celebrate the 20th anniversary of this remarkable fundraising program. As the needs of St. Jude and its patients continue to grow, Country Cares is poised to play an even bigger role—with an expanding network of stations, country music artists and other industry professionals who are passionate about the hospital's work.

Country Cares began with a heartfelt plea from St. Jude founder Danny Thomas to country music legend Randy Owen, of the Grammy® Award-winning group ALABAMA. Owen recalls meeting Thomas in 1988 and learning about the hospital's phenomenal success increasing childhood cancer survival rates.

"He explained that the hospital depended on public support to carry on this great cause, and he needed my help," Owen says. "His devotion was inspiring. Soon after, I visited St. Jude, and it changed my life. I was amazed by the courage of the patients and their faith that St. Jude could help them. I became a true believer in

PHOTO COURTESY OF BIOMEDICAL COMMUNICATIONS



Under the leadership of entertainer Randy Owen, Country Cares for St. Jude Kids® has become one of America's largest radio fundraising programs. At a Country Cares seminar, Owen visits with St. Jude patients (from left) Amber Frans, Hutch Mohr, Joshua Morales and Leah Parks.

"Danny Thomas explained that the hospital depended on public support to carry on this great cause, and he needed my help."

the hospital's mission and wanted to do something to make a difference."

Soon, Owen had the entire country music industry—artists and their managers, songwriters, record label representatives and radio station staff—banding together in an unprecedented way for a radiothon program to benefit St. Jude. Launched the following year, Country Cares raised \$1.5 million in pledges from radio listeners.

Today, more than 200 radio stations host radiothons annually, and countless artists continue to contribute their time and talent to the program.

"We are fortunate to have such wonderful friends in the country music industry," says David L. McKee, chief operating officer and interim chief executive officer of ALSAC, the fundraising organization of St. Jude. "The support of the industry and country music fans has made a lasting difference in the lives of St. Jude patients and their families and inspires hope for sick children around the world."

To learn more about Country Cares for St. Jude Kids and the 20th anniversary celebration, visit the Country Cares Web site, www.countrycares.org. ●



MVP of Surgical Oncology Care

Training at St. Jude helps children claim victory over cancer.

Serious athletes know what it takes to win the game. They rarely enjoy the luxury of downtime in the offseason and often endure rigorous training to master skills required to conquer the opposition. In essence, serious athletes strive for the big “W” with the focus of a laser beam.

As members of the multidisciplinary team at St. Jude Children’s Research Hospital, surgeons focus on defeating cancer with the same vigor that drives athletes to the top of their game. The strategy: a strong commitment to training and education.

Champions in training

General pediatric surgeons often find themselves working in the oncology field. In fact, of the 6,000 cases of pediatric solid tumors treated in the United States each year, 80 percent of the operations are performed by general pediatric surgeons.

“It’s a challenge for the field of pediatric surgical oncology because there are only a handful of surgeons who really concentrate on oncology,” says Stephen Shochat, MD, longtime educator and St. Jude Surgery chair. The hospital seizes the chance to address this disparity through educational opportunities.



BY JOYCE M. WEBB

*“When I return to my country,
I will be one of only three
pediatric surgical
oncologists in Chile.”*

Four years ago, Shochat launched a Pediatric Surgical Oncology Review Course for general pediatric surgical fellows. Each spring, 25 fellows from the United States and Canada converge on the St. Jude campus for two days of intensive training on the current methods of pediatric surgical oncology care. St. Jude faculty and visiting pediatric surgical oncologists give presentations concerning the management of pediatric solid tumors such as neuroblastoma, Wilms tumor, sarcomas, liver tumors and germ cell tumors. The attendees also get a review of rare pediatric malignancies and discuss operative management and combination therapies for pediatric solid tumors.

The review course is the only one of its kind in the nation.

“Over the course of 10 years, most board-certified pediatric surgeons who have gone through a fellowship training program will have attended this course at St. Jude,” says Andrew Davidoff, MD, chief of General Surgery. “This really gives us a chance to educate surgeons and improve surgical oncology care in this country.”

