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a Legacy**  
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Perspective on a Promise



St. Jude ranked No. 1 pediatric cancer hospital  
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## Promise

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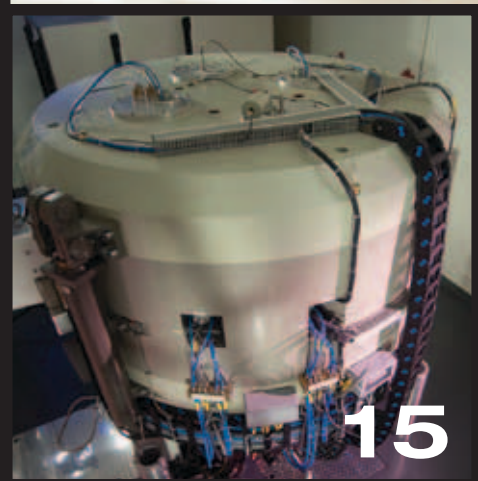
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# Promise

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# Highlights



## St. Jude named nation's top children's cancer hospital

St. Jude has been named the nation's top children's cancer hospital in the 2010–11 Best Children's Hospital rankings published in *U.S. News & World Report*. St. Jude received the best overall score summarizing quality of care. "This recognition is an outstanding external acknowledgment for our institution, but more importantly for the dedicated St. Jude faculty and staff who devote their time, talent and lives to the young patients we see every day," said Dr. William E. Evans, St. Jude director and CEO.

This year's rankings were based on how well a hospital did in three areas: reputation; medical outcomes such as cancer survival; and care-related indicators of quality such as the number of patients, nursing staff and other factors.

The 2010–11 Best Children's Hospitals rankings are posted at [www.usnews.com/childrenshospitals](http://www.usnews.com/childrenshospitals) and will be published in the magazine's August issue.

SETH DIXON



## Study yields dramatic AML survival increase

More individualized therapy and better supportive care helped push the survival for children with acute myeloid leukemia (AML) to 71 percent three years after diagnosis, according to new research led by St. Jude investigators and reported in *The Lancet Oncology*. The survival rate of 71 percent is 20 percent better than previously reported U.S. rates, said the study's lead author, Jeffrey Rubnitz, MD, PhD, of St. Jude Oncology.

Results of the study are among the best reported nationally or internationally.

This study featured several firsts, including the first use of minimal residual disease (MRD) to guide the timing and makeup of later chemotherapy. MRD measures cancer cells that survive treatment. The study also marked the first time all patients received antibiotics after each course of chemotherapy, a strategy that dramatically decreased infection rates. The study also used genetic factors and tailored treatment depending on risk factors. Rubnitz said saving even more lives will likely require new medications and novel treatments.

## Gene linked to varied treatment responses

Mary Relling, PharmD, Pharmaceutical Sciences chair, (center) is senior author of a paper demonstrating that a single gene is linked to a varied response to the anti-cancer drug methotrexate. A team that included first author Lisa Trevino, PhD, (at left) and Wenjian Yang, PhD (at right) found that normal variation in the makeup of the *SLC01B1* gene accounts for individual variation in how quickly blood levels of methotrexate drop. Common inherited differences in the gene were a stronger predictor of individual response to the drug than factors like a patient's age, race, sex or even kidney function. *SLC01B1* is widely studied for its role in the body's response to the cholesterol-lowering drugs known as statins. But the gene had not been strongly associated with methotrexate until St. Jude scientists completed the first genome-wide search for the genetic basis of the drug's pharmacokinetics in children with acute lymphoblastic leukemia. A report on this study recently appeared in the *Journal of Clinical Oncology*.



## Clinicians praise power of teleoncology

Motivated clinicians and an Internet connection combined with computers and e-mail access have the power to transform pediatric cancer treatment in the most remote corners of earth, according to a St. Jude investigator writing in *The Lancet Oncology*.

“A successful teleoncology program does not require a lot of expensive equipment. The most important element is having committed people,” said Ibrahim Qaddoumi, MD, telemedicine director of the St. Jude International Outreach Program. He co-authored the recent report on telemedicine as a tool for improving worldwide cancer treatment.

Like other telemedicine efforts, teleoncology initiatives

range from e-mail exchanges and real-time videoconferencing to educational seminars available through websites such as [www.cure4kids.org](http://www.cure4kids.org), a St. Jude site that provides educational materials and online collaborative tools. Such activities unite providers worldwide, allowing them to review pathology and radiology images as well as other important clinical data in hopes of improving cancer diagnosis and treatment.

Qaddoumi wants to create greater awareness of how teleoncology can be used to improve childhood cancer treatment worldwide and to prompt more institutions to get involved. “At St. Jude we are lucky; outreach is part of the culture,” he said.

## Flu shots may offer long-term benefits

Researchers have promising news for millions of Americans who were vaccinated against swine flu in 1976. New St. Jude research suggests the vaccine may have provided some protection against the 2009 pandemic H1N1 influenza virus. The findings also raise hope that those vaccinated against the 2009 H1N1 pandemic strain might enjoy a similar long-term advantage.

In a study of 116 St. Jude employees and spouses age 55 and older, researchers found those who received the 1976 swine flu vaccine mounted an enhanced immune response against both the 2009 pandemic H1N1 virus and a

different H1N1 flu strain that circulated during the 2008–09 flu season.

“While immunity among those vaccinated in 1976 has waned somewhat, they mounted a much stronger immune response against the current pandemic H1N1 strain than others who did not receive the 1976 vaccine,” said Jonathan McCullers, MD, of St. Jude Infectious Diseases. He was lead author of a report on this work that appeared in the journal *Clinical Infectious Diseases*. The research also suggests that routine vaccination against seasonal flu might confer a broader-than-realized protection.

## Focus on science

Postdoctoral fellow Crystal Burke, PhD (at right), of Infectious Diseases and two high school seniors watch the process of DNA separation on an agarose gel during a Career Day event at St. Jude. Seniors from the Memphis Health Careers Academy participated in hands-on science activities and met with St. Jude clinicians and postdoctoral fellows. “These students are about to embark on a new phase of life—college—and we wanted to give them as much information as we could to help them choose the career path best for each of them,” said one of the event’s organizers, Racquel Collins-Underwood, PhD, of Pathology.



ANN-MARGARET HEDGES



## Immune insights may have cancer applications

Thirumala-Devi Kanneganti, PhD (at right) of Immunology, postdoctoral fellow Md. Hasan Zaki, PhD, also of Immunology, and their colleagues recently conducted research that identifies potential new targets for treatment of colitis and other inflammatory bowel diseases. In the journal *Immunity*, the investigators report that a protein made by a gene already associated with some inflammatory immune diseases plays a pivotal role in protecting the intestinal tract from colitis. The *NLRP3* gene is part of the body's innate immune response, which is programmed to fight infectious diseases and other threats. "I believe if we target molecules that are part of the innate immune response, we can find cures for many diseases, including cancer," Kanneganti said.

*"I believe if we target molecules that are part of the innate immune response, we can find cures for many diseases, including cancer."*

## Flu virus takes wing

Sparrows are to chicken houses what party-crashers are to the Academy Awards. Both show up uninvited and help themselves to the buffet table. Now there is new evidence from St. Jude researchers that the little birds are also capable of spreading a deadly H5N1 influenza virus as they flit from chicken flock to chicken flock.

"This study shows experimentally that sparrows picked up the virus from chickens," said the study's senior author Robert Webster, PhD, Infectious Diseases. "It is a formal demonstration of the wisdom of biosecurity in chicken houses," he added, referring to measures designed to protect chickens from exposure to infectious diseases and other threats.

Heather Forrest, DVM, also of Infectious Diseases, said additional studies are needed into H5N1 transmission from infected sparrows to chickens. She and Jeong-Ki Kim, PhD, formerly of St. Jude, are lead authors of a report on this work that appeared in the *Journal of Virology*.

## Discovery opens door to new possibilities

St. Jude investigators have identified a gene that plays an essential role in the developing lymphatic system, a finding that helps unravel the formation of this important vascular network and might eventually lead to new methods for treating lymphatic disorders or blocking cancer's spread via the lymphatic vasculature network.

The gene is named *Coup-TFII*. A team led by St. Jude researchers showed that Coup-TFII activity is necessary to switch on the *Prox1* gene early during the development of lymphatic progenitor cells. Previous work from the same St. Jude scientists showed *Prox1* is the master regulator charged with formation and maintenance of the lymphatic vascular system.