Teaming up for cures

Another training opportunity at St. Jude is a two-year clinical pediatric surgical oncology fellowship in which trainees work alongside surgeons to perform solid tumor resections, limb-salvage and central venous line procedures, lymph node biopsies and other procedures in general pediatric surgical oncology.

“If we provide this training to our fellows and each of them provides the best possible surgical care to 100 children, then we’re well on our way to improving pediatric surgical oncology care in the United States and around the world,” Shochat says.

St. Jude is the only U.S. pediatric oncology hospital to have surgeons dedicated to the care of children with cancer. This was more than enough to pique the interest of Gloria Gonzalez, MD, of Santiago, Chile. She researched opportunities at top medical institutions before landing a St. Jude fellowship in pediatric surgical oncology.

“This was the best option for me. By the time I complete training at St. Jude, I will have knowledge of all

the diagnostics, pre-operative workup and tools associated with managing oncology cases,” Gonzalez says. “When I return to my country, I will be one of only three pediatric surgical oncologists in Chile.”

Kenneth Gow, MD, and other former St. Jude fellows hold dual roles as practitioners and educators in pediatric oncology care.

“My training allowed me to gain a remarkable focus on pediatric surgical oncology and to work directly with leaders in the field,” says Gow, pediatric surgeon at Seattle Children’s Hospital and an associate professor of Surgery at the University of Washington. “On top of this, I spent a year doing basic sciences research at St. Jude. This has allowed me to stay current with groundbreaking aspects of diagnosis and therapeutics.”

Bracing for the win

Fewer than 30 percent of children with cancer worldwide have access to modern treatment. However, thanks to partnerships with hospitals in 20 countries, children who may never touch American soil still have access to quality care using St. Jude protocols.

Bhaskar Rao, MD, surgery director of the hospital’s International Outreach Program, travels to remote regions of the world to assist surgeons in developing treatment protocols for the management of oncology cases. He also imparts his knowledge about the latest surgical techniques during lectures and in operating rooms. Rao’s expertise in limb-salvage surgery has advanced the surgical treatment of bone tumors in many developing countries.

“Because most of these countries lack the resources and expertise to treat bone tumors, the first thing a surgeon does for a child with a bone tumor is amputate the limb,” Rao says.

Through training and developing infrastructure, St. Jude medical teams have succeeded in boosting cure rates and improving the quality of life for children in South and Central Americas, the Middle East, Africa, China, Taiwan, Mexico, Russia and Singapore. Brazil and Lebanon have seen great improvements in treating bone tumors.

“During the past six or seven years, Lebanon has increased the number of limb-sparing surgeries. If surgeons in Jordan, Iraq, Egypt or Palestine need help, they can get the same

level of care St. Jude provides by visiting the center in Lebanon,” Rao says.

Instead of amputation, 75 percent of children at the Children’s Cancer Center of Lebanon in Beirut and 90 percent of children at Hospital Luis Calvo Mackenna in Santiago, Chile, benefit from limb-salvage surgery. To date, Rao has performed more than 275 limb-salvage operations at St. Jude and around the world.

Through basic and translational research, St. Jude surgeons continue to develop novel therapies to increase cure rates. Offering new hope for children with malignant tumors, these clinicians help children worldwide celebrate victories in their contests with cancer. ●



Each spring, 25 fellows from the United States and Canada undergo two days of intensive training at St. Jude, under the tutelage of the hospital’s faculty and visiting pediatric surgical oncologists. The course is the only one of its kind in the nation.





Frederico Xavier, MD, and the rest of the St. Jude medical team speak the language of hope with Helen Tully and her family, who hail from Latvia.

Language Lessons

Cerība. It's the Latvian word for hope. One family traveled 5,000 miles to experience its power.

BY SUMMER FREEMAN

In a place far from their home, Andra Tully holds her daughter and gently whispers words of encouragement in a language seldom heard in the halls of St. Jude Children's Research Hospital. Waiting together for an early morning appointment in one of the hospital's play areas, 17-month-old Helen responds with a bright smile and a bout of giggles.