A better understanding of how *Prox1* is regulated and how the lymphatic vasculature develops would provide new strategies for stopping the spread of cancer, since tumors use the lymphatic vascular network to spread. R. Sathish Srinivasan, PhD, was first author of a report on this work that appeared in *Genes & Development*. Srinivasan is a postdoctoral fellow in the laboratory of the study's senior author, Guillermo Oliver, PhD, Genetics and Tumor Cell Biology.



## When it comes to injections, less is more

A multicenter trial led by St. Jude investigators may transform how children with cancer are treated for neutropenia. Characterized by a dangerous drop in white blood cells, neutropenia leaves patients at increased risk for infections and can delay chemotherapy.

In a study of 44 young cancer patients, investigators reported that the drugs pegfilgrastim and filgrastim were similarly safe and effective at restoring a safe level of neutrophils following chemotherapy. Although filgrastim has been widely used to speed neutrophil recovery, administration of the drug involves daily injections for a week or longer. On the other hand, pegfilgrastim treatment requires a single injection.

“This study will make a big impact on the quality of life for patients and their families,” said Sheri Spunt, MD, Oncology, who was lead author of the study that appeared in the *Journal of Clinical Oncology*.

## Hicks wins international award



**Judy Hicks and St. Jude patient Rebeca Salazar**

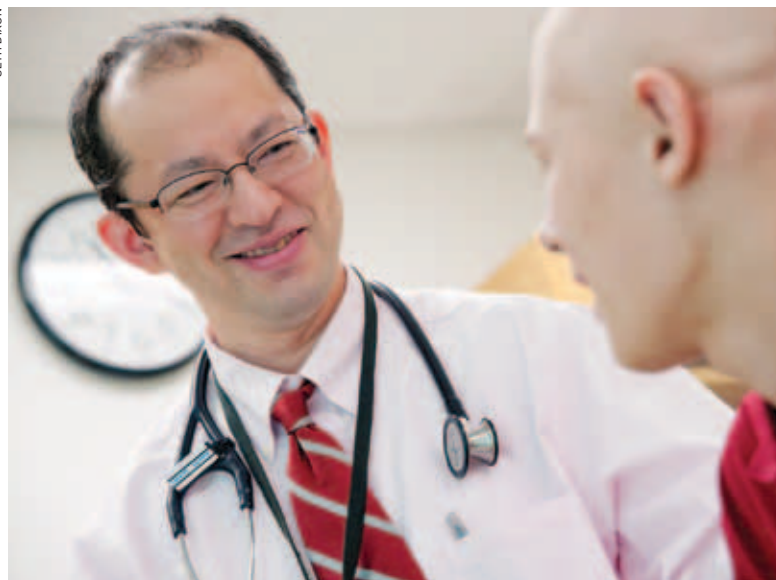
St. Jude social worker Judy Hicks has been named the 2010 Social Worker of the Year by the Association of Pediatric Oncology Social Workers. The international award recognizes Hicks' contributions to children and families affected by life-threatening illnesses. Hicks is the third St. Jude social worker to receive the honor. Social Work director Fran Greeson won the award in 2007 and social worker Beverly Bagwell received the recognition in 1998.

## Good news for long-term survivors

Modern, risk-adapted therapies may reduce rates of late death among long-term survivors of childhood cancer, according to a new analysis from St. Jude investigators.

The study, recently published in the *Journal of Clinical Oncology*, is the first to show that patients in more recent eras, who likely received treatments tailored to their risk status, are not only surviving their primary cancer, but are also less likely to die later of treatment-related complications.

When researchers compared childhood cancer patients treated from 1974–80 with patients treated from 1995–2000, they found that deaths due to second cancers, heart, lung and other problems fell 33 percent. The work focused on deaths that occurred more than five years after the original diagnosis. “This study suggests we may be reducing the risk for late mortality due to cancer treatment side effects,” said the paper's first author, Gregory Armstrong, MD, Epidemiology and Cancer Control.



## Who is at risk for lung problems?

Oncologist Hiroto Inaba, MD, PhD (at left), is lead author of a study that identified childhood cancer survivors who are at increased risk for lung problems, partly because of lifesaving bone marrow transplants that occurred years earlier. Published in the journal *Cancer*, the study is the most comprehensive look yet at the long-term lung function of childhood leukemia survivors whose treatment included bone marrow transplantation. The results may help physicians identify leukemia patients at increased risk for post-transplant lung problems and adjust treatment to avoid those problems. Wing Leung, MD, PhD, is the study's senior author and St. Jude director of Bone Marrow Transplantation and Cellular Therapy.

# Focused on Cures

Investigators collaborate on developing new drugs designed against the specific mistakes that drive tumors like retinoblastoma.

BY MARY POWERS

In the surgical waiting room at St. Jude Children's Research Hospital, Teresa "Esa" Neiswender is a busy girl. She is working a puzzle with her father, Blair, while trying to reach Minnie Mouse on a blue plastic telephone and keeping an eye on her younger sister Taya, who is still learning to walk.

"Esa finds happiness in everything," says Terise Neiswender, mother of 3-year-old Esa. "She wakes up happy. She likes to sing and cook and color. She makes it possible to take life one day at a time."

Not bad for a girl who arrived at St. Jude as a 5-month-old with retinoblastoma, a cancer of the retina, the seeing part of the eye. Both of Esa's eyes were affected. Diagnosed in about 300 U.S. children annually, retinoblastoma is the third most common cancer in infants after leukemia and nerve tumors called neuroblastomas.

The retina provides a connection between the outside world and the brain. In Esa's case, the tumor in her left eye was so large the retina had detached and pulled away from its normal position at the back of her eye. Chemotherapy and laser



Esa Neiswender shares a storybook with surgeon Matthew Wilson, MD, after receiving good news—her most recent exam indicates no sign of retinoblastoma. Meanwhile, in labs across St. Jude, Wilson's colleagues are developing drugs to target genetic mistakes that threaten the lives of children like Esa.

treatments helped kill the tumors in both eyes. Injections of an anti-cancer drug in the tissue around the eye also helped destroy cancer cells floating in the jelly-like vitreous within one of her eyes.

## Rosy view

The Neiswenders returned to St. Jude early on a recent morning so that Matthew Wilson, MD, could check for any signs Esa's cancer had returned. Wilson specializes in treating tumors involving the eye and related structures.

Esa is among the 40 percent of retinoblastoma patients who are candidates for a lifetime of close monitoring. The same genetic mistake responsible for her retinoblastoma leaves her at greater risk for developing other cancers. This checkup brought good news: Wilson found no new tumors.

The news has also been good recently in the St. Jude laboratories where scientists such as Michael Dyer, PhD, are working to understand both normal retinal development and the missteps that lead to the uncontrolled cell growth that is a hallmark of all cancers,

including retinoblastoma. Dyer, of Developmental Neurobiology, is among the St. Jude investigators leading a push to develop new drugs designed against the specific mistakes driving tumors like retinoblastoma. Researchers expect this new generation of medicines to be more effective and less toxic.

## Visualizing new drugs

Earlier this year a project led by Dyer and R. Kiplin Guy, PhD, Chemical Biology and Therapeutics chair, identified a molecule with the potential to be the founding member of a new class of cancer drugs. The drugs would be the first designed specifically against a childhood tumor.

Known as SJ-172550, the new compound targets what researchers believe is the Achilles heel of retinoblastoma and certain other cancers. Earlier work from Dyer's lab found the vulnerability. Scientists showed the vast majority of retinoblastoma tumors, as well as nearly 20 percent of breast, colon and lung cancers, have extra copies of the gene that carries instructions for assembling a protein named MDMX.



That is a problem because an overabundance of MDMX disrupts the pathway used to eliminate rogue or damaged cells. A protein named p53 plays a critical role in that pathway, inducing the death of the damaged cells that give rise to cancer. But when MDMX levels are high, p53 gravitates toward MDMX, slipping into the same pocket where SJ-172550 also fits. With p53 out of the picture, cell division proceeds unchecked with disastrous results.

## Insight and identification

The new insight led investigators to screen a chemical library of nearly 300,000 compounds effective against the excess MDMX. After identifying SJ-172550 as a possible candidate, researchers demonstrated in the laboratory that the molecule killed retinoblastoma cells that carried extra copies of the *MDMX* gene. Even more tumor cells died when investigators combined SJ-172550 with another experimental drug targeting a different protein that at excessive levels disrupts the p53 pathway.

Scientists are now tweaking SJ-172550 to enhance its medicinal qualities, including making it smaller and more easily dissolved in liquids.

“It is like taking a puzzle piece and figuring out ways to make it fit even better,” Dyer says. “That is a lot of work. It will take years, which is why drug development takes so long.”

Dyer says the continuing effort to find and develop compounds like SJ-172550 illustrates the strength of St. Jude drug development efforts. Those include Chemical Biology and Therapeutics, where faculty and staff focus on finding and then enhancing potential new drugs. In Pharmaceutical Sciences, researchers focus on how candidate drugs move

through the body, including how they are absorbed, broken down and eventually eliminated. Finally, St. Jude investigators have developed a variety of laboratory models where promising new drugs can be tested.

“This project highlights why at St. Jude it works so well. We have all three of the research components combined with outstanding clinical care. That is what makes St. Jude special,” Dyer says.

## Keeping the goal in sight

Patients like Esa are already benefiting. She enrolled in a research study, or protocol, that included the drugs topotecan and vincristine given intravenously combined with carboplatin injections around her right eye. St. Jude researchers pioneered the use of topotecan for retinoblastoma. “We believe the protocol saved her eyes,” her mom says.

Dyer, Guy and other St. Jude investigators are pursuing additional promising leads and collaborations to find new, more tailored treatments of retinoblastoma and other childhood

tumors. The prospects include the experimental drug nutlin-3a. The compound is in early testing in adult cancer patients, and St. Jude researchers reported evidence it might play a role against retinoblastoma—possibly in combination with the newly identified SJ-172550.

With current treatments, more than 95 percent of St. Jude retinoblastoma patients are cured. But Wilson says treatment remains arduous for patients and families. Surgical removal of one or both eyes is sometimes necessary.

“The overall trend in cancer therapy has been toward more targeted, less toxic therapies. But childhood tumors are rare. They are not the kind of cancers being targeted by drug companies,” Wilson says. “I am enthusiastic about the collaboration underway at St. Jude. We are identifying candidate drugs and moving those candidate drugs forward. We are making progress in understanding childhood cancers like retinoblastoma and ways to treat it.”●

PHOTOS BY PETER BARTA



**Developmental neurobiologist Michael Dyer, PhD (top left), along with R. Kiplin Guy, PhD (below left), Chemical Biology and Therapeutics chair, recently led a project that identified a molecule with the potential to be the founding member of a new class of cancer drugs. The drugs would be the first designed specifically against a childhood tumor.**



# Re

Fortitude and determination honed through competitive rock climbing have helped Ciera Blackburn keep her focus—and her sense of humor—during an arduous battle with B cell lymphoblastic lymphoma. She credits John Sandlund, MD, of Oncology and Nurse Practitioner Martha May, RN (pictured on facing page), with inspiring her along the way. “I definitely want to go into pediatric oncology, and I only hope to be as amazing as Dr. Sandlund is,” Ciera says.



# Reach for the Sky

BY ELIZABETH JANE WALKER

Rock climbing taught **Ciera Blackburn** to keep her eyes on the summit. Thanks to St. Jude, Ciera's aspirations have never been higher.

**A**s a competitive rock climber—and one of her state's top women boulderers—Ciera Blackburn performed a high-altitude dance of strength, courage and sure-footed concentration. With her goal squarely in sight, Ciera moved inexorably skyward.

“When I’m climbing, I’m just thinking about getting to the top,” she says. “I’m constantly planning my next move and making sure I stay on my route.”

In the summer of 2009, the 17-year-old embarked on the most demanding ascent of her life. Standing in the shadow of the mountain known as cancer, Ciera looked upward, focused on the summit and began to climb.

## A different kind of problem

As a high school junior, Ciera had already proven her mettle in an array of sports ranging from soccer and volleyball to softball.

ANN-MARGARET HEDGES



After one visit to her high school's climbing gym, she was hooked.

“I immediately fell in love with it,” she says. “I went out and bought my shoes and harness that weekend.”

As she honed her skills, Ciera amassed impressive upper-body strength as well as impeccable

balance. Soon, she could execute two-finger pull-ups as easily as a football player might do chin-ups. Upon completing an exhilarating “problem,” or route, Ciera would pause at the apex, reveling in her accomplishment.

“I like the height, honestly. While I’m climbing, I have this





BETH DIXON

**Ciera (at right) pauses with her friend Kassi Herdt at the 2010 St. Jude Teen Formal.**

adrenaline rush because I know it's dangerous but at the same time I know I can't get hurt doing it because of the safety equipment," she says.

Soon Ciera embraced a sport called bouldering, which is climbing in its purest form. Boulders execute shorter but more technical climbs without the encumbrance of ropes and harnesses.

"In our gym, we practice bouldering on a wall that has a 45 degree incline," Ciera explains. "One of the reasons I like it is because a lot of girls can't do it. You have to be able to lift your whole body weight off the ground with your arms."

In June of 2008, a painful, pea-sized knot arose on Ciera's shin. Although an X-ray identified the culprit as shin splints, the pain persisted. Ciera underwent MRI scans every few months until a specialist ordered a biopsy.

"I'm 99.9 percent sure it will be benign," the physician predicted. But after the procedure, he looked solemn. "First of all, I need to tell you that I am shocked," he said, explaining that Ciera had cancer.

For the next six weeks, pathologists unsuccessfully attempted to

determine the type of cancer, finally performing a second biopsy. "We're almost positive that it's localized," the physician said.

Frustrated by their daughter's 14-month ordeal, Sherri and Mike Blackburn turned to friends for advice. Several people suggested that the family obtain a referral to St. Jude Children's Research Hospital.

### **Preparing for the climb**

When Ciera arrived in Memphis a week later, she finally obtained a diagnosis: B cell lymphoblastic lymphoma. Clinicians discovered that the cancer had spread to her kidneys, breasts, pancreas, adrenal glands and spinal fluid. Nevertheless, her parents felt reassured and hopeful.

"I was definitely scared at first, but once we were shown around, I loved every single person on Ciera's team," Sherri says. "You can tell that they're here for the children and their families. My insecurities and fear were gone; suddenly we were in a comfort zone. St. Jude even took away the financial stresses, since the costs were covered. That's a blessing in and of itself."

Because of the cancer's advanced stage, Ciera faced an intense treat-

ment regimen. But she faced the challenge with pragmatism.

"I cried when I first found out I had cancer," Ciera says, "but I told myself from the beginning that I wasn't going to sit around and be depressed because that wouldn't make the cancer go away."

Instead of lamenting the size of the mountain before her, Ciera surveyed her options and plotted a path that would benefit others. Realizing that high-dose chemotherapy would decimate her lush, waist-length mane, Ciera opted to donate her hair to an organization that makes wigs for patients. The day before her first chemotherapy treatment, Ciera and her mom rode the downtown trolley to a Memphis salon. As Ciera's glorious tresses fell to the floor, Sherri and other patrons shed tears.

"That was probably the hardest day of my life," Sherri recalls.

St. Jude oncologist John Sandlund, MD, says that event provided him with insight into Ciera's personality.

"The fact that she would do that is reflective of who she is and where her priorities are," Sandlund says. "Even at the beginning of

therapy, Ciera was thinking about how she could use her experience to help another person. At a time when most people would be thinking, ‘Oh, no, I’m going to lose my hair,’ her first reaction was, ‘How can I turn this into something positive for somebody else?’ That’s very telling about her.”

## A rock and a hard place

The first 11 months of treatment have been arduous. St. Jude school-teacher Dennis Medford helped Ciera complete her academic requirements so that she could graduate with her senior class. But French, English, economics and American government were a breeze when compared to the side effects of therapy.

Ciera has endured weakness, nausea, weight gain, mouth sores and avascular necrosis (AVN), a disease that occurs when loss of blood supply causes the bone and surrounding tissues to deteriorate. Because AVN is a side effect of the steroids integral to Ciera’s treatment, Sandlund ordered a baseline MRI soon after therapy began. Surprisingly, the scan indicated the presence of AVN in her hips, knees and shoulders.

“She’s one of the earliest AVN patients of this severity that I’ve seen,” Sandlund observes.

As a result, Ciera underwent

an operation in April to address the problem in her hip. Orthopedists will continue to monitor her bone issues.

In the past, Ciera and five other members of her family have suffered from a condition called supraventricular tachycardia (SVT). Since beginning cancer therapy, Ciera experienced several episodes of the frightening condition, which caused her heart rate to accelerate to 230 beats per minute. When an episode would occur, clinicians would quickly administer a medication that would break the high rhythm and lower her heartbeat to a normal rate. Tests indicated that a blood clot had formed in Ciera’s heart. In July she underwent open heart surgery to correct the problem.