Now at the halfway point of Helen's treatment, the Tully family derives a sense of calm from the familiar flow of appointments as well as from the hope for recovery—a marked turn from the ominous whirlwind that swept the family to the United States early last year.

The journey began more than 5,000 miles away in Latvia, a country in northern Europe's Baltic region. Andra, a Latvian attorney, and her husband, John, an American business owner, juggled careers with raising an energetic toddler named Martin. In June 2007, the couple welcomed a beautiful baby girl, Helen.

Initially an alert and happy baby with an irrepressible smile, Helen became increasingly fussy. When Andra noticed a bruise on the infant's bottom, she was immediately

alarmed. "It looked like she had been slapped," Andra recalls. "The next morning, there was swelling on one side."

A doctor suggested that the bruise might have occurred when Helen rolled over on a toy. Unconvinced, Andra took Helen to another physician, who also dismissed the bruise and swelling.

After listening to Andra's persistent pleading, the physician reluctantly offered to order an ultrasound. The test revealed a large growth in Helen's pelvis.

Terminology of despair

The doctor offered bleak odds for recovery.

As a last resort, the physician recommended an operation that would be experimental at best. "He said that they would operate to remove the tumor, but that we should not hope," Andra recalls.

Desperate for a way to save their baby, John and Andra agreed to the procedure.

While waiting for the operation, Andra e-mailed a family friend for whom she did pro bono work, telling him that she would be taking time off work to care for Helen. The friend, director of a children's medical care foundation based in Los Angeles, asked Andra to send him Helen's scans so that he could obtain a second opinion in the United States.

"The U.S. doctors were terrified by what they saw," Andra says. "We were given the names of three hospitals that could best handle the type of tumor Helen had." Among the three listed was St. Jude, located in John's hometown of Memphis, Tennessee.

The language of possibility

Meanwhile, Carlos Rodriguez-Galindo, MD, of St. Jude Oncology received an e-mail from a colleague who had spent a summer in training at St. Jude. The physician in Eastern Europe was seeking counsel about a baby with an advanced pelvis tumor. Then another physician, who worked with the medical foundation Andra represented, contacted Rodriguez-Galindo about the same baby.

"This child needed help," says Rodriguez-Galindo. "Removing a tumor that size in a child as small as Helen is precarious."

At 2 a.m., Andra's phone rang. "It was Dr. Galindo calling to tell us that St. Jude had a protocol open to treat Helen," Andra recalls. "I told John, 'I'm not sure if this is a dream, but I think something good just happened.'"

The next couple of days moved quickly as the Tullys prepared for their trip to Memphis. In a rush, they said goodbye to Andra's family and packed to cross the world for Helen's last chance.

Words of comfort

The diagnosis made in Latvia was based only on an ultrasound. Upon arrival at St. Jude, Helen underwent an array of additional tests. Physicians determined the growth had been incorrectly identified in Latvia and was actually an aggressive soft tissue tumor called rhabdomyosarcoma. The tumor extended across Helen's pelvis, expanding up into her chest and had already spread to her bones, marrow and lungs.

Rodriguez-Galindo and Frederico Xavier, MD, of St. Jude Oncology met with Helen's parents to discuss the protocol. "Treatment for rhabdomyosarcoma usually consists of surgery, radiation therapy and chemotherapy, but Helen was



Top: Helen and her mom, Andra, read a book while waiting for an appointment.

Bottom: Excellent medical care and hearty hugs from staff members such as Michelle Myles help Helen retain her happy disposition.



In Latvia, doctors misdiagnosed Helen's cancer and warned her parents against holding out hope for their daughter's survival. By the time Helen arrived at St. Jude, the tumor had spread throughout her pelvis, chest, bones, marrow and lungs. Today, Helen is a happy, active toddler who is responding well to therapy.

“If we had not come to St. Jude, I don’t think Helen would have celebrated her first birthday.”

too small for all of this,” Xavier says. “So we mapped out a 54-week chemotherapy treatment plan to shrink the tumor.”

In Latvia, the Tullys had been told that Helen’s only option was surgery; now, as the St. Jude physicians explained their approach, the family was overwhelmed. The diagnosis, flurry of travel and fear culminated for Andra in tearful desperation. “I was in the process of a meltdown,” Andra recalls.

Helen’s nurse practitioner JoAnn Harper stepped in and provided comfort. “She told me that they would get us through this, and because everyone at St. Jude had been so supportive and wonderful, I had to believe her,” Andra says. “I still hold onto this idea to get through bad days.”

Speaking of courage

After Helen’s first two cycles of chemotherapy, the tumor shrank by 60 percent and the cancer was cleared from her lungs, bones and marrow.

“In the beginning she had a lot of pain, but she has responded well to chemotherapy,” Xavier says. “She’s growing and developing—and loves to play. Sometimes she has nausea, and the medications we use to combat that make her sleepy. But she fights sleep hard so she won’t miss the chance to play.”

As Helen’s treatment progressed, her parents settled into their new life in Memphis. “Andra and John

are both brave,” Rodriguez-Galindo says. “Andra has been amazing and strong. Through all of this, John has been going back and forth to Latvia, keeping the family afloat and running the company.”

Sibling activities led by St. Jude Child Life specialists helped Helen’s big brother, Martin, adjust to the move. “Martin thinks St. Jude is a pretty cool place,” Andra says. “It’s not a sad place to him. It’s a place where he can have ice cream and play video games.”

Cerība

Andra and John recently learned that Helen’s tumor is now small enough to be surgically removed this winter. After the tumor is removed, doctors plan to continue Helen’s treatment with additional courses of chemotherapy as well as a treatment called brachyradiotherapy.

Although routinely used to treat rhabdomyosarcoma, radiation therapy can damage the neurological, cognitive and hormonal systems of extremely young children, affecting their growth and development. Because of Helen’s age, doctors have chosen to use brachyradiotherapy, a treatment in which surgeons place tiny radioactive seeds no larger than sesame seeds around the tumor site. These seeds kill any remaining harmful cancer cells without damaging the normal cells.

“In babies, conventional radiotherapy presents a challenge,”

Xavier explains, “because we must deliver the beams to the tumor site without hitting other vital organs, which are in extremely close proximity. However, with brachyradiotherapy, the radiation source is placed directly on or very close to the structure to be irradiated, minimizing the amount of radiation that the structures around it receive.”

“Before coming here, we didn’t have these options,” Andra says. “If we had not come to St. Jude, I don’t think Helen would have celebrated her first birthday.”

With each passing day, the word the Tullys were forbidden to utter grows louder. Once a quiet whisper, it is now a powerful declaration: “*Cerība!*” Hope. ●



Perspective

BY DWAYNE M. MURRAY, JD

Sundays Herald Hope

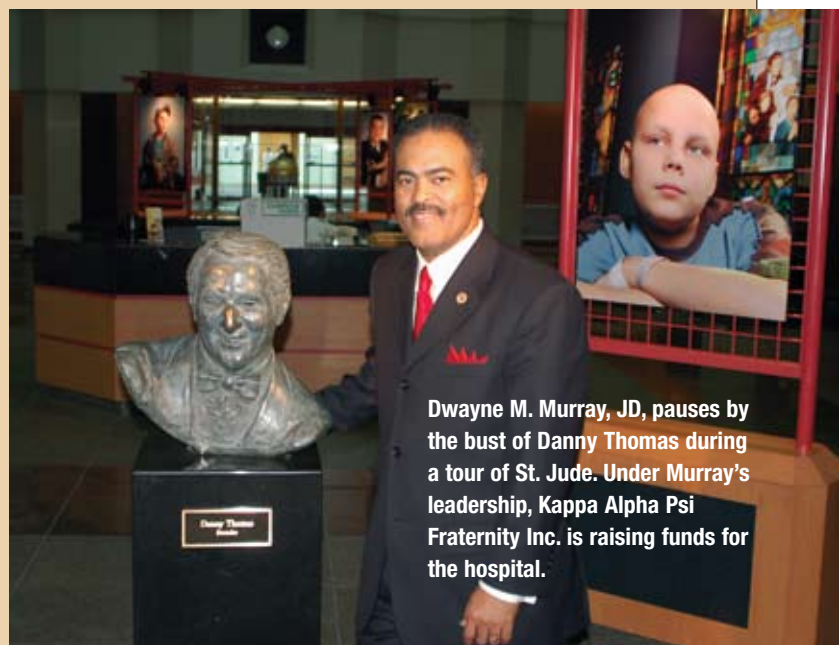
“There has been a war on crime; there has been a war on poverty; but in America there needs to be a war on childhood diseases.”