Throughout treatment, Ciera has retained her bubbly personality and has delighted her medical team with her inquisitive nature and keen intelligence. She constantly researches medical topics and quizzes her physician to obtain additional information.

“She always has a lot of good questions,” Sandlund says, with a smile. “People who are extremely bright, like Ciera and her parents, inevitably want to be engaged in the medical process. They’re constantly looking beyond the next step. They’re evaluating the implications, side effects, prognosis, short-term issues

and long-term issues. Because of that, Ciera is very much a part of the decision-making process.”

## View from the summit

Ciera has approached her medical treatment as a learning experience as well as an opportunity for spiritual growth. As a result, she plans to pursue a career that allows her to help other teens and children with cancer.

“Dr. Sandlund is my biggest inspiration,” she says. “I definitely want to go into pediatric oncology, and I only hope to be as amazing as Dr. Sandlund is. I believe that everything happens for a reason. And I personally believe that my reason for being diagnosed with cancer is to meet Dr. Sandlund and realize that this is what I need to do with my life.”

Sandlund says Ciera has the acumen, focus and empathy to excel in her chosen field.

“Pediatric oncology is not merely a career that intrigues her; I think she views it more like a calling,” he observes. “To me, her career choice is a continuum of her very first day, when she cut her hair and gave it away to help someone else. The foundational thing is that Ciera wants her life to count. She wants to use her gifts and abilities to do something that she feels is a ministry to others. It’s not really for herself; it’s for other people.”

Ciera constantly adds items to the list of activities she has planned for the future. Those aspirations include hiking, kayaking, camping, touring Paris and attending medical school. For now, though, she concentrates on completing her treatment, which will continue through March of 2012. Ciera knows she still has a steep climb ahead, but the view from the top will be worth the journey. ●



**Ciera (shown here pre-diagnosis) cut her hair before chemotherapy began and donated it to an organization that makes wigs for patients. “Even at the beginning of therapy, Ciera was thinking about how she could use her experience to help another person,” Sandlund says.**

BY CARRIE L. STREHLAU

**R**elect on the younger years—those awkward teenage years. Braces, poofy hairdos, acne, trying to fit in somewhere with someone—those are almost requirements for growing up in that self-conscious stage. For many adolescents and young adults, the middle ground between childhood and adulthood is rocky and confusing. For teens diagnosed with cancer or catastrophic diseases, the load can be exacerbated by hair loss, weight gain, isolation, questions about mortality and depression.

“When teens with cancer are admitted to a hospital, they lose the sense of freedom they were just learning how to gain,” said Kelly Anderson, a Child Life specialist at St. Jude Children’s Research Hospital. “Their friends and family are worried and are checking on them more than usual. The autonomy is gone. They also look at themselves then and now, comparing how it used to be.”

As its name suggests, St. Jude is a children’s hospital, but its staff also diligently and passionately works to ensure that the adolescent and young adult patients treated fit in as much as possible.

“Teens here grow up quickly because of their experience as cancer patients. They see a bigger picture than what they would if they were not here,” Anderson says.

## A place of their own

The teenage world is difficult even outside the St. Jude walls. An environment of support and contact may be replaced with one of isolation.

“Teens will be teens,” Anderson says. “As teens, they are typically focused on helping their friend who has cancer at first. Then, they go back to their lives. They do not realize that the teen patient needs the continued support. We talk to patients about this and encourage them to share with us how they are feeling. We introduce them

to other teens at St. Jude. Some of them even take on parenting-like roles with our younger patients.”

At St. Jude, teens have their own place to hang out and spend time with friends their own age while undergoing treatment. The Teen Rooms feature games, art supplies, movies, a pinball machine and a jukebox. Patients must be at least 13 years old to enter. No parents, no doctors or nurses are allowed.

“It’s that age when everything is important to them—their looks, their friends, their social activities, their participation in sports. Many of our teens are uprooted from their entire lives and their whole support systems,” Anderson says. “The Teen Rooms—one on our main floor, one for bone marrow transplant patients and one in patient housing—provide areas for them to get away from the little kids and parents. At some point, they all need that.”

## A normal life

Special hospital activities allow teens to experience typical rites of passage such as high school graduation and the St. Jude Teen Formal. Organized by the hospital’s Child Life department, the St. Jude Teen Formal receives enthusiastic input from patients and their siblings. From the pamper party to the stretch limos and red carpet, the goal is normalization and entertainment.

“One of the things we got to thinking about was that a lot of the teenagers miss their formal and the other dances that they do at their schools. We wanted to provide an opportunity for them to have something that would bring some of their normal life at the hospital,” Anderson says. “Weeks before, they’re saying ‘I can’t wait for prom to get here. I can’t wait to try on my new dress. I can’t wait to just get to hang out.’ I think that they really enjoy having something that’s solely provided for them.”

Success with teens is parallel to having staff who are focused on them.

## In the Middle

**They aren’t yet adults, but they’re no longer kids. They yearn to blend in, but their mirrors reflect hair loss or other side effects of cancer treatment. St. Jude helps teenaged patients cope with their unique set of challenges.**







**Child Life Specialist Kelly Anderson (at left) is one of the few adults allowed in the Teen Room at St. Jude. Patients such as (from left) Janet Gatewood, Jacob Huff and Jeremiah Dirks take advantage of the special room, which is off limits to parents, doctors and nurses.**

“They need a space to call their own,” Anderson says. “They need to feel like someone is on their side. They need a place to escape and a support system. It is also important that we speak to them as teens.”

## **Bridging the medical gap**

The phenomenon is not only psychosocial; it is also medical. In 2006, the National Cancer Institute (NCI) reported a lack of progress in survival rate improvement among older adolescents and young adults relative to all other ages. The incidence of cancer in this age group has increased steadily in the last 25 years.

“Pediatric oncologists have become much more aware of this population since the NCI report, but a major gap still exists,” says St. Jude oncologist Sheri Spunt, MD.

“Adult practitioners have little access to pediatric trials, and vice versa, so fewer adolescents and young adults participate in clinical trials,” Spunt continues. “And we know that patients who participate in clinical trials fare better than those who do not.”

As Spunt points out, “If a 19-year-old is treated for cancer at a pediatric center and then relapses at age 22, often that patient cannot be treated on a pediatric trial, and it is sometimes difficult to transition care to an adult center with clinical trial availability.”

According to the NCI, this age group has a unique distribution in the types of cancers that occur. “The most common diseases are lymphomas, melanoma, and testicular and ovarian tumors,” Spunt says. “But they can also have cancers that are typically seen in the younger population such as acute leukemia and sarcoma.”

Although doctors nationwide have reported higher success rates in certain cancers for teens on pediatric trials versus adult trials, teenage survival rates still need improvement.

## **Tuned in**

Jennifer Windham, a social worker at St. Jude, says teens understand the implications of treatment. “Teens really know what they are losing as they go



**Social Worker Jennifer Windham encourages teens to express their thoughts and feelings through positive outlets. She and her colleagues created a special journal that is used not only by teen patients but also by the teenaged siblings of patients.**

through treatment. We focus on maintaining normalcy and balance. This time of life is crucial, so we work on short-term goals; talk about graduation, prom, senior pictures.”

Social Work teams with Child Life and other clinical staff to assess the patients and focus on where children are and where they want to be.

“We are also here as a sounding board,” Windham says. “Teens can be cruel, rumors can start, and we want them to feel like we are there for them to talk to about it all.”

Cruelty stems from misunderstanding and misinformation. Treatment can lead to body and weight issues; some chemotherapy can bring with it massive

outbreaks of acne and hair loss.

“St. Jude is unique because I feel like we can do more for them than other hospitals can because of our resources,” Windham says. “With almost 20 social workers, we can be more tuned into their needs. Some of them want to talk a lot; some express themselves with art; some connect with another staff member; some act out and some internalize everything. It is our job to help them feel safe enough to share in the ways they feel comfortable.”

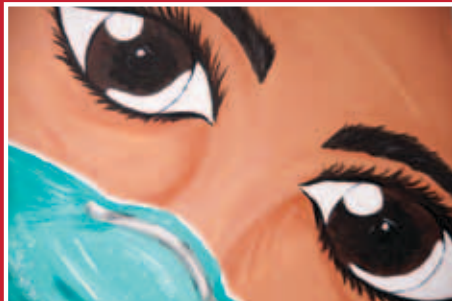
With the advent of social media, blogging and other online resources, this age group has a plethora of outlets and ways to connect with other teens across the world who might be going through the same thing. “They need to connect with children their own age

and feel like they are understood,” Windham observes.