This month, in churches throughout our nation, thousands of people will participate in the second annual Sunday of Hope campaign. The members of Kappa Alpha Psi Fraternity Inc. are leading this initiative, which benefits St. Jude Children’s Research Hospital. Through the Sunday of Hope program, men in our alumni and undergraduate chapters visit church congregations in January to collect donations for St. Jude. As the national president of Kappa Alpha Psi, I’m extremely proud to be a part of this project.

The members of Kappa Alpha Psi believe that through service to others, we serve Kappa best. When our Grand Board wanted to help an organization that helps others, St. Jude was the perfect fit. Our Sunday of Hope program is designed to familiarize our members and the world with the mission and goals of St. Jude and to encourage long-term relationships that will draw attention to the hospital and its work.

Because our members are spread throughout the world, we developed a concept called “ONE KAPPA” to unite our entire membership in a common cause. We have more than 700 chapters in areas ranging from South Africa to Japan to the continental United States. All of these chapters have causes that they support in their respective communities, but in January we unite to focus our energies on one program. Sunday of Hope reaches out to every community with a chapter of Kappa Alpha Psi. As One Kappa, all of those chapters are focused on the same idea on the same day at the same time. That brings national attention to St. Jude and its work. We are excited to be able to do this because St. Jude has done so well for so long for so many.

When we began the Sunday of Hope program in 2008, our goal was to raise \$500,000 in five years. In its inaugural year, we raised more than \$280,000. We should reach the \$500,000 goal soon, and then we want to continue the



Dwayne M. Murray, JD, pauses by the bust of Danny Thomas during a tour of St. Jude. Under Murray's leadership, Kappa Alpha Psi Fraternity Inc. is raising funds for the hospital.

program in perpetuity. Each year, the month of January will be designated as the Sunday of Hope celebration.

There has been a war on crime; there has been a war on poverty; but in America there needs to be a war on childhood diseases.

The health and moral welfare of this nation is vitally important. By supporting St. Jude, Kappa Alpha Psi plays a small role in winning this war. If all of America can recognize what St. Jude offers to young children, then this world will be a better place.

Dwayne M. Murray, JD, is the 31st Grand Polemarch of Kappa Alpha Psi Fraternity Inc. Since its inception in 1911, the fraternity has trained more than 125,000 men to hold leadership roles in their communities and to attain a high degree of academic excellence. ●



Dylan – Acute Myeloid Leukemia

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You can play a vital role in helping secure a healthy future for children battling cancer with a gift to St. Jude Children's Research Hospital® through your will. Join others who share the desire to leave a legacy of hope to catastrophically ill children by considering a bequest gift to St. Jude. To learn more about these special gifts and the Danny Thomas – St. Jude Society recognizing these contributions, please call us at 800-395-1087, visit www.stjudelegacy.org today or complete the enclosed postage paid envelope today.

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St. Jude patient Samantha Elliott, walks the December 2008 Memphis Grizzlies House 5K race with her father, Andy, as Mike Neel, MD (at right), of St. Jude Surgery paces the course in reverse. Neel, who performed Samantha's knee replacement in January 2008, agreed to walk the race backwards if Samantha participated. "Her goal was to walk the 5K and raise money," Neel said. "I told her if she could walk it, then I would walk it backwards." Fourteen thousand runners registered to take part in the St. Jude Memphis Marathon, Half-Marathon and the Grizzlies 5K.

ANN-MARGARET HEDGES


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