“This is a challenging age group,” Spunt adds. “But, I feel like St. Jude has a good focus on teens in their social environment.”

Seventeen-year-old Kayla McMillen appreciates the emphasis St. Jude places on teens.

“I have grown a lot since I came to St. Jude,” says McMillen, who is receiving treatment for Ewing sarcoma. “I have been put in a situation where I had to grow up. I have learned a lot: to accept new things that come up, to adjust to new environments, to adjust to new kinds of people. I accept cancer now—I don’t accept it with an open heart, but I do accept that it is real.” ●



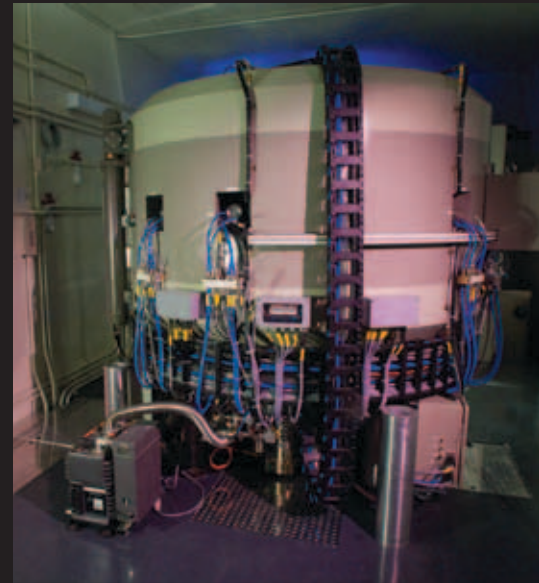
**St. Jude recently transformed a hospital hallway into the Teen Art Gallery, which displays brightly colored, powerful artwork created exclusively by teen patients. Using paint, canvas and other media, young artists effectively communicate raw emotions that may otherwise be difficult to verbalize. “It is hard to swallow the pill that you have cancer and accept it,” observes 17-year-old Kayla McMillen. “Once you have cancer, your world changes.”**



# Accelerating Research

St. Jude creates powerful tracer molecules to hasten our understanding of childhood cancers.

BY ELIZABETH JANE WALKER



(Above) Scott Snyder, PhD, director of Molecular Imaging Research, demonstrates how radioactive chemicals that have been created in the St. Jude cyclotron (pictured top right) are converted into drugs in the radiochemistry lab. (At right) Barry Shulkin, MD, Nuclear Medicine chief, and Beth McCammon, RN, of Radiological Sciences discuss ongoing research projects in the hospital's PET scanning area.



BMC PHOTOS

Early on a misty morning, 11-year-old Latrevious Moore arrives at St. Jude Children's Research Hospital for a test that is an essential part of his cancer therapy. As the procedure begins, the sleepy sixth-grader listens to a favorite radio station and anticipates the upcoming day's activities—breakfast, followed by a clinic appointment and an enjoyable afternoon of playing video games.



Latrevious undergoes positron emission tomography (PET) scans as part of his treatment for Hodgkin lymphoma, a cancer of the immune system that can affect the lymph nodes, bone marrow, spleen and other internal organs. Before dawn broke this morning, scientists in a basement laboratory were racing to produce the radioactive drug that now moves through Latrevious' body.

The radioactive chemicals used in that drug are created in a powerful machine called a cyclotron, or a particle accelerator. The St. Jude cyclotron is the only one of its kind solely dedicated to producing radioactive "tracer molecules" for pediatric treatment and research.

## Racing against the clock

PET scanning is an extremely sensitive imaging technology that can measure biological processes as they occur in real time. Scientists start with a compound normally used by the body—such as glucose, water or ammonia—and tag it with a radioactive atom called an isotope. A technologist then injects a small amount of that material into the patient. Clinicians use the PET scanner to track the movement of the tagged molecule, or tracer, as it travels through the body. With this special camera, they can diagnose illnesses, measure blood flow, monitor tumor growth and track the progress of therapy.

"PET scanning is what we call functional imaging," explains Barry Shulkin, MD, chief of Nuclear Medicine. "It not only tells you what something looks like, but more importantly, it tells you what it is doing. MRI and CT are principally anatomic imaging; they tell you what something looks like—but not always what it is doing."

The challenge of using PET is that the radioactive isotopes used



**Eleven-year-old Latrevious Moore twirls a yo-yo outside the Chili's Care Center, where he undergoes PET scans as part of his cancer treatment. The radioactive chemicals used in the scans are created in the hospital's cyclotron.**

have short lifespans. Only one PET drug is commercially available—a tracer called fluorodeoxyglucose, or FDG. This drug has a two-hour half life, which means that half of its radioactivity dissipates every two hours. Most hospitals obtain FDG from local producers, who deliver the drug as soon as it has been produced. Other PET imaging drugs have half-lives of only 10 to 20 minutes, so they must be produced at the facility where they will be used. Several years ago, St. Jude clinicians and researchers realized that these drugs would help them accelerate the treatment and research of childhood cancer. As a result, in 2008 St. Jude obtained the most powerful medical cyclotron available—the first one of its kind installed in the United States.

## A closer look

The ability to create radiopharmaceuticals has enabled St. Jude researchers to pursue new areas of investigation that have exciting implications for children with cancer. Several days each week, scientists in the Molecular Imaging Research laboratories produce carbon-11 (C-11) methionine, a drug with a half-life of 20 minutes. Methionine is a type of amino acid,

a building block of proteins. Because tumor cells grow rapidly, they create many new proteins. "Using carbon-11 methionine, you can measure how fast the tumor is making new proteins or making new components for the cell," says Scott Snyder, PhD, director of Molecular Imaging Research. "The advantage of methionine is that it only accumulates in tissues that are actively producing new tissue."

When compared with FDG, the drug C-11 methionine is much better suited for brain imaging. The brain and its tumor both absorb FDG, so brain tumors are not easily visible in scans created using that drug.

"If you use fluorodeoxyglucose in the brain, it's kind of like seeing the stars when the sun is out," Shulkin says. "The stars are there, but you can't see them, because there is so much light in the background."

On the other hand, tumors absorb C-11 methionine but the surrounding brain does not take up that drug; thus, scans created using C-11 methionine provide clearer images. Shulkin and his colleagues are also using C-11 methionine on other kinds of tumors to determine whether that drug can provide new information as well as predict the outcome of therapy.

C-11 methionine has a long

lifespan when compared with N-13 ammonia, a radiopharmaceutical that has a half-life of only 10 minutes. This drug can be used to measure blood flow in the heart.

“Eventually we want to help evaluate some long-term survivors of childhood cancer and determine their risk for coronary disease,” Shulkin says. “We’re also interested in looking at patients who have more recently had therapy to determine very early whose hearts may have been affected by therapy. If we can identify people who are at risk, then we can help doctors determine whether an intervention—say, medicine or exercise—could help prevent that possible side effect.”

Two upcoming studies using radiopharmaceuticals may also hold promise for children with neuroblastoma. Shulkin is collaborating with chemists at the National Institutes of Health to test a radioactive drug called fluorodopamine for use in

children with neuroblastoma.

“We believe that neuroblastomas will have excellent uptake of this drug,” he observes.

Another project involves the neuroblastoma antibody that is currently in production at St. Jude.

“What we want to do is to attach a little bit of radioactivity to that antibody to tell us where the cells are and whether the treatment has a likelihood of success in a patient,” Shulkin explains.

## Pondering the possibilities

Someday, doctors may use a drug called C-11 acetate to monitor how well children like Latrevious Moore are responding to therapy. Typically, clinicians measure tumors, administer treatment and then measure the tumors again in six months or so. But Snyder predicts that C-11 acetate may help change that scenario.

“We might be able to tell as little as a few days after the therapy whether or not the treatment is

actually working,” he says. “Instead of going through three six-week courses of chemotherapy, a patient might be able to go through the first six weeks, take a week or two off and get this scan to tell whether the chemo is working. If it has worked very well, then the child might not have to go the entire 18 weeks of doses; if it has not worked, then we will know early on that we should try something else.”

Latrevious is not interested in the latest radiopharmaceutical drugs or the science behind PET scanning. He is much more intrigued with the possibility of learning the saxophone, planning his birthday and mastering his latest video game.

“They do PET scans to see if my chemo’s working,” he says matter-of-factly, as he rewinds the string on his yo-yo.

For Latrevious, that’s the bottom line: PET scanning gives doctors information that will save his life—and make all of his plans possible. ●

## Birth of a PET drug

The St. Jude cyclotron, or particle accelerator, creates radioactive chemicals that can be used to create drugs for PET imaging.

The massive machine is housed in an underground bunker with 7-foot-thick concrete walls and a multi-ton door that glides into place along metal tracks. To enter the cold cyclotron vault, a researcher must first don a lab coat, goggles and radioactivity detector, then pass through four levels of security.

To make a drug, scientists place a nonradioactive material, such as pressurized nitrogen gas, into cylinders located along the edges of the cyclotron.

Hydrogen gas passes through a high-voltage electrical current, creating electrically charged, or ionized, gas in the center of the cyclotron. Two large, D-shaped magnets push and pull the ionized hydrogen particles, causing them to accelerate, spiraling toward the outside edge, where the cylinders are located.

As the high-energy proton beam bombards the canisters of nitrogen gas, energy is transferred into the nitrogen. The

30-minute process converts a fraction of the nitrogen into carbon-11 carbon dioxide, a material that is radioactive, but not yet clinically useful.

The radioactive material is pumped into a lead-shielded cabinet known as a hot cell. An automated chemistry device in the hot cell converts the radioactive chemical into a drug, which is then filtered and collected in a glass vial.

The chemist transfers that vial into a lead-shielded sterile cabinet called an isolator, where a robot fills syringes with the appropriate amount of radioactive drug.

The first syringe drawn from the batch is a quality-control sample. In an adjoining quality control laboratory, scientists test the dose for purity, sterility and safety.

As soon as the tests are complete, a pharmacist reviews the results and verifies that the dose is ready for use. Scientists place the dose into another lead container and rush it to the Nuclear Medicine Clinic through a dedicated pneumatic tube.

After further safety checks, the imaging technologist administers the drug to the child, and the PET scan begins.



# Five Fabulous Years

**For the last two decades, St. Jude has been at the forefront in identifying the underlying genetic abnormalities of childhood cancers. The last five years have marked steady progress—each piece of information uncovered, revealing new ways to fight cancer with more effective, less toxic treatments.**

BY SUMMER FREEMAN

**CANCER** is triggered by harmful mutations in the genes of normal cells. These mutations can happen by accident, be caused by our environment or be inherited. By pinpointing the underlying genetic mutations that cause a normal cell to become cancerous, scientists hope to develop new medicines and optimize the use of current therapy. Although researchers worldwide have extensively studied cancer genetics, the vast number of genetic changes that lead to cancer have not yet been identified; as a result, the true genetic causes of most cancers remain elusive—especially in children.

St. Jude Children's Research Hospital has been a leader in identifying the underlying genetic abnormalities of childhood cancers. Researchers have made key discoveries about leukemia, brain tumors and the eye cancer retinoblastoma, as well as how children's DNA influence their response to certain medications.

In the past five years alone, St. Jude genetic research has had a worldwide impact on our knowledge of childhood cancer:



2005

**By identifying a specific pattern** of gene expression linked to multiple-drug resistance of leukemic cells, St. Jude investigators provided crucial information into why standard therapies fail to cure some children with acute lymphoblastic leukemia (ALL).

**St. Jude scientists determined** that the patterns of gene expression in tumor samples show how brain tumors called ependymomas arise from rare stem cells in the nervous system and how targeted treatment of specific signal pathways can advance care of solid tumor patients.

2006

**Investigators worldwide** were granted free access to a St. Jude tool for studying brain development. The Internet-based tool is one of the largest gene expression maps of an organ ever developed. The map may help scientists discover the genetic origins of brain cancers, which could speed development of novel drugs to treat them.

**Scientists devised a new strategy** to determine which biochemical signaling pathway triggers and sustains the brain tumor medulloblastoma by identifying key genes linked to that pathway. The technique could also be used to identify specific pathways in other types of cancer and could speed development of molecular-targeted therapies.

**While studying the eye cancer** retinoblastoma, St. Jude researchers determined how the disease is triggered by genetic loss of a protective mechanism that normally kills aberrant cells. Researchers then demonstrated in the laboratory a new, locally applied treatment for retinoblastoma that greatly reduced tumor size without causing the side effects common with standard chemotherapy.

2007

**St. Jude researchers gained a better look** at the mutational landscape of ALL, discovering previously unsuspected mutations that contribute to ALL's formation. The study demonstrated that it is possible to significantly speed the identification of the genetic lesions that are the underlying cause of not only ALL but also many other cancers, including those affecting adults.

**In the largest study to analyze malignant transformation** of gliomas in children, scientists found genetic abnormalities that might warn clinicians that a child's low-grade tumor was likely to undergo malignant transformation.

**Researchers from St. Jude discovered** that individual children with ALL respond differently to the same drug treatment, and that the variances could be explained by differences in the children's genetics. The insights gained in the study work toward the effort to individualize chemotherapy according to a patient's genetics.

2008

**St. Jude investigators discovered evidence** that a series of genetic mutations work together to initiate most cases of an aggressive and often-fatal form of ALL. The new study adds further support to a key concept in cancer genetics: Malignancies frequently require mutations in multiple genes in order to develop. These findings provide new avenues to pursue to gain a better understanding of these disease processes and to develop better therapies.

2009

**Which patients with ALL are most likely to relapse?** Hospital investigators identified a gene abnormality that makes that prediction. This could lead to a genetic test to identify children at high risk of relapse; if the abnormality were identified in a patient, physicians could then assign more aggressive treatment in hopes of warding off relapse.

2009

**Scientists discovered** in children with ALL scores of inherited genetic variations that clinicians might be able to use as guideposts for designing more effective chemotherapy for this cancer. The newly discovered genetic variations will likely give scientists a clearer understanding of why treatments fail in some patients with ALL, and how to predict early in treatment which children could be successfully treated with less aggressive treatment.

**Building on previous genetic studies**, St. Jude researchers pinpointed a new class of gene mutations that identify cases of ALL that have a high risk of relapse and death. The finding suggested specific drugs that could treat this high-risk leukemia subtype in children, using drugs that are already in clinical trials for similar blood diseases in adults.

**After launching the most comprehensive analysis yet of the genome** for childhood acute myeloid leukemia (AML), scientists found only a few abnormalities in the genetic blueprint. The finding suggests this cancer arises from just a handful of missteps and that the development of pediatric AML may require fewer genetic alterations than other cancers.

**Hospital investigators published the first complete search of the human genome** for inherited risk factors of pediatric ALL. Scientists identified variations in two genes that account for 37 percent of cases of this cancer, including a gene that may help predict drug response. The research—based on a complete survey of the human genome—offered the first proof that inheritance plays a role in childhood ALL.

**St. Jude researchers championed efforts to understand the genetic mistakes** that give rise to pediatric ALL, identifying a new chromosomal abnormality responsible for some cases. The research focused on the link between a deletion in a chromosome and a form of ALL that is particularly common in children with Down syndrome. The discovery has already resulted in new diagnostic tests and potential tools for tracking these patients' response to treatment.

2010

**The most comprehensive analysis yet of the genetic imbalances** at the heart of childhood brain tumors known as high-grade gliomas (HGGs) identified a cancer gene that is unusually active in some tumors and is now the focus of a St. Jude clinical trial.

**St. Jude and Washington University School of Medicine embarked on a bold, three-year initiative** to identify the mutations underlying childhood cancer. Scientists in the St. Jude Children's Research Hospital – Washington University Pediatric Cancer Genome Project will sequence the entire genomes of both normal and cancer cells from 600 patients, comparing differences in the DNA to identify genetic mistakes that lead to cancer.

Despite this progress, cancer remains the leading cause of death by disease in U.S. children over 1 year of age. St. Jude scientists hope their current research will lead to breakthrough treatments and help save the lives of children worldwide.

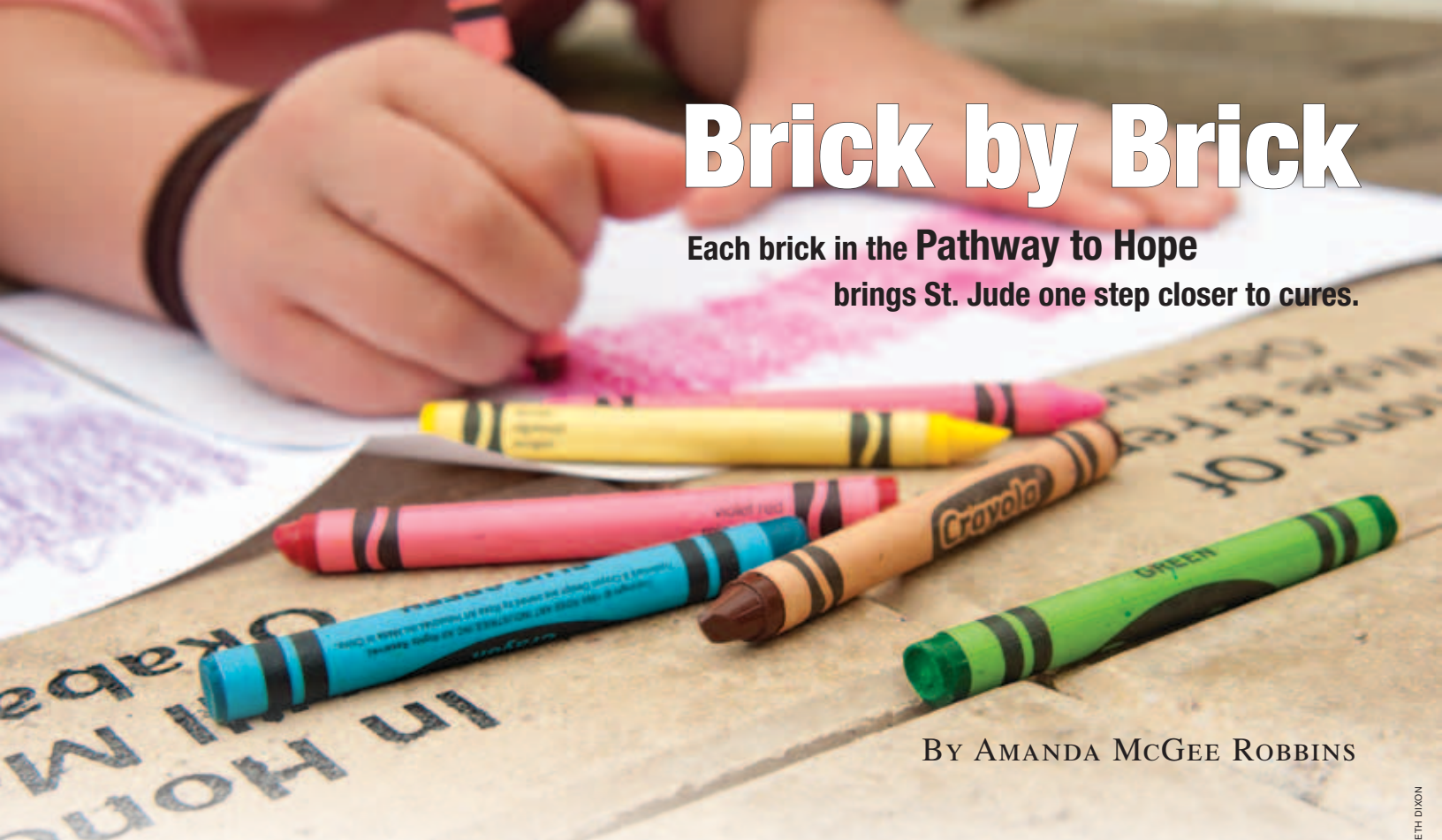
“We are on the threshold of a revolution in our understanding of the origins of cancer,” says Dr. William E. Evans, St. Jude director and CEO.

The next five years promise to be even more exciting than the last. ●

# Brick by Brick

Each brick in the Pathway to Hope  
brings St. Jude one step closer to cures.

BY AMANDA MCGEE ROBBINS



In Honor Of  
Children Of St. Jude  
Inspiration To All

For David Critelli, the above inscription on a Pathway to Hope brick captures how his family feels about St. Jude Children's Research Hospital.

A parent of three boys, Critelli says he considers the children of St. Jude to be part of his family. "My wife and I decided that, since they are our family, we should dedicate this brick to them," he says.

An accountant, financial planner and longtime supporter of St. Jude, Critelli was honored in 2009 as the Partner In Hope of the Year by the ALSAC/St. Jude Boards of Directors and Governors. His family joined the first Pathway to Hope campaign in 2007. Since that time the pathway has branched through serene gardens bordering both sides of the entrance to the hospital's Patient Care Center.

Today, the path includes more than 7,000 bricks, purchased by

individuals, churches, businesses and other organizations throughout the country. Each brick bears a tribute of the donor's choice, with many honoring close friends and family members. Donors can choose between small bricks for \$1,000 and large bricks for \$1,500, knowing their gift will support the lifesaving mission of St. Jude. Since the campaign began, their gifts have totaled more than \$7.9 million.

A desire to teach her nephews the importance of charitable giving led Michelle Smith to purchase her first brick last year. She asked her nephew, Cole Rupnow, to pick a charity and she would make a donation in honor of his 10th birthday. When one of his choices was to help sick kids, Smith suggested St. Jude.

Smith next challenged her three nephews to raise money for the charity of their choice, money that she would match dollar for dollar. The boys—Cole, 11; his brother Jay, 10; and their cousin, Zach Buhro, 11—did not hesitate. They chose to support St. Jude.

"I was so impressed that they ran with it," Smith says. "They set

their minds to it and it grew, and people supported what they were doing."

The boys organized a soccer fundraiser called "Shooting for a Cure. One Goal at a Time." The event raised more than \$3,000, enough to purchase three bricks on the Pathway to Hope.

Smith says her nephews not only benefited from the experience of helping the kids of St. Jude, but also from knowing that their help is represented in the Pathway to Hope.

Critelli expresses appreciation for what the Pathway to Hope symbolizes to all who walk it, describing it as "a continuous reminder of the good that is being done at St. Jude.

"Buying a brick," he says, "is like cementing your place in the St. Jude family."

*Orders for bricks during this year's campaign will be accepted through August 31 and will be put in place on the Pathway to Hope by the fall of 2011. To order a brick, please visit [www.stjude.org/brick](http://www.stjude.org/brick) or call 1-800-822-6344. ●*



# Sickle Cell Support

**Jim and Darrell Byrd** work to help find a cure for sickle cell disease.

BY JANICE HILL

**B**rothers, close friends and business partners, Jim and Darrell Byrd share much in common—including a determination to help St. Jude Children’s Research Hospital find a cure for sickle cell disease.

In addition to their personal commitment, the McDonald’s restaurant franchisees work hard to raise awareness and support for the St. Jude sickle cell disease program.

“Our goal is to raise \$1 million a year over the next 10 years,” Darrell says. Michigan natives who have called Memphis home for 25 years, the Byrds host receptions each quarter to educate colleagues and friends about St. Jude research and treatment for sickle cell disease, which is the world’s most common genetic disorder.

“Everyone knows St. Jude does great work for children, but the sickle cell program is its hidden gem. Not many people know about the hospital’s leadership in researching and treating the disease and why it is so important,” Jim says.

The brothers also intend to develop a national network of support for St. Jude sickle cell research. “We want to reach young people with this message, including musicians and athletes,” Darrell continues. “We see it as our responsibility to educate them about the disease and about the importance of giving back to help others.”

Jim and Darrell became involved with St. Jude when Jim began serving on The Ronald McDonald® House of Memphis board of directors. The residential facility provides a home for St. Jude families staying from eight to 90 days for treatment. “Once I started looking at the mission and work of St. Jude, I was hooked,” he says.

One day he attended a meeting at the hospital where he learned about the sickle cell disease program. “That’s when I really started looking at how the disease affects people of color all over the world and the important research St. Jude is doing,” Jim says. “We want to help them find a cure.”

People with sickle cell disease have an abnormal type of hemoglobin in their red blood cells that can block small blood vessels and cause complications such as pain, organ damage and stroke. Worldwide, the disease is most common in India, Africa, the Mediterranean, and Central



Darrell Byrd (at left) and Jim Byrd learn about St. Jude sickle cell disease research in the lab of Derek Persons, MD, PhD, of Hematology.

and South America. Between 50,000 to 70,000 people in the United States are affected by the disease, and approximately one in 375 African Americans is born with it each year.

Although they have no family members with sickle cell disease, Jim and Darrell say personal loss has increased their determination to make a difference in the lives of others dealing with catastrophic illnesses. They watched their father succumb to the debilitating effects of diabetes two years ago. Darrell lost his first wife, Regina, to lupus several years ago; seeing her struggle with pain strengthened his resolve to help others overcome disease.

Now Darrell and his second wife, Charlotte, have a blended family that includes a grown son, three teenage daughters and a baby girl. Jim and his wife, Valerie, have three daughters, including twins who are college students and an older daughter who is a journalist in New York.

“Our support of St. Jude is a small way that we are able to make a difference for other families,” Darrell says. “We can play a part in finding a cure.” ●



# Stringing a Legacy... One Bead at a Time

The St. Jude Legacy Beads Program offers patients a creative way to chronicle their treatment experiences.

BY ELIZABETH JANE WALKER

**T** Tyler Murphy has endured more operations, needle sticks, chemotherapy treatments and medical procedures than most people experience in an entire lifetime. Because he is only 2 years old, Tyler may remember blessedly little of his battle with the rare disorder called Langerhans cell histiocytosis. As a result, his mom, Lindsey, is creating a visual symbol to ensure that one day her son understands the magnitude of his treatment.

Lindsey and Tyler participate in the Legacy Beads Program at St. Jude Children's Research Hospital. This activity allows patients to collect colorful, glass beads that represent their treatment experiences. Children net one bead for each event: a square, orange one for physical therapy; a green, cone-shaped bead for a CT scan; silver for a final chemotherapy session; gold for remission. During the past year, the hospital has purchased more than 90,000 beads for the program; if placed end-to-end, the string of baubles would extend longer than six football fields.

Child Life Specialist Cara Sisk says St. Jude created the program specifically to meet the needs of families. Participants receive special beads emblazoned with the hospital's logo; pieces of string; and square, ceramic beads that spell out their names. Then they begin amassing their unique collections.

"If they visit the clinic three times in one day, they get three blue beads," Sisk says. "Eventually they can say, 'This is how many times I went to the clinic.'"

## Colorful stress relievers

The Legacy Bead activity is only one of numerous offerings sponsored by the St. Jude Child Life Program. Child Life helps minimize the stress and anxiety associated with treatment and hospitalization. One way that Child Life specialists help children cope is by allowing them to express their feelings and chronicle their journeys. Some patients create scrapbooks or take photos; others tell their stories through journals, videos or art projects. Begun in April 2009, the Legacy Bead program provides an additional avenue for expression.

Although some hospitals offer bead programs, most offer a limited number of options.

"At other hospitals, one bead might represent four or five different activities," Sisk says. "We wanted our program to be more customized to St. Jude." More than 500 patients now participate in the program, which offers nearly 50 different beads.

It's no surprise that Paola Flores collects them. After all, this 7-year-old appreciates all things sparkly—dangly earrings, bright fingernail



**More than 500 St. Jude patients—including (from left) 16-year-old Carissa Barrett, 7-year-old Paola Flores and 2 year-old Tyler Murphy—collect Legacy Beads. During the past year, the hospital has purchased more than 90,000 beads for the program; if placed end-to-end, the string of baubles would extend longer than six football fields.**



polish, pretty dresses. Nearly a dozen bracelets encircle her slim wrists, softly jangling and rattling as she moves. Although Paola lost both eyes to a cancer called retinoblastoma, she adroitly identifies her favorite Legacy Beads by shape, size and texture.

“This triangle bead is for a needle stick,” she says with a smile. “It’s sharp and pointed like a needle.”

As her hands wander down the necklace with practiced ease, she pauses at a round, yellow bead.

“I got this one for changing the dressing on my leg,” says Paola, who is now receiving treatment for the bone cancer osteosarcoma. With maturity that belies her years, Paola explains the significance of the beads she finds most interesting. “I strung them myself,” she proudly declares.

### Bejeweled journals

St. Jude families find novel ways to display their Legacy Beads. Some fashion strands that can be hung from the ceiling; others adorn strollers, purses or backpacks with the baubles.

Teens say the beads give weight

and heft to their stories, providing a tactile method for demonstrating the breadth of their experiences. “It gives them a concrete way of sharing their stories,” Sisk says. “It helps bridge that gap back to home, as they talk with people who don’t understand what they’ve been through.”

During the past year, 16-year-old Carissa Barrett has accumulated more than 450 Legacy Beads.

“At first I really wasn’t sure about whether I wanted to participate in the program,” admits Carissa, who hails from Pennsylvania and is receiving treatment for adrenal cortical carcinoma. “But as time went by, I started to collect them. What’s neat is that each bead represents a treatment milestone. I even got a bead to mark my relapse. I’ll be able to show my family and friends all that I’ve been through—some good memories and some not so good.”

### Sentimental journey

Lindsey says her toddler likes to help string the beads, examining each one before handing it to her.

“When the times get really tough, stringing beads is a good way to get our minds off the bad things that are happening,” she says.

In the past year, she has collected 307 beads for Tyler, signifying operations and procedures; chemotherapy treatments and hair loss, bad days and good days, needle sticks, inpatient admissions, platelet transfusions and many other events. Lindsey plans to hang the long strings of beads in her son’s bedroom as a symbol of his treatment and a celebration of his bravery.

“I show them to Tyler when he’s having a bad day,” Lindsey says, with a catch in her throat. “I’ll say, ‘You’ve got to keep fighting! Look how much you’ve already done. Look how strong you are!’”

“I not only do this for Tyler, but also for me,” she admits. “The beads have sentimental value. Someday, I’ll tell him, ‘You were so strong and you fought so hard, and this is everything you went through.’”●

PHOTOS BY SEITH DIXON





# Perspective

BY MICHAEL SWART

## A Perspective on a Promise

**A former St. Jude patient celebrates the legacy of hospital founder Danny Thomas.**



**Former patients (from left) Tonya Monk, Michael Swart and Gabriela Salinas celebrate their friendship at a Target House event last summer.**

**M**any nights, after long days in the Medicine Room, I'd sit upright in the middle of my bed, legs crossed, unable to sleep. A heavy regimen of chemotherapy can catapult you into a chaotic chasm where even the simplest dichotomies of day and night, awake and dream, life and death seem indistinguishable. Your mind races your body into fatigue, and your dreams drive you down paths unfamiliar. You wander through where and when, seeking to make sense of a metamorphosis taking place—your rebirth. I'd write poetry about the peculiar commonalities we share in life or sketch the visions from my dreams. Sometimes I'd play Tetris, maybe as a metaphorical attempt to put things back together again. Other times I'd just sit and watch reruns of Danny Thomas on Nick at Nite.

On those late nights in black and white, I watched Danny's warm and funny character, garnering glimpses of a man I never knew. I contemplated his successes. Danny Thomas' hard work was the expression of a tireless spirit that

celebrated life to its fullest. Of all his accomplishments, his fulfillment of his promise to St. Jude Children's Research Hospital is, to thousands of children and their families around the world, his greatest gift.

When my family and I entered the Patient Care Center in 1998, Nurse Practitioner Marion Donohoe and Dr. John "Torrey" Sandlund met us at the door. They assured us that everything was going to be all right. That was the most promising news we had heard. For the first time, my parents, who had been heroically methodical, swift and unwavering, broke into tears of joy.

When I needed a place to call home—while getting weekly chemotherapy thousands of miles away from my home—the staff and families of Target House welcomed me with open arms and open hearts. When times were difficult, Target volunteers brought fun and smiles to our faces. When I returned last September for the 10-year anniversary of Target House, I saw a spectacular celebration of the miracles that happen every day at St. Jude.

I wish I'd met Danny Thomas, shaken his hand. I would have been honored to sit down with him during his trips through the hospital, even if for only a moment, to express my gratitude, my love. His promise transformed into St. Jude, and together, the men and women of St. Jude and ALSAC are committed to that promise—every day.

Now, every day I am grateful when I wake up. Every day, I am grateful to grow more, to grow up. Every day I laugh, love and live life. Every day, I get another chance to contribute to making the world better than when I got here. Every day, I promise.

*Michael Swart was treated for acute lymphoblastic leukemia at St. Jude and is now a graduate student at Teachers College, Columbia University in New York. ●*





*St. Jude patient Anna, age 6 years, 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 that recognizes these contributions, please call us at 800-395-1087, visit [www.stjudelegacy.org](http://www.stjudelegacy.org) or complete the enclosed postage paid envelope today. Ensure that our research continues until the day we have conquered childhood cancer. The promise of your charitable legacy helps make it possible.

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## Star treatment

Model and TV personality Daisy Fuentes receives an enthusiastic hug from 8-year-old Derek Pele during a visit to St. Jude. A strong hospital supporter since 1997, Fuentes helped launch the FedEx/St. Jude Angels and Stars Gala in Miami and has served as the gala's celebrity spokesperson since 2002. During her most recent visit, she also toured the hospital's research facilities and medical laboratories, spoke with leaders of the International Outreach Program, toured Target House and participated in an arts-and-crafts activity with patients.



